On being a consumer living with dementia,

a socio-legal study of the contractual consequences

Submitted by Tania Marina Barton, to the University of Exeter as a thesis for the degree of Doctor of Philosophy in Law, 3 March 2021.

I certify that all material in this thesis that is not my own work has been identified and that any material that has previously been submitted and approved for the award of a degree by this or any other university has been acknowledged.

(Signature)

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In memory of my mum
who lived with dementia

A huge thank you to all who advised, listened, encouraged and helped move this project along!

In particular, I would like to express my gratitude and say **thank you** to

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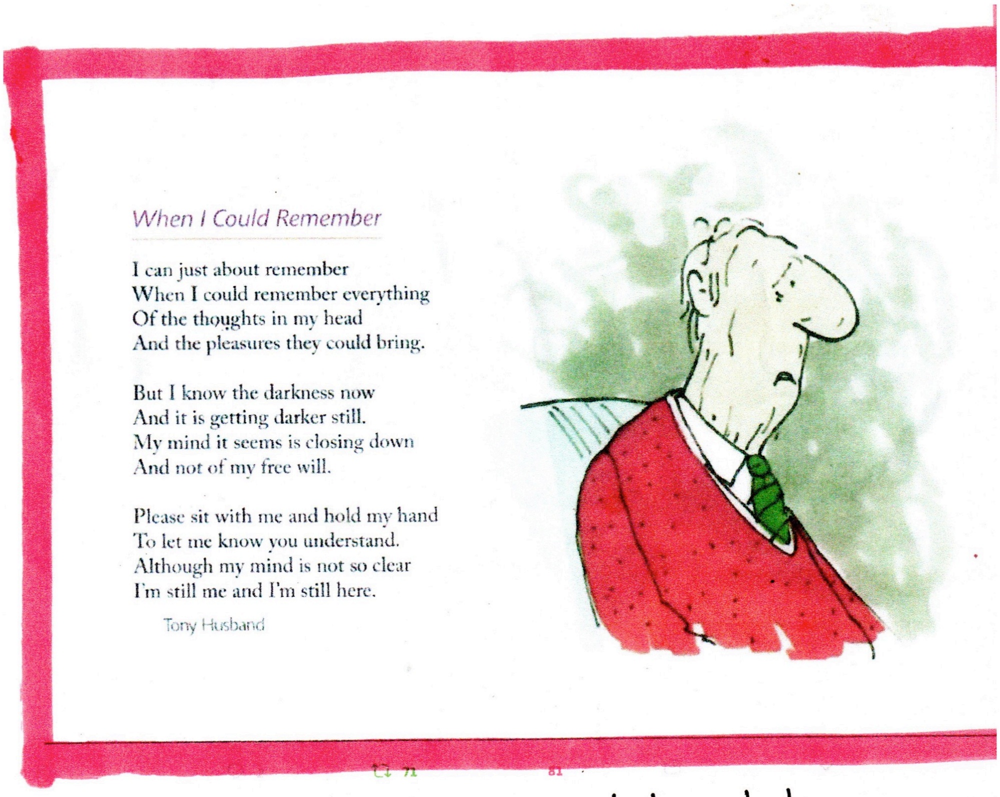

When I Could Remember

I can just about remember
When I could remember everything
Of the thoughts in my head
And the pleasures they could bring.

But I know the darkness now
And it is getting darker still.
My mind it seems is closing down
And not of my free will.

Please sit with me and hold my hand
To let me know you understand.
Although my mind is not so clear
I'm still me and I'm still here.

Tony Husband

my poem abot mydad

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Abstract

This research investigates the experiences encountered when persons living with dementia enter into contracts as consumers with businesses, and what consequences may result from such transactions for the person living with dementia and their families. In doing so, this research seeks to clarify what, if any, legal protections are afforded to persons living with dementia who are often still legally capable, but in practice experience difficulties in fully understanding complex consumer contracts with businesses.

Relevant academic literature is reviewed in a scoping exercise to gain a clear picture of the concepts of capacity and financial decision-making in a contractual setting. The review demonstrates that for a person living with dementia, capacity to make financial decisions will deteriorate as the disease progresses. Whilst there is no single path to assessing financial capacity, recognising any reduction of financial capacity is seen as important in ensuring long-term financial security and independence for those living with dementia. The review also highlights a clear gap in literature relating to *consumers* living with dementia.

A doctrinal review of relevant laws is undertaken, and includes analysis of contract law, capacity law, consumer rights, as well as human rights in the context of equality and non-discrimination laws. The thesis highlights the lack of cohesion between the various laws, resulting in some consumers living with dementia falling through the gaps and not being adequately protected when entering into contracts with businesses.

In addition to the close examination of the law, new empirical data is sought through semi-structured interviews with a number of stakeholders, including persons living with dementia, their family members and carers, as well as charities that advise and work with people affected by dementia. Analysis of the results indicates multiple concerns relating to capacity, knowledge, and protective measures aimed at countering financial harm.

In practice, as roles within families evolve, capacity is often ignored in favour of safety and security of the person living with dementia. Where capacity is considered, difficulties arise as to how and who should assess a person’s legal capacity to make decisions. The thesis highlights the difficulties of understanding and/or remembering the terms of the contract, which can lead to unintentional breaches of contract. Fear of stigma results in many consumers living with dementia deliberately refusing to disclose their condition, resulting in the business’s lack of knowledge of any issue. There is a sense of powerlessness in seeking to terminate consumer contracts outside of the (often onerous) terms of the contract, although pragmatic solutions were presented, such as withholding payments, pleading for understanding and questioning the risk to reputation of the business. Building on from these practical solutions, the thesis suggests a range of legal solutions, such as a review of doctrine and legislation, to improve the contractual position of consumers living with dementia.

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Chapter 1 Introduction to the thesis

1.1 Introduction

Dementia is a disease affecting many lives, either directly or indirectly. It impacts both cognitive function, and emotional control, social behaviour, and motivation[1] and is a huge challenge worldwide. Globally, there are an estimated 50 million persons living with dementia.[2] This is expected to increase exponentially, nearly doubling every 20 years, reaching 75 million in 2030 and 131.5 million in 2050.[3]

In addition to the person developing dementia, their family, friends, colleagues and neighbours will all be touched by the illness as well. Beyond this circle of persons, society at large must consider and deal with issues and challenges relating to dementia. From funding of care[4] to medical advances and considerations of well-being (for example in the time of Covid-19 where isolation of older people is law),[5] dementia is a disease that cannot be ignored.

Consequently, researchers are increasingly exploring all aspects of what it means to live with dementia. Research in various guises looks at either the causes or the consequences of living with dementia. This thesis joins this growing area of literature. Its focus is on consumers living with dementia, and before setting out the research question and the structure of this thesis, a number of common situations are presented that illustrate some of the challenges that such individuals might face.

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[1] World Health Organization (2020) Dementia fact sheet, available at https://www.who.int/news-room/fact-sheets/detail/dementia, last accessed on 14 February 2021.

[2] ibid.

[3] Alzheimer's Disease International (2015) *World Alzheimer Report 2015*. Alzheimer's Disease International London, at 22.

[4] Alzheimer's Society (2020) *Dementia tax*, available at https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/dementia-tax, last accessed on 14 February 2021.

[5] Dementia UK (2020) *Dementia UK advice for people with dementia and their families, regarding the coronavirus*, available at https://www.dementiauk.org/dementia-uk-coronavirus-advice/, last accessed on 14 February 2021.

When Ester agreed to sell her house

Ester felt she was getting on. She wanted to downsize; the house was too big, too dusty, too far from her kids. She called and arranged for an estate agent to pop by, then another, and another. One after the other, the agents turned up at her house, looked at the space and asked her to sign on the dotted line – three exclusive deals to sell her house, all at the highest commission possible; Ester had not negotiated that point or any other. When days later people came to look at her house, she was confused. Why would anyone come and see her home? What did they want? Who were they? Ester could not remember any of the contracts signed, let alone any of the terms of the contract, or even that she had wanted to sell her house. The agents insisted a valid contact had been formed. It took her children months to extract her from the contracts.

When Vishal bought a mobile phone

Vishal was feeling well. He and his wife lived comfortably, their routine was pleasant. There was just a small matter that bothered him today. He had been into town that morning, as he needed a mobile phone. At the shop he had spoken to a helpful young sales assistant who seemed to know him, joked in a friendly manner and helped him fill in the forms to set up a two-year contract for his new smart phone. Vishal had smiled, thinking of all this new technology, it was a constant marvel to him! He wandered home pleased to have accomplished that job for the day. But when he got home and went to store away his new phone, he found four other identical phones in his desk drawer. Where did they come from? He put the phone away and decided to worry about it later. A few months later, his wife was shocked to find a substantial amount of money being debited each month from their current account to cover the cost of five mobile phone contracts. The deadline to retract from the contracts had passed, penalties would be payable to terminate the contracts. The sales assistant had moved to another job and could not comment.

When Nita’s savings were transferred

Nita was living in a care home. It was a time in her life when things had slowed down considerably. One main activity was planned each day at the care home and she would make sure she was present for that; it seemed like a good way to pass an hour. This afternoon, the visitor was a financial adviser. He talked to the residents about various savings and investment options. He handed out brochures and asked people to sign up for a new financial product, an investment fund that had the potential to yield higher returns on her savings. She signed up too. When her sister came to visit, she was shocked to find that Nita’s savings account had been emptied. The transfer fees into the new fund were high and the funds were not easily available – how would she be able to make payments when they fell due in these circumstances? The contract could not be annulled; Nita’s sister had to battle, first with an adjudicator and then on appeal with the financial ombudsman to have the transaction revoked, costing her time, money and energy.

When Derek replaced his windows

Derek knew the house was no longer at its best. Renovations were needed. A flyer had been left with the post; he called a company that offered ‘the best prices’ to replace windows with new double-glazed versions. A meeting was arranged in which a sales rep explained the work required and the price to be paid. When Derek said he did not have those kinds of savings, a simple solution was at hand: the company could assist in arranging a loan. The sales rep read out all relevant disclosure documents and handed Derek the standard terms and conditions. He asked him to sign and Derek obliged. Derek’s sons were outraged at the terms that their father had agreed to; the interest rate was high, the term of the repayments lengthy, the selected windows not suited to the house or the neighbourhood. Derek was unsure of what he had agreed to. When his sons, using their lasting power of attorney, attempted to block the payments, the company took Derek to court. After a lengthy and costly legal battle, it was held that Derek was legally capable, had been given all necessary information and was entitled to make his own decisions, however unwise. The contract stood.

When Jana wanted her sons to step in

Jana had had a life she loved, with her husband Harry, in their beautiful home where the kids had been raised. Today, she was a widow. After Harry had died it had been up to her to pay bills, manage direct debits and standing orders, budget and ensure the upkeep of the house. She had never done any of this in her 40-year marriage and was daunted by the task. When she was diagnosed with dementia, she realised she would find these financial obligations more difficult still as the disease progressed. She asked her two sons, now family men themselves, to step in and take over. To do so, a lasting power of attorney was prepared and she selected to give power to her attorneys immediately. She trusted her sons and was overwhelmed by the financial demands she faced. However, despite the costly and time-consuming process of registering the lasting power of attorney, companies would regularly refuse to deal with her sons, despite seeing a copy of the power. Most recently, Jana was asked to respond directly to cancel a mobile phone contract that she had taken out in her name.[6] She could not understand why her sons could not help.

Ester, Vishal, Nita, Derek and Jana all have in common that they live with dementia, acted as consumers and that the consequences of their decision-making are now troublesome to them and their families.

These vignettes are an original amalgamation of the experiences of a number of participants as well as reports in the media.[7] They will be returned to at the end of the thesis in Chapter 11, where the suggestions, opinions and thoughts expressed throughout the thesis by participants, and the subsequent analysis and discussion, will be applied in order to demonstrate what other outcomes

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[6] This was in part inspired by a problem letter sent to consumer affairs at the Guardian, Tims, A. (2020) 'My mother has dementia but Vodaphone won't cancel her mobile' *Guardian*, available at https://www.theguardian.com/money/2020/dec/02/my-mother-has-dementia-but-vodafone-wont-cancel-her-mobile, last accessed on 14 February 2021.

[7] The first four examples were first presented in the dissertation for the pilot scheme: Barton, T. (2016) 'What do you mean, we have a deal? Considering the concerns that arise when a person with dementia enters into a commercial contract' *Unpublished, University of Exeter*, the fifth example was devised for the purposes of this thesis.

might be achieved if the changes to the law as proposed in this thesis [8] were to be implemented.[9]

1.2 Brief problem statement

Consumers living with dementia

This thesis focuses on consumers living with dementia, an eclectic and diverse group of persons, whose experiences will vary in each case. However, because of the nature of their condition, they will have a number of elements in common.

First, they are defined by the fact that they are all *consumers*, i.e. individuals, acting outside of their trade, business or profession, purchasing or hiring goods, services or digital content from a trader.[10] Consumer law today in the UK is drafted with the aim of protecting the consumer when interacting with a business, as well as "*build[ing] and enhance[ing] a climate of trust in which UK business operates*".[11] The relevant law, the Consumer Rights Act 2015, [12] sets out clear principles to ensure trust by legislating that fairness [13] is a fundamental aim for all businesses when dealing with their customers. However, fairness in consumer law relates to the terms of the consumer contract, rather than to the parties to that contract. Indeed, in order to be fair, the law stipulates that the terms of the contract must be transparent and clear.[14] Whether the parties can understand these clear and transparent terms is however not considered within the legislation.

Indeed, it is important to note that the Consumer Rights Act defines the average consumer as "*a consumer who is reasonably well-informed,*

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[8] See Chapter 11, Section 11.2.

[9] The concept of providing concrete examples and later reviewing these in light of the analysis and discussion is inspired by Foster, C. and Herring, J. (2017) *Identity, personhood and the law.* Springer.

[10] Consumer Rights Act 2015, s. 2.

[11] Cable, V., Secretary of State for Business, Innovation and Skills (2014) *Consumer Rights Bill, 28 January 2014*, Hansard, House of Commons, Volume 574, Column 768.

[12] Consumer Rights Act 2015, c.15.

[13] Consumer Rights Act 2015, s. 62.

[14] Consumer Rights Act 2015, s. 64(3) and s.68.

observant and circumspect".[15] However, not all consumers fall within this description of ability, and as a result there is a gap between the transactional protection under the Consumer Rights Act of the 'average' consumer and other consumers, such as consumers living with dementia.

A second element that this group of consumers living with dementia have in common is that they live with a disease that may make it difficult to understand and process complex information.[16] As such, they fall within the category of consumers who, despite the legally required steps in the legislation to ensure that contract terms are sufficiently transparent and prominent[17] within a consumer contract, may nevertheless have some difficulties in understanding the complexity of the consumer contracts presented to them by businesses. Consequently, consumers living with dementia may fall in a category of persons deemed potentially more vulnerable than others because of mental health issues, learning disabilities or cognitive impairment.[18]

In the UK, in 2014 it was estimated that over 850,000 people were living with dementia,[19] of which over 60% were living independently in their own homes, usually relying on help and assistance provided by informal carers, be they spouses, family members or friends.[20] Of those living independently, approximately 120,000 people with dementia live alone in their own homes.[21] These figures are set to increase significantly, with the number of people

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[15] Consumer Rights Act 2015, s. 64(5).

[16] World Health Organization (2020) *Dementia fact sheet*, available at https://www.who.int/news-room/fact-sheets/detail/dementia, last accessed on 14 February 2021.

[17] Consumer Rights Act 2015, s. 64.

[18] Wallbank J. and Herring J. (2013) 'Introduction: vulnerabilities, care and family law' in Wallbank J. and Herring J. (eds) *Vulnerabilities, care and family law*. Routledge, at 25.

[19] Prince, M. et al. (2014) *Dementia UK: Update.* Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society, at 43.

[20] Robinson, L., Tang, E. and Taylor J.-P. (2015) 'Dementia: timely diagnosis and early intervention' *British Medical Journal* 350: h3029, no page numbers.

[21] Alzheimer's Society (2019) *A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years*. AS Fact Sheet.

living with dementia in the UK expected to rise to over 1.3 million by 2030 and to over 2 million by 2050.[22] Furthermore, the Alzheimer's Society is predicting that the number of people with dementia living alone will double in the next 20 years to 240'000 in 2039.[23]

A significant majority of people with dementia are therefore living independently and as such will be engaging with businesses as consumers on a near-daily basis. From the newspaper bought at the local newsagents to the double-glazing purchased on credit from the door-to-door sales person, from the utility companies offering various deals on gas and electricity to the mobile phone providers selling goods, services and digital content, the person living with dementia is likely to be interacting as a consumer with all or some of these, and many more, which is why an examination of the law underpinning such transactions is so important.

Beyond the person with dementia

Dementia affects more than just the person living with dementia, since those close to the person living with dementia are also profoundly affected.[24] The World Alzheimer Report of 2015 states that:

> *Whilst dementia shortens the lives of those affected, its greatest impact is upon the quality of life, both of those living with dementia, and their families and caregivers.*[25]

The quality of life referred to in the above statement relates to the care received in terms of medical treatment, but also the care and attention paid to

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[22] Prince, M. et al. (2014) *Dementia UK: Update.* Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society, at 46.

[23] Alzheimer's Society (2019) *A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years*. AS Fact Sheet.

[24] Lethin, C., Renom-Guiteras, A., Zwakhalen, S., Soto-Martin, M., Saks, K., Zabalegui, A., Challis, D.J., Nilsson, C. & Karlsson, S. (2017) 'Psychological well-being over time among informal caregivers caring for persons with dementia living at home' *Aging & Mental Health* 21(11): 1138-1146, at 1138.

[25] Alzheimer's Disease International (2015) *World Alzheimer Report 2015*. Alzheimer's Disease International London, at 69.

persons living with dementia and those that help them outside the medical sphere in their day-to-day encounters.

Many carers are themselves elderly and might find their social world reduced as their partner's health declines. Actions by their partners living with dementia may cause difficulties, stress or worry to them as carers and family members. For example, if a person living with dementia were to spend huge amounts of money on unrequired goods or services, this may impact on the finances of the marital couple with significant consequences in relation to the quality of life of both the person living with dementia and their spouse.[26]

Family members will often (officially or unofficially) take on a role of attorney, assistant or representative of the person living with dementia. In their role as decision-maker, decision-supporter or decision-facilitator for the person living with dementia, they will be weighing up questions of capacity, security and safety of the person with dementia. These family members will be looking at their financial situation for them, and will often be the ones (instead of the person living with dementia), who in practice will look to terminate or challenge a consumer contract entered into by the person living with dementia, if that contract is subsequently deemed 'unwise',[27] unaffordable or unrequired.

Brief problem statement

It might be assumed that consumers living with dementia are already protected through current legislation, either through the Consumer Rights Act 2015[28] for those consumers that have capacity, or the Mental Capacity Act 2005[29] for those consumers that lack capacity.

Any such assumption would depend on capacity being a binary proposition; a person either has or does not have capacity. As set out above, for either of

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[26] This will also have a knock-on effect on the wider community, if as a result of financial dependence the couple come to rely on the state for their care and well-being.

[27] This is the term used in the Mental Capacity Act 2005, s. 1(4).

[28] Consumer Rights Act 2015, c.15.

[29] Mental Capacity Act 2005, c.9.

these two binary situations, legislation *seems* to be in place. However, there are a number of factors that undermine any such assumption.

First, a lack of capacity (as determined under the Mental Capacity Act)[30] by one of the parties to a contract is not sufficient by itself to ensure that such contract is in fact null and void. As will be demonstrated in more depth in Chapter 7, which deals with the lack of legal remedies for the consumer living with dementia,[31] even when capacity is deemed lacking, a contract may still be valid,[32] depending on the knowledge of that lack of capacity by the other contracting party. In other words, if a business does not know that the consumer lacks capacity, the contract will remain valid and binding on the parties.[33] This is relevant in consumer matters, where businesses are often unfamiliar with the consumers they are transacting with. Consequently, a business' lack of knowledge of its customer means that contracts are less likely to be void or voidable, leading to a situation that is to the detriment of the vulnerable consumer.

In addition, some individuals will fall outside of both the definition of a person lacking capacity[34] under the Mental Capacity Act, and the definition of the "*average consumer*"[35] as set out in the Consumer Rights Act. Consequently, these are adults who still have mental capacity as set out in the Mental Capacity Act,[36] and are deemed to be able to make decisions. However, in practice, they may have considerable difficulties in understanding, processing or memorising the information provided to them by the businesses in the terms and conditions of the consumer contract. They can therefore be said to

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[30] Mental Capacity Act 2005, s. 3(1).

[31] See Sections 7.2 and 7.3 for available legal remedies and their limitations for the consumer living with dementia.

[32] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.

[33] ibid.

[34] Mental Capacity Act 2005, s. 2.

[35] Consumer Rights Act 2015, s. 64(5).

[36] Mental Capacity Act 2005, s. 3(1).

be both capable of making decisions,[37] whilst at the same time not being sufficiently "*well-informed, observant and circumspect*".[38]

As set out in Chapter 6,[39] the courts recognise that certain vulnerable contracting parties do indeed face this predicament, referring to them as being in *"a jurisdictional hinterland".*[40] Herring highlights the challenges faced by persons who "*will be deemed to have capacity under the Mental Capacity Act 2005, but should not be regarded as being able to make an autonomous decision*".[41] In Chapter 3 below, the notion of the (actual or potential) vulnerability of certain groups of people will be explored in great detail. In that context, Chapter 3 also examines how the concept of vulnerability informs this research.[42]

1.3 Aims and scope

While in theory the general legislative ideal in a democracy is to ensure equality for all people,[43] including for people with disabilities,[44] in practice there are situations where such equality is not fully achieved. For example, consumers with disabilities may face certain hurdles, such as difficulties in gaining physical access to goods and services. Other barriers will be imposed through complex consumer contracts that might be out of reach for some consumers with mental health issues, learning disabilities or cognitive impairment.

In order to explore the extent to which some consumers may encounter difficulties and challenges, the aim of this thesis is to examine the situation of

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[37] Mental Capacity Act 2005, s. 3(1).

[38] Consumer Rights Act 2015, s. 64(5).

[39] See Chapter 6, Section 6.3.

[40] Re L (Vulnerable Adults with Court's Jurisdiction) (No 2) [2012] EWCA Civ 253.

[41] Herring, J. (2016) *Vulnerable adults and the law* Oxford Press, at 70.

[42] See Chapter 3, Section 3.3.

[43] Universal Declaration of Human Rights 1948, European Convention of Human Rights 1950, Equality Act 2010, c.15, Convention on the Rights of Persons with Disabilities 2006.

[44] UN Convention on the Rights of Persons with Disabilities 2006, Equality Act 2010, c.15.

consumers living with dementia through empirical research into the experiences of consumers with dementia, and analysis of the law governing their contracts. This research looks at the situation where a person living with dementia enters into such a ‘business to consumer’ contract.

Consequently, this research seeks to answer the following question:

What are the consequences, legal and practical, when a person living with dementia enters into a consumer contract with a business?

There is a clear need to identify these issues, so that the person living with dementia can be adequately protected where necessary. However, as alluded to above, in asking this question, the objective is to consider not only the person living with dementia, but also others that might be affected by such a consumer transaction, such as for example the spouse or other family members of the person with dementia. The empirical data obtained through interviews will review the extent to which others beyond the person living with dementia might in practice be significantly impacted by the contractual actions of the person with dementia acting as a consumer.

Using a multi-methods approach, the specific aims of this research are to:

(1) analyse the different areas of law applicable to consumer contracts entered into by a person living with dementia in order to assess how and whether the law currently protects such consumers;

(2) determine how people living with dementia experience entering into consumer contracts and what the consequences are for them;

(3) explore the challenges these situations may produce, beyond the person with dementia, for their family members, such as spouses or (grown-up) children; and

(4) consider if as a result of the above, practical and/or legal solutions can be suggested to assist consumers living with dementia.

1.4 Original contribution to knowledge

This research is situated within the wider field of socio-legal research on dementia. There have been many valuable socio-legal research projects on various dementia aspects. For example, Harding considered the "*duties to care*", exploring dementia, relationality and the law in a socio-legal project.[45] Further socio-legal studies relating to dementia (many conducted by Harding in collaboration with others) cover, among others, lasting powers of attorney,[46] the health and care system, [47] medical treatments and medication,[48] assisted dying, [49], financial abuse, [50] and aging and sexuality. [51]

Much less has been written about consumer issues in this context. In particular, there are no existing studies that focus on the consumer living with dementia. This thesis is therefore the first socio-legal investigation of the experiences of people living with dementia and their family members when the person living with dementia was acting as a consumer, and as such makes an important and original contribution to the field. In addition to the contribution made to the field of socio-legal studies, this thesis also provides new input into contract law, consumer law, and capacity law, none of which currently adequately protect the consumer living with dementia. This thesis

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[45] Harding, R. (2017) *Duties to Care: Dementia, Relationality and Law.* Cambridge University Press.

[46] Harding, R. and Peel, E. (2019) ''Polyphonic Legality: Power of Attorney Through Dialogic Interaction'. *Social and Legal Studies* 28(5): 675-697.

[47] Peel, E. and Harding, R. (2014) 'It's a huge maze, the system, it's a terrible maze': Dementia carers' constructions of navigating health and social care services. *Dementia* 13(5): 642–661.

[48] Harding, R. and Peel, E. (2013) 'He was like a zombie': Off-label prescription of antipsychotic drugs in dementia. *Medical Law Review* 21: 243–277.

[49] Peel, E. and Harding, R. (2015) 'A right to 'dying well' with dementia? Capacity, 'choice' and relationality'. *Feminism & Psychology* 25(1): 137–142.

[50] Dalley, G., Gilhooly, M., Gilhooly, K., et al. (2017) 'Exploring financial abuse as a feature of family life: An analysis of court of protection cases'. *Elder Law Journal* 7(1): 28–37.

[51] Westwood, S. (2020) 'Older lesbian, gay and bisexual people: socio-legal perspectives on healthcare inequalities in later life'. in Jacob, M.A. and Kirkland, A. (eds.) *Research Handbook on socio-Legal Studies in Medicine and Health*. Edward Elgar Publishing.

further considers autonomy, vulnerability and relational autonomy specifically as it relates to the person living with dementia when acting as a consumer.

In relation to contract law, the key finding is that it is too easy for consumers living with dementia to enter into contracts that are financially detrimental to them, and too hard for them to disentangle themselves from these. The issue here is that a contract can only be set aside if the other party was aware of the consumer's lack of capacity but that consumers living with dementia will often not disclose their health status, either because they are unaware of the diagnosis or for fear of stigma.

With regards to consumer law, the key finding is that the protective mechanisms set out under the Consumer Rights Act 2015 that are intended to provide clarity and transparency for the consumer may not be suitable in assisting the consumer living with dementia, if they have cognitive impairment or memory loss. In such situations, the full disclosure of financial aspects and other significant terms of the contract may not be effective protection for the consumer, because they may not be able to recall, or fully understand the implications of, the contract or its terms.

The main finding regarding capacity law in relation to the consumer living with dementia is that the use of the four-tiered test of capacity as set out in the Mental Capacity Act [52] can lead to a number of situations where the consumer living with dementia is bound by a contract because they are deemed to have capacity, whilst not fully understanding the complexity of the consumer contract terms. This can be problematic in relation to contracts that have significant financial implications for the consumer living with dementia or their family.

The overarching finding, however, is that a holistic approach to the law is needed. While each of these areas of law is individually important for consumers living with dementia, they need to be considered and applied in a complementary way (ensuring that these areas of the law are interconnected and interdependent) to adequately protect consumers living with dementia.

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[52] Mental Capacity Act 2005 c9, s 3(1).

Finally, this thesis also illustrates the concepts of autonomy and vulnerability. Autonomy is a key concept in the law, which is constructed around the ideal of "*a man who is autonomous, self-sufficient, in control, capacitous and independent*". [53] This ideal however does not fully reflect most people, including persons living with dementia. The findings show that persons living with dementia may not have all these attributes. The concept of autonomy is nevertheless not fully dismissed in this thesis. The findings show that many persons living with dementia are keen to remain autonomous, i.e. free to make their own choices, with dignity and a sense of independence. [54] In this context, the thesis also explores the notion of relational autonomy. The data demonstrates that choices made by both persons living with dementia and their family members are made by taking into account their relationships and interdependence with others.

In addition, the other key notion, vulnerability, is explored looking at both the narrow and wider sense in which vulnerability is understood. Persons living with dementia might be considered at risk of harm and vulnerable when acting as consumers, by family members, other third parties, or themselves. Of particular concern is the situation when a person living with dementia is thought to be vulnerable yet still capable. For the consumer living with dementia, this means that they are capable of entering into consumer contracts despite their potential or actual vulnerability. Whilst such freedom of choice is desirable, the law however does not adequately protect those in this particular circumstance from financially detrimental decision-making. The findings show that some persons living with dementia reject any notion of being vulnerable, which results in both a refusal to accept help from family members, and a refusal to acknowledge their illness to the business counterpart. In other cases, consumers living with dementia will willingly inform others of their diagnosis of dementia, and rely on family to assist in exercising their choices.

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[53] Herring, J. (2016) *Vulnerable Adults and the Law.* Oxford University Press, at 1.

[54] Here, autonomy is used as described by the CRPD, Article 3. For a detailed discussion of autonomy, see Chapter 3.

1.5 Overview of thesis

Chapter 2 demonstrates *why* this is an important topic to research. It introduces various concepts that will then be further described and analysed throughout the thesis.

Chapter 2 sets the scene by exploring facts and figures relevant to current consumer trends and dementia statistics. Decision-making in general, and contractual and financial decision-making in particular, requires a number of skills and these are examined herein. This chapter also reviews different types of contracts that a person living with dementia may enter into, and in so doing, explains the varying levels of difficulty associated with these different categories of contracts. Finally, decision-making has a direct effect on a person's well-being, and this chapter therefore also looks at the issue of well-being in relation to the financial, physical and emotional independence of persons living with dementia.

Following this overview of background facts on consumers living with dementia, **Chapter 3** examines the concepts of autonomy and vulnerability, which inform the analysis of subsequent empirical findings.

The reason for this detailed analysis is because the person living with dementia will often be considered at a crossroads; in law they may be deemed to have autonomy to act as a consumer if they are capable under the relevant legislation, but they may also be deemed vulnerable (i.e. at risk of harm) depending on the progression of the disease. By challenging the notion that the norm within society is that of a rational person, capable and independent, this chapter examines how this concept of the autonomous person ignores the reality of our collective and individual dependence and interdependence. Chapter 3 explores Fineman's concept of universal vulnerability.[55] Dependency and interdependency are inevitable, from infancy through childhood to adulthood.[56] Whilst persons still seek to act

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[55] Fineman, M. (2008) 'The Vulnerable Subject: Anchoring Equality in the Human Condition' *Yale Journal of Law & Feminism* 20(1): Article 2, at 1.

[56] Fineman, M.A. (2017) 'Vulnerability and Inevitable Inequality' *Oslo Law Review* 4(3): 133-149, at 144, 145.

autonomously and make their own choices, that autonomy is seen as relational, in that it depends on the interconnection between people. [57] The relational aspect allows for the will and preference of the person deemed vulnerable to be heard and supported in the decision-making process. As such, these concepts move towards a more socially aware society where vulnerability, interdependency and relationality are recognised and valued.

Chapter 4 describes the methodology and methods used. For this thesis, it is important that the voices of those most directly affected are heard. A multi-method approach was therefore chosen in order to fully understand the issues that arise for consumers living with dementia. First, the relevant laws were analysed in detail by examining how the person living with dementia is situated within the law, how their actions as a consumer are viewed and protected, and where the various laws work together or conversely where they create gaps in legal protection. In addition, new data was sought through empirical study, to identify the experiences of people living with dementia, their family members and carers. It is these experiences of the law in practice that highlight most clearly the gaps in legislation for the consumer living with dementia.

The chapter explains the choice of individual and group semi-structured interviews, which allow participants to express their thoughts, opinions and experiences openly and freely, and the topics addressed. These covered decision-making by the person living with dementia, and capacity issues, including how, when and by whom capacity is to be assessed. The participants talked about assisted or supported decision-making, be it informally with friends or family members helping take decisions, or formally though a legal construct, such as a lasting power of attorney. The interviews also tackled the issue of stigma and the consequential disclosure (or non-disclosure) of a diagnosis of dementia when entering into contracts.

Chapter 4 also considers the ethical dimension of the project, and reflects on the potentially difficult-to-discuss nature of the topics and the awareness and

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[57] Harding, R (2018). *Duties to Care, Dementia, Relationality and Law*. Cambridge University Press, at 25.

sensitivity required when interviewing.

Next it is necessary to review what has already been researched with regards to consumers living with dementia. Beyond exploring the gaps in literature and therefore the place of this thesis within the field, the aim of the literature review is to systematically identify the issues and challenges faced by persons living with dementia when making decisions that have a financial impact on them.

In **Chapter 5**, a scoping literature review considers the question of persons living with dementia and their financial decision-making. In doing so, the review identifies the challenges that persons living with dementia may face when intending to make financial decisions, as well as exploring how financial decision-making may be assessed by (medical or legal) professionals in order to ascertain if a person has financial decision-making capacity. Finally, this chapter also examines the risks of abuse or fraud that have been uncovered in relation to financial decision-making by people living with dementia.

Whilst these aspects allow the project to be situated within the relevant literature, the review will highlight a clear gap in current research on the specific topic of *consumers* living with dementia. This emphasises the need to shed light on the topic of persons living with dementia who enter into consumer contracts, which has been neglected so far. This thesis aims to fill this void.

Chapters 6 and 7 then analyse the current laws that apply to consumers living with dementia. **Chapter 6** explores the *legal categories* that consumers living with dementia fall into, reviewing contract law, consumer law, capacity law and human rights law to ascertain how each area identifies and categorises such consumers.

Chapter 7 then explores the legal remedies that are available to those living with dementia, depending on the category and status afforded to them by a particular area of law. It considers both established legal remedies and what might be termed ‘outlier remedies’, i.e. remedies that the courts have occasionally accepted but which are not yet the legal norm.

This chapter demonstrates that the multitude of different legal rules all address the concerns of the consumer living with dementia in part only. None of these distinct remedies alone provides the full extent of protection required for the consumer living with dementia.

Chapters 8, 9 and 10 analyse the findings from the interview data in the light of the current legal framework. These chapters follow the lifecycle of the contract.

Chapter 8 is themed around the concept of capacity and the related topic of providing adequate consent to enter into the contract. In so doing, Chapter 8 also explores decision-making by the consumer.

The issue of capacity is considered by examining the perceived ability (or inability) of persons living with dementia to make decisions. The question of capacity goes to the heart of whether a legally binding contract is entered into. Related to this is the notion of assisted and supported decision-making.

In addition, Chapter 8 also reviews the differences between legal, financial and mental capacity and reflects on what is considered, in practice, by people with dementia and their family members when addressing their concerns around capacity and consumer contracts.

Chapter 9 explores the challenges that arise when either both or one of the parties to a consumer contract are not aware of the disease. It also looks at the consequences of the disclosure or non-disclosure of information relating to a diagnosis of dementia.

Dementia is an invisible disease, and for many people with dementia, they will not disclose to the business they are contracting with that they have a form of dementia. This might be because they do not know they are living with dementia (i.e. they may be undiagnosed), they have forgotten their diagnosis, or they consciously choose to keep that information private. This chapter also addresses the important issue of stigma surrounding the notion of dementia.

In addition, in Chapter 9, issues that arise during the life of the contract are reviewed. In particular, the on-going rights and obligations of the parties can lead to expected and unexpected challenges as the illness develops. Empirical data reveals the difficulties experienced by people with dementia and their family members in trying to comply with contract obligations that may have been neglected due to the disease. Such contract obligations include the requirements to make regular payments, provide timely notices regarding any change of circumstances, or comply with other specific obligations (e.g. meter readings). Of particular concern is the practice of automatic renewal of contracts.

Finally, in **Chapter 10**, the issues that arise at the end of the contract, at the moment of termination, are considered. Consequently, Chapter 10 will look at the expressed powerlessness of either people living with dementia or their families, when a person living with dementia has entered into an ‘unwise’ (or financially detrimental) consumer contract.

Chapter 10 explores ways in which in practice family members have sought to terminate contracts, either because the person living with dementia actively asked them to do so, or because the contract was, in the eyes of family members, deemed not to be in the best interests of the person living with dementia. This chapter also considers what success their efforts have had. Empirical data describes the attempts made by people with dementia or their family members to cancel or void contracts without incurring termination penalties or fees. The interview data reveals that in many cases in practice family members and people living with dementia experienced much resistance when attempting to do so.

Furthermore, in Chapter 10, possible solutions as envisaged by family members and people living with dementia are presented and considered critically.

Following on from the presentation and analysis of findings of the new interview data, **Chapter 11** summarises and integrates the findings from the work presented in this thesis in an overall discussion. It aims to draw from all the above to present potential solutions. These solutions cover both practical steps that can be taken to assist the consumer living with dementia, as well as possible legal remedies to be considered by policy makers to ensure further protection for this specific group of persons in particular, and (vulnerable) consumers more generally.

In this chapter, the examples first presented in Chapter 1 are revisited and outcomes re-imagined, were the proposed legal changes implemented today.

Chapter 2 Context of the research

2.1 Introduction

In order to answer the research question and identify the consequences, legal and practical, when a person living with dementia enters into a consumer contract with a business, it is important to fully explore the issues regarding consumers living with dementia. In this background chapter, relevant data, statistics and information are provided. By looking at the number of people currently diagnosed with dementia in the UK and globally, as well as forecasts of the proportion of people who will be living with dementia in the short and medium term, the urgency and importance of the topic is highlighted.

Section 2.2 provides a range of statistics on dementia. For example, this section explores the issues surrounding the proportion of people living with *undiagnosed* dementia. In relation to this significant group of people, it is important to consider if there are specific contractual matters that arise in consumer contracts when the disease is unknown to both parties.

Different *types* of dementia, as well as different *stages* of the illness will determine, to some extent, a person's ability to live independently and enter (confidently) into a consumer contract. This section questions how and to what extent these variations are impactful when making financial and contractual decisions.

Finally, the *age* at which dementia is developed may in some instances affect a person's ability to interact with a business. Whilst most older consumers have embraced new technologies, for some older persons communication with businesses has become more difficult if they are unfamiliar with email or using websites. For those who experience the cognitive challenges of dementia, more recent technologies may compound their inability to interact with a business successfully due to their inability to retain new information on how to use new web-based communication channels.

Section 2.3 then analyses the difficulties that may arise for a person living with dementia in the context of decision-making and contract law generally.

This section also looks at different types of contracts in order to distinguish these for the purpose of this research. Indeed, the person living with dementia may have to make contractual decisions, which for the purposes of this research have been categorised as fundamental liberties, unilateral contracts or bilateral contracts.

'*Fundamental liberties*' relate to basic human choices and needs. Examples include decisions regarding medical treatment, or decisions about where to live. '*Unilateral contracts*' require the person to make decisions that will benefit others, but without the counterpart providing anything in return. These include decisions about their last will and testament, lasting powers of attorney, or donations, be it to family members or charity. Finally, '*bilateral contracts*' are agreements where both parties contractually promise to either give a benefit or incur a detriment. A typical and relevant example for the purposes of this research is the consumer contract where one party, the business, provides goods, services or digital content in exchange for money from the other party, the consumer.

Next, **Section 2.4** considers current consumer trends. In doing so, this section explores the shift by businesses that has occurred towards the older consumer in recent years, due to changing demographics and spending power. This section then lays out what these new consumer trends might mean in the context of this project. Finally, **Section 2.5** will provide concluding remarks.

2.2 Relevant dementia statistics

Dementia is defined by the World Health Organization as the deterioration in both (a) cognitive function (i.e. the ability to process thought), and (b) emotional control, social behaviour, or motivation.[1] Over time its effects can be devastating on the person living with dementia and their family members.

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[1] World Health Organization (2020) *Dementia fact sheet*, available at https://www.who.int/news-room/fact-sheets/detail/dementia, last accessed on 14 February 2021.

The above definition recognises that dementia can be considered from both a clinical and a social perspective. The idea of the social model of disability is not a new concept and can be traced back to early disability studies work by Michael Oliver.[2] The 2007 report[3] by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) highlights these two aspects of dementia. The clinical perspective considers medical and pharmacological interventions*,* whilst the social model [4] explores the impact that the disease will have on every-day activities, such as shopping, financial decision-making and personal care. It is this social perspective that is of particular relevance for this thesis.

The All Party Parliamentary Group on Dementia published a major report in association with the Alzheimer's Society in 2019 identifying dementia as a disability.[5] Whilst traditionally the definition of disability was focused on what the person could not do, now disability is seen as stemming not from the person but rather from their surroundings; in other words, a person is not *per se* 'dis-abled' to do certain things, but rather they may be placed in a (societal) situation which is not catered to their needs.

For example, a person in a wheelchair would be able to access all buildings, were it not for a lack of ramps or other external supports; a person living with dementia would be able to participate with confidence in all consumer transactions, were it not for a lack of (legal) protection from financial or other disadvantages.

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[2] Oliver M. (1990) 'The Cultural Production of Impairment and Disability' in *The Politics of Disablement. Critical Texts in Social Work and the Welfare State*. Palgrave, London; Oliver M. (1996) 'The Social Model in Context' in *Understanding Disability*. Palgrave, London.

[3] NICE-SCIE (2007) *Dementia: The NICE_SCIE Guideline on supporting people with dementia and their carers in health and social care. The British Psychological Society and Gaskell*, available at https://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf?res=true, last accessed on 14 February 2021.

[4] ibid. at 70.

[5] All Party Parliamentary Group on Dementia (2019). *Hidden no more: Dementia and disability*. Alzheimer's `society, available at https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf, last accessed on 11 August 2021.

The NICE-SCIE report of 2007 also emphasises this idea, stating

> *From the perspective of the social model, people with dementia may have an* ***impairment*** *(perhaps of cognitive function) but their* ***disability*** *results from the way they are treated by, or excluded from, society.*[6]

Throughout this project, dementia is therefore to be understood in context.[7] This means that it requires a "*broad view, one in which dementia is seen as a condition that people live with; and thus one which quintessentially involves persons*".[8] These will include the person living with dementia, their family members, friends, carers, as well as businesses and society at large.

Considering the numbers and the percentage of the population that are likely to be affected (the detail of which is set out below), this situation requires immediate and careful review from both the medical/clinical point of view, as well as from a social perspective, i.e. in terms of how persons living with dementia are treated in society and how the law caters for it. It is important to look at their role and position within the community, their actions as consumers, their participation in day-to-day events, but also their isolation, the risks they encounter and consequently our societal responsibility towards those that live with dementia. This research specifically explores how society currently looks at and deals with dementia, and the societal issues that emerge when persons living with dementia transact and interact with others as consumers.

Dementia in numbers

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[6] NICE-SCIE (2007) *Dementia: The NICE_SCIE Guideline on supporting people with dementia and their carers in health and social care. The British Psychological Society and Gaskell*, available at https://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf?res=true, last accessed on 14 February 2021, at 71.

[7] See Chapters 6 and 7 for an examination of dementia in the context of current legislation, and Chapters 8, 9 and 10 for the exploration of how persons with dementia experience the disease in daily life.

[8] Hughes, J. C. (2011) *Thinking through dementia* Oxford University Press, at 14.

As was touched upon in the introductory chapter, dementia is a global challenge with an estimated 50 million persons living with dementia worldwide.[9] In the UK, in 2014 there were approximately 850,000 people living with dementia.[10] So far, there is no cure or treatment in sight that might reduce or reverse the steady growth of the disease. It has overtaken cancer as the most common cause of death in England and Wales, accounting in 2018 for 12.7% of all deaths registered.[11]

Difficulty of diagnosis

As will be further discussed below, the symptoms of dementia are such that decision-making, especially for complex consumer contracts, will be more challenging for the person living with dementia due to their illness and resulting cognitive impairment. Consumer transactions may be entered into that are (financially) detrimental to the person living with dementia.

Whilst such a correlation between dementia and detrimental contracts can be established when there is an awareness of the illness, in many cases people living with dementia and their friends or family members are not (yet) aware of any issues. The dementia in these cases is still undiagnosed.

It is understood that in developed countries at least half of all dementias are undiagnosed.[12] The issue of diagnosis is significant not only in relation to early intervention and care options, but also when considering the

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[9] World Health Organization (2020) *Dementia fact sheet*, available at https://www.who.int/news-room/fact-sheets/detail/dementia, last accessed on 14 February 2021.

[10] Prince, M. et al. (2014) *Dementia UK: Update.* Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society, at 43.

[11] Office of National Statistics (2018) *Deaths registered in England and Wales (series DR): 2017*, available at https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2017 last accessed on 14 February 2021.

[12] Savva, G.M. and Arthur, A. (2015) 'Who has undiagnosed dementia? A cross-sectional analysis of participants of the Aging, Demographics and Memory Study' *Age and Ageing* 44(4): 642–647, at 642.

consequences for all involved when people living with dementia enter into contracts as consumers.

Where dementia is undetected, this will have a detrimental effect on well-being, support services and relevant capacity considerations.[13] This is because in such cases where there is no diagnosis, there is no recognition of the impact that dementia will have on a person's ability to make a decision that is right for them. Memory loss is often – wrongfully - considered part of the normal aging process and not taken particularly seriously. During this time *before* diagnosis, a person with undiagnosed dementia may interact in a way that is out of character, does not reflect their values and principles, or is not in their best interests. However, they may not consider that they have any reasonable grounds to question or contest the contract they have entered into. Consequently, many people will live independently, transact with businesses, and blame themselves when contracts are later unwanted, unnecessary or unaffordable, without realising that their actions can be explained, at least partially, as the result of their cognitive impairment due to dementia.

Different forms of dementia

Dementia is a progressive and mainly irreversible disease that is characterised by a gradual impairment of mental ability.[14] The main forms of dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementias.[15] The symptoms for all forms of dementia are generally mild to start with, but will worsen over time and start to interfere with daily life. Whilst there are clear differences in what might trigger a dementia and even to some extent in how

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[13] Lang, L., Clifford, A., Wei, L., Zhang, D., Leung, D., Augustine, G., Danat, I. M., Zhou, W., Copeland, J. R., Anstey, K. J., & Chen, R. (2017) 'Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis' *British Medical Journal 7*(2): e011146, at 1.

[14] NICE guidance (2016) *Dementia: supporting people with dementia and their carers in health and social care*. NICE Clinical guideline CG42.

[15] For other forms see Alzheimer's Society (undated) *Rarer types of dementia*, available at https://www.alzheimers.org.uk/about-dementia/types-dementia/rarer-types-dementia, last accessed on 14 February 2021.

the symptoms and consequences of dementia are experienced and lived, there are a number of common traits that will make decision-making as a consumer more difficult.

Table 2.1 sets out the symptoms of the most common forms of dementia, showing their common features, as well as some differences.

	Memory loss	**Reasoning**	**Orientation**	**Delusion**	**Out of character**	**Other symptoms**
Alzheimer's disease	✔	✔	✔	✔	✔	✗
Vascular dementia	✔	✔	✔	✔	✔	✗
Dementia with Lewy bodies	✔	✔	✔	✔	✔	✔ (Parkinson symptoms)
Fronto-temporal dementia	✗	✔	✔	✔	✔ (Loss of inhibition)	✔ (Speech impediment)
Mixed dementia	✔	✔	✔	✔	✔	✔

Table 2.1 Typical symptoms of common forms of dementia

As stated by the World Health Organization,[16] there is a certain commonality in relation to the symptoms, many of which are, generally speaking, recognisable to a degree in all forms of dementia. Indeed, as is visible from the table, most common forms of dementia have a number of similar symptoms.

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[16] World Health Organization (2020) *Dementia fact sheet*, available at https://www.who.int/news-room/fact-sheets/detail/dementia, last accessed on 14 February 2021.

It is clear that a number of these symptoms will be of particular concern when considering the implications for consumer contracts. These can include some, any or all of: [17]

- Challenges with understanding, reasoning, thinking and judgment: in order to assess the value of a deal, it is necessary for each contracting party to be able to understand the terms of the agreement, weigh up the advantages and disadvantages and judge if the deal is of benefit to them. These are traits that may not be fully available to people living with dementia.[18]

- Memory loss: memory is crucial in day-to-day dealings with businesses. Without sufficient memory a person may not realise whether they already have the services or goods on offer, whether they can afford these or whether other providers have better deals. *Before* an agreement is struck, memory loss may result in confusion about whether a certain product or service (and consequently the contract) is required. *After* the contract is finalised, memory loss may result in the person living with dementia potentially not remembering or understanding the contract as a whole, or certain of the terms and conditions entered into.

- Language impairment: where language is no longer clear, contracts, even in plain English, may no longer be as easily comprehensible to the person. Challenges faced by the person living with dementia when attempting to reason and communicate their thoughts on the contract terms might also prevent them for negotiating the contract or amending a term of the contract effectively.

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[17] NICE guidance (2016) *Dementia: supporting people with dementia and their carers in health and social care*. NICE Clinical guideline CG42.

[18] Most participants in this study recounted events where a lack of understanding had led to contracts subsequently being challenged. See for example in Section 8.3, Lauren who challenged a verbal gardening contract entered into by her mother who was living with dementia.

- Fluctuating alertness, alternating lucid moments with moments of confusion: the trouble with fluctuations in alertness is that a person can safely rely on their ability one minute, but may have severe difficulties entering into a contract the next. As the fluctuations arise without warning, the risk of entering into a contract in a moment of intense confusion is real.

- Out-of-character behaviour (such as disinhibited behaviour): many family members and carers will point to this symptom as troublesome. Reckless behaviour with finances or frequent and costly expenses incurred for out-of-character goods or services (e.g. pornography) may mean that a person living with dementia is spending money that they can ill afford to lose on things they would not usually choose. In particular for people living with fronto-temporal dementia, the potential loss of inhibitions may mean that such people are more inclined to enter into contracts that they would not have chosen before the illness. In doing so, they may be making (financially) risky, reckless or unwise decisions, due to compulsions brought on by the disease. They are often deemed to be behaving in socially inappropriate ways or acting in an impulsive or rash manner. It can also often be difficult for family members to talk about these choices, as the disinhibited behaviour can radically alter the previous core characteristics of the person.

All of these symptoms will affect a person's ability to enter into a consumer contract knowingly and freely.[19] The symptoms are likely to make decision-making generally, and entering into a contract specifically, more challenging. Given the symptoms, it is at least questionable if a person living with dementia is always fully aware of the impact the contract will have on their finances.

The Alzheimer's Society suggests that these symptoms may first become apparent when managing work or financial matters.[20] This project proposes that entering into consumer contracts is a subset of financial matters, and should be afforded particular attention.

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[19] See Chapter 6, which sets out the fundamental principles of contract law.
[20] Alzheimer's Society (2014) *What is Alzheimer's disease?* Factsheet 401LP.

Whilst the most common symptoms in relation to the various forms of dementia are identifiable in general terms, everyone's experience with dementia will vary depending, not only on the form of dementia, but also on the individual, the stage of the illness, the person's general health and constitution, their nutrition and exercise regimes, access to treatment and assistance, position or role within their community, and a dose of luck.

Consequences of dementia

Dementia is not just a health issue, but also a social/societal challenge. The consequences of this neuro-degenerative disease include stress, fear, isolation and abuse. It has been emphasised that in order to combat these negative effects of the illness, the focus must be on providing thoughtful support and ensuring that the person living with dementia can live as well as possible with the condition.[21] This too has implications when entering into consumer contracts, as this section will explain.

The IDEAL study (Improving the experience of Dementia and Enhancing Active Life)[22] has identified the many factors that will have an impact on a person's ability to live well with dementia. These factors are summarised in the following Figure 2.1.

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[21] Banerjee, S. (2010) 'Living well with dementia - development of the national dementia strategy for England' *International Journal of Geriatric Psychiatry* 25: 917-922, at 917.

[22] Clare, L. et al. (2014) 'Improving the experience of dementia and enhancing active life - living well with dementia: study protocol for the IDEAL study' *Health and Quality of Life Outcomes* 12: 164.

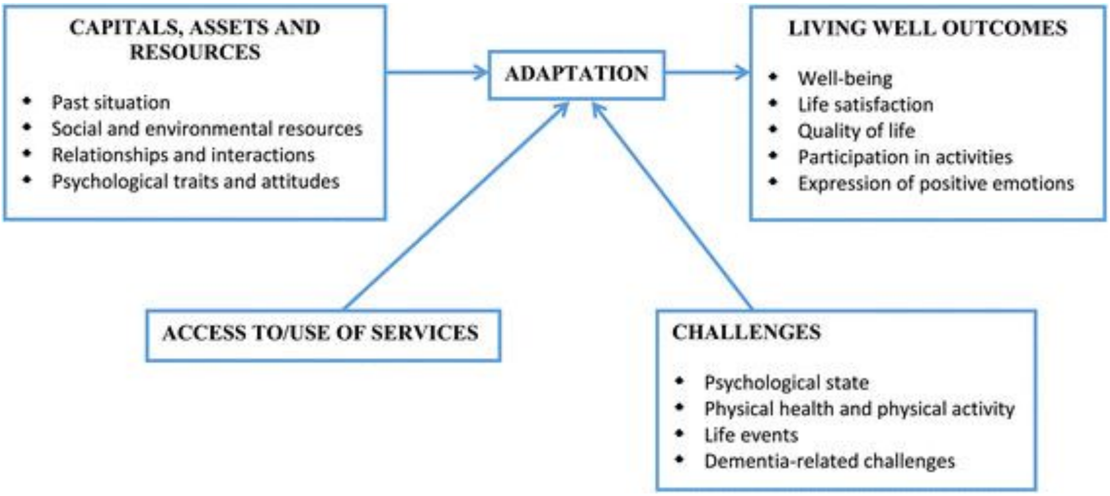

Figure 2.1. Clare, L. et al. (2014) *Improving the experience of dementia and enhancing active life - living well with dementia: study protocol for the IDEAL study*. Health and Quality of Life Outcomes 201412:164

As seen from the above figure, living well covers a wide range of aspects of a person's life. Internal 'challenges' relate for example to the person's psychological state and physical health, external elements include a person's social and environmental resources, as well as the relationships and interactions with others. It is in relation to these external elements that society can make a difference in the way persons living with dementia are treated. The amalgamation of both internal and external experiences will determine the 'quality of life' of the person living with dementia, with the aim of ensuring that all persons can live as well as possible.

Living well is also described as living with dignity and confidence.[23] It includes being able to make choices and decisions, managing the health of one's own body and mind, living independently but not in isolation, and enjoying both physical and financial safety. It is shaped by the physical, social and cultural

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[23] Johnston, B., Lawton, S., McCaw, C., Law, E., Murray, J., Gibb, J., Pringle, J., Munro, G., Rodriguez, C. (2016) 'Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy' *International Journal of Older People Nursing* 11: 107-120, at 108.

surroundings of the person.[24] Relationships with others are vital and will include the interactions as consumers with businesses. Whilst living well is the objective, this is not always fully achievable. Some authors have pointed out the challenges of living well with dementia.[25] As referred to in chapter 1, the World Dementia Report of 2015 highlights that *"its greatest impact is upon the quality of life* [26] of all affected by the disease.

In order to improve quality of life, it is essential to give the person living with dementia confidence that their choices and decision-making will be taken seriously for as long as possible. However, this should not imply that decisions made by the consumer living with dementia cannot be reviewed. Living well also means that people with dementia should be able to count on the fact that their actions can be undone if they make a decision when their cognitive skills were reduced, and which they later wish to revise.

This thesis suggests that 'living well' must also include giving people living with dementia the freedom to make decisions, interact and transact with businesses and other commercial parties, in the knowledge that there are protections in place to preserve and uphold that person's interests if or when a contract is entered into. This should be the case especially if it transpires at a later date that the contract was misunderstood, unwanted, unhelpful or unaffordable. In Chapter 7 below[27] on the legal protections available to the person with dementia, the aim is to analyse the extent to which the law achieves this balance today.

Different stages of dementia

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[24] Harris, J.R. and Wallace, R.B. (2012) 'The Institute of Medicine's new report on living well with chronic illness. Preventing chronic disease' *PMC* 9: E148, at 1.

[25] Bartlett, R., Windemuth-Wolfson, L. Oliver, K. & Dening, T. (2017) 'Suffering with dementia: the other side of living well' *International Psychogeriatrics* 29(2): 177-179.

[26] Alzheimer's Disease International (2015) *World Alzheimer Report 2015*. Alzheimer's Disease International London, at 69.

[27] See Sections 7.2 and 7.3.

Dementia is often described in three distinct categories, namely: early stage, medium stage and, finally, later stage.[28] Progression of the illness differs for each person but in general, these stages can span over a time frame of up to 20 years.[29] The stage of the disease will directly impact on a person's ability to make decisions.

During the early stage of the disease, the person living with dementia is generally functioning well independently. Whilst they may take longer to read and understand a consumer contract, they will generally still be able to do so at this stage.

It is during the middle stage of dementia that specific legal protective measures are most needed. At this middle stage, the person living with dementia may still be *capable* [30] of making decisions, and indeed in practice may still be making decisions as a consumer. A person living with moderate dementia can usually hold short, casual conversations, and as a consequence, the disease may not be apparent to strangers, including contractual counterparts. This is particularly significant for this research, as sales representatives who meet the consumer living with dementia only briefly will often be unable to detect that there is some cognitive impairment. This in turn will have consequences for the validity of any consumer contract entered into.[31]

Finally, at the advanced stage of dementia, from a pragmatic standpoint, most people living with dementia will no longer be in a position to enter into contracts as consumers. This is because few people living with advanced

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[28] Alzheimer's Association (2018) *Stages of Alzheimer's disease*, available at https://www.alz.org/media/Documents/alzheimers-stages-early-middle-late-ts.pdf, last accessed on 14 February 2021.

[29] 'LiveBetterWith' (undated) *What are the stages of dementia?*, available at https://dementia.livebetterwith.com/blogs/advice/what-are-the-stages-of-dementia?rdrt=uf, last accessed on 14 February 2021.

[30] In Chapter 8 on capacity, a distinction is drawn by the participants to this project between capacity as determined under the Mental Capacity Act and capacity in practice which was usually decided by family members and took into account not only the ability of the person to make decisions, but also the family's concerns of perceived risks.

[31] See Section 7.2 on the conditions of voiding a contract for lack of capacity of one of the contracting parties.

dementia can still do so independently. Instead they are either living with family or in a care or nursing home, where carers will usually form a barrier to consumer transactions. The lack of independence at this stage would make encounters with commercial counterparts unlikely.

Yet, this does not mean that legal protection is not needed. In fact, where a contract with a business was nevertheless entered into at this stage, it would more easily be questioned and contested by carers, family members or attorneys. The (more obvious) lack of capacity, which the business representative "*knew about or ought to have known about*",[32] would render contracts void, as discussed in Chapter 6.[33]

Different ages of the person living with dementia

So far, this section has explored a number of aspects that can contribute to the challenge faced by consumers living with dementia. These have included factors such as whether there is a *diagnosis* of dementia, what *form* the dementia may take, and at what *stage* a person might find themselves within the evolution of the illness.

In addition, the *age* of the consumer living with dementia may impact on their ability to fully understand the new technologies used by businesses to interact with consumers. Whilst most consumers of all ages are comfortable with new technologies, the extensive use of the internet in day-to-day life as well as automated call systems may be more challenging for some older consumers who are not as familiar with that technology. This is however not a given development [34] and many older persons have embraced and adopted all new technology as it becomes available.

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[32] Ayres v Hazelgrove (QB, 9 February 1984, unreported); for a detailed discussion, see Section 6.1.

[33] ibid.

[34] Hall, M.I. (2019) 'Situating Dementia In The Experience of Old Age: Reconstructing Legal Response' *International Journal of Law and Psychiatry* 66:2, at 1, 2.

In those minority cases where there is a difficulty experienced with new technology by some older consumers, this may be heightened for those consumers living with dementia.

So far this background chapter has provided relevant information on dementia and how the illness will impact the person living with dementia when transacting as a consumer. Next, a key issue that will be explored throughout the thesis is the concept of decision-making with regards to the person living with dementia

2.3 Decision-making and contract law

The ability to make a decision is essential when entering into a contract. Indeed, decision-making is linked to two fundamental principles that govern the law on the formation of contracts, namely the need to have both the intention and the capacity to enter into a contract. However, decision-making is no simple task. It can be hard for most people, but for the person living with dementia, decision-making can be even harder.

As seen above, the World Health Organization describes dementia as the deterioration in cognitive function [affecting] memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment, as well as emotional control, social behaviour, or motivation. [35] These two aspects of the disease will be considered in light of decision-making, before exploring the many decisions a person will face when a diagnosis is first delivered.

Cognitive function and decision-making

In order to explore more specifically the decision-making process required when entering into a consumer contract, an *ideal* decision-making process is considered when taking out a loan. Of course, many consumers will act without forethought, however where there is no cognitive impairment or

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[35] World Health Organization (2020) *Dementia fact sheet*, available at https://www.who.int/news-room/fact-sheets/detail/dementia, last accessed on 14 February 2021.

learning disability, consumers would be able, if desired, to consider the loan carefully.

The first decision to be taken would be to identify whether the loan was needed and wanted. The second decision was then to consider whether the particular loan offered by a bank meets the requirements for which it is taken out. Finally, a third decision would relate to whether this loan was the most appropriate for the borrower's needs, compared to the wider market of loans available to them. For all of these decisions, the potential borrower would need to be able to **think** about the offer made, **comprehend** the terms and conditions attached to the offer, understand the **language** used, **remember** other deals to draw comparisons, **calculate** the interest rates and repayment cost over the loan period and use **judgment** to weigh all the elements up and come to a decision. All these are cognitive functions that the person living with dementia may lose over the course of the illness.

Current consumer laws provide protections to consumers because their lesser economic power is recognised in relation to the commercial counterpart. The business must use clear language,[36] highlight restrictive or costly clauses[37] and clearly disclose all financial obligations.[38] However, simplifying the language or providing a comprehensive list of disclosure requirements, as suggested by the Consumer Rights Act,[39] will not necessarily assist the person living with dementia. The issues are more fundamental and not solved by clearer or further information.

Emotional control and decision-making

In addition to the cognitive demands required for decision-making, the person with dementia may find that their personality changes.[40] These changes can lead to irrational **social or emotional behaviours** – a person who was

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[36] Consumer Rights Act 2015, s. 64(3) and 68.
[37] Consumer Rights Act 2015, s. 64(4).
[38] Consumer Rights Act 2015, s. 62(5).
[39] Consumer Rights Act 2015, s. 68.
[40] Balsis, S., Carpenter, B.D., Storandt, M. (2005). 'Personality Change Precedes Clinical Diagnosis of Dementia of the Alzheimer Type' *The Journals of Gerontology: Series B*, 60(2): 98–101, at 99.

cautious might become reckless, another person who was confident might become fearful. Some might find themselves disinhibited.[41] The new behaviours may result in decisions being taken which are out of character, and crucially may be unwise and even harmful to the person, emotionally or financially.

Diagnosis and decision-making

The difficulties faced by a person living with dementia when making a decision are obvious. And yet, at the time any diagnosis of dementia is made, there are usually a multitude of decisions that need to be taken.[42] The person may be asked what their long-term aims are in managing the situation. Questions will be asked about whether they want to stay living independently at home or whether it might be more reasonable to think about nursing homes. Their opinion is sought regarding treatment options, both immediately and looking ahead at long-term care and treatment decisions that might need to be addressed at a later stage.[43]

General practitioners and family members may talk about assisted or delegated decision-making, for example by lasting power of attorney. Decisions need to be made about whether the person living with dementia wants to entrust such power to make decisions in their stead, whether such delegation should relate to financial matters, health matters or both, who should be their attorney, and when any such transfer of power should occur.[44] Well-meaning relatives and carers will give their opinion, but unless they are declared legally to lack capacity in line with the Mental Capacity Act 2005,[45]

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[41] Alzheimer's Society (2016) *What is frontotemporal dementia (FTD)?* Factsheet 404LP.

[42] Vernooij-Dassen, M., Derksen, E., Scheltens, P., & Moniz-Cook, E. (2006) 'Receiving a diagnosis of dementia: The experience over time' *Dementia* 5(3): 397–410, at 401.

[43] Fisk, J.D.; Beattie, B.L.; Donnelly, M.; Byszewski, A.; Molnar, F.J. (2007) 'Disclosure of the diagnosis of dementia' *Alzheimer's & Dementia* 3(4): 404-410, at 408.

[44] Alzheimer's Society (undated) *Lasting power of attorney*, available at https://www.alzheimers.org.uk/get-support/legal-financial/lasting-power-attorney, last accessed on 14 February 2021.

[45] Mental Capacity Act 2005, s. 2.

the person living with dementia will have to make the decision as to what they want to do and decide whose advice and guidance they want to trust and follow. Their decisions at this stage may have consequences for any consumer contracts that they might want to enter into at a later stage.

More generally, donation requests might be raised with the person living with dementia, for example by charities that will seek contact by post, email, telephone or on the doorstep. Family members might talk about funding various projects; a testament should be written.[46] These are yet more decisions for the person living with dementia to have to grapple with.

Of course, the person living with dementia is still (for a long time) an active member of society and as such is subjected daily to a deluge of offers from businesses. Advertisers, cold callers, and sales persons in shops and on their doorstep all vie to conclude a deal. Whilst the rules and regulations regarding advertising, marketing, consumer and commercial practices, as discussed in detail in Chapter 6 below,[47] can curb certain more aggressive sales behaviours, much is within the authorised limits of advertising. The person living with dementia, as everyone else, will have to make decisions on what they want, what they need, and what they can afford.

Different decisions of varying difficulty

These decisions that the person living with dementia is faced with are not all equal, but can be categorised into separate types of choices to be made. Harding and Tascioglu differentiate between three types of decisions, namely

> …*everyday preferences, life choices, and difficult decisions. Everyday preferences include the kinds of choices that most people make on a day-to-day basis, about what to wear, what to eat, what to do or where to go that day. We describe decisions about working, learning, housing*

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[46] NHS (2018) *Giving someone power of attorney*, available at https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/giving-someone-power-of-attorney/, last accessed on 14 February 2021.

[47] See Section 6.4 on unfair practices legislation.

> *and relationships as ‘life choices’ and legal, financial and medical decisions as ‘difficult decisions’.*[48]

Whilst the everyday preferences are often decisions that are easier to make and can more easily be supported by carers, life choices and difficult decisions are more complex, both for the person living with dementia and in terms of the support that is available to them. The focus of this research is on a particular subset of the ‘difficult decisions’ identified by Harding and Tascioglu, those relating to financial decisions as a consumer.

In this research, these life choices and difficult decisions have been further categorised and differentiated as fundamental liberties,[49] unilateral contracts[50] and bilateral agreements. Focus in this thesis is on a subset of the last group, namely bilateral *consumer* contracts, where a person living with dementia acts as a consumer, purchasing or hiring goods, services or digital content from a commercial entity, the trader, in exchange for money. Such contracts raise particularly difficult issues for consumers living with dementia because of the conflict between the assumption of classical contract law that both parties understood the deal and accepted the terms of their transaction and the reality of consumers being usually faced with adhesion contracts, i.e. a set of standard terms and conditions of great complexity, in relation to which they have no negotiation power.[51] As a consequence, the subject matter of the contract can be highly complex, and the sale or hire of the goods, services or

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[48] Harding, R. & Tascioglu, E. (2018) ‘Supported Decision-Making from Theory to Practice: Implementing the right to enjoy legal capacity’ *Societies* 8(2) 25: 1-17, at 4.

[49] These relate to decisions regarding the person making the decision, such as where to live, medical treatment, or end-of-life treatment. See eg Hall, M.I. (2009) ‘Capacity, Vulnerability, Risk and Consent: Personhood in the Law’ in O’Connor, D. and Purves, B. (eds) *Decision-making, Personhood and Dementia: Exploring the Interface*, Jessica Kingsley Publishers: London and Philadelphia, at 121.

[50] For example decisions regarding donations, their ‘last will and testament’ and any delegation of power to an attorney.

[51] Elshout, M., Elsen, M., Leenheer, J., Loos, M., & Luzak, J. (2016) *Study on consumers’ attitudes towards Terms and Conditions (T&Cs): final report*. Brussels: European Commission, at 17, 18.

digital content may be conditional upon a multitude of terms and conditions, i.e. financial and legal provisions that will affect the use of the underlying item.

2.4 Consumer trends

Consumer trends have been shifting in recent years.[52] With falling birth rates, slowing population growth and greater longevity of life, the world's population is aging. The total number of people aged 65 or older is expected to more than double globally from 617 million in 2016 to 1.6 billion by 2050.[53] In the UK, households in which the household reference person is aged over 50 have increased from 12 million in 2003 to 14 million in 2012.[54] The 'over 50s' are estimated to represent over 50% of the UK's incomes,[55] 68% of the UK's wealth and 76% of the UK's financial wealth,[56] and accounted for £320 billion (47.6%) of UK household expenditure in 2012.[57]

Older consumers are therefore being courted by businesses. The term 'silver pound' or 'grey pound' has been coined to describe the buying power of these older purchasers of goods and services. This has become more visible in advertisements and marketing campaigns fronted by older models and spokespersons.

The way in which consumers are shopping is also changing. As described in

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[52] Office for National Statistics (2003) *Family Spending Survey, 2003* and Office for National Statistics (2012) *Family Spending Survey, 2012.*

[53] He, W., Goodkind, D. and Kowal, P. and U.S. Census Bureau (2016) *An aging world: International Populations Reports*. U.S. Government Publishing Office, Washington, DC, at 133.

[54] Office for National Statistics (2003) *Family Spending Survey, 2003* and Office for National Statistics (2012) *Family Spending Survey, 2012*.

[55] Office for National Statistics (2012) *Family Spending Survey, 2012.*

[56] Financial wealth includes "*assets, for example, savings accounts, financial investments and stocks and shares*", whereas 'wealth' encompasses "*financial wealth, pensions, physical and property wealth*". Available at https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/bulletins/totalwealthingreatbritain/april2016tomarch2018, last accessed on 14 February 2021.

[57] Cebr (2014) *Consumer spending key trends among over 50s, a report for Saga*, February 2014, at 5, available at http://www.cpa.org.uk/cpa-lga-evidence/Saga/Saga(2014)-Consumer_spending_key_trends_among_the_over_50s.pdf, last accessed on 14 February 2021.

its latest report on Internet access, the Office for National Statistics explained that "[*in] 2019, for the first time, more than half of adults aged 65 years and over shopped online*".[58] This has implications for the way in which consumers may be encouraged to enter into consumer contracts with businesses and will be further considered when exploring the legal protections in Chapter 7.

In addition, there is a growing awareness within the business world of the profits to be made from products and services catered for the dementia-related market. Connected to this is the emergence of the term "*dementia pound*".[59] The Alzheimer's Society explains in their dementia-friendly business guide[60] the need for businesses to embrace this latest consumer trend. It is thought that the average household affected by dementia spends £16,800 per year, and that overall the "*dementia pound*" in England was worth £11bn in 2014, and is expected to double to £23bn by 2030.[61]

However, for many of these businesses vying for the attention of the older consumer, no strategy has been put in place to consider age-specific issues that might affect a small minority (estimated to be between two and ten per cent) of this group of consumers. There remains a lack of laws, advice or information on the prevalence of dementia in business-to-consumer settings. This project aims to fill this gap.

2.5 Concluding remarks

In this chapter, various relevant background aspects to the research question have been presented. These have covered statistics regarding dementia, thoughts on the decision-making process, contractual challenges faced as a consequence, and information on consumer trends that are pertinent to this

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[58] Office for National Statistics (2019) *Internet access – households and individuals, Great Britain: 2019.*

[59] Alzheimer's Society (2018) *Dementia-friendly business guide*, at 14, available at https://www.alzheimers.org.uk/sites/default/files/2018-04/Alzheimer_s_Society_NEW_Business_guide_Web.pdf, last accessed on 14 February 2021.

[60] ibid.

[61] Cebr (2014) *The rising costs of dementia*, available at https://cebr.com/reports/the-rising-costs-of-dementia/, last accessed on 14 February 2021.

research.

By setting out the multiple facets of dementia the aim is to set out a complete picture of the many challenges that need to be taken into account when considering a consumer living with dementia. In highlighting the prevalence of dementia in today's society globally, the urgency of acting is brought to the foreground. By understanding the challenges faced in terms of diagnosis and the consequences for undiagnosed persons living with dementia, a picture emerges that requires any solution to go beyond the limits of a small defined cohort of 'people known to be living with dementia' to be protected. Similarly, the different forms of dementia demonstrate that there is much communality in relation to the symptoms and subsequent challenges encountered when entering into contract, and that consequently solutions must be sought that are relevant to all types of dementia.

The aim of providing a detailed examination of the different forms of decision-making is to highlight the many ways in which the person living with dementia will be challenged daily. It also assists in narrowing this research project to include only bilateral consumer contracts, entered into by the person living with dementia as a consumer, with the business as their contractual counterpart.

Finally, it is important to explore the trend in consumer matters towards the older consumer. As businesses recognise that older consumers are increasingly numerous and affluent, advertising and focus turns to this previously neglected demographic. This means that consumers living with dementia are also part of the group that will be specifically and strongly targeted by businesses with products and services.

In the next chapter, attention will be on the underlying theories that drive this research. To do so, concepts of autonomy and vulnerability are examined in more detail. These will shape the rest of the thesis.

Chapter 3 Exploring autonomy and vulnerability

3.1 Introduction

In the previous chapter, the context was set by reviewing significant background information on dementia, decision-making and consumer trends.

In this chapter, the concepts of vulnerability and autonomy are reviewed. This is no easy task, as both concepts have been defined in different ways for different purposes, generating a considerable body of scholarship. The aim of this chapter is not to provide a full overview of those debates but simply to show how the concepts of vulnerability and autonomy can help to understand the experience of being, or supporting, a consumer with dementia, and the legal responses to those experiences.

In **Section 3.2** the concept of vulnerability is reviewed, looking at both narrow and wide understandings of the concept. This includes a review of the growing field of academic voices expressing their support for the universal vulnerability theory (or a variation thereof), as initially suggested by Martha Fineman.[1] This section highlights literature that suggests that there are fundamental difficulties when a law is drafted which categorises people within the binary distinction of being either autonomous or vulnerable. As I will discuss, how vulnerability is perceived will depend to a large extent on whether vulnerability is conceptualised as exceptional or universal.

In **Section 3.3**, the concept of autonomy in law and practice is examined. Like vulnerability, autonomy can also be understood in different ways. For the purposes of this thesis, two different understandings of autonomy are relevant. First, there is the ideal of the autonomous individual that continues to underpin law in general and contract law in particular, despite numerous scholars rightly pointing out that such an individual is a figment of the legal imagination. This ideal is particularly significant when considering the law as it

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[1] Fineman, M. (2004) *The Autonomy Myth: A Theory of Dependency* The New Press; Fineman, M. (2008) 'The Vulnerable Subject: Anchoring Equality in the Human Condition' *Yale Journal of Law & Feminism* 20(1): Article 2.

applies to consumers living with dementia. In contract law, the classical position assumed two autonomous parties, both free to enter into contracts and free to decide the terms of their deal. Whilst this autonomy has been somewhat tempered through legislation (such as the Consumer Rights Act 2015) [2] and the development of legal doctrine (such as the doctrine of unconscionability), the basic premise of the autonomy of the parties remains significant. The result is that the law is unlikely to take sufficient account of the circumstances of the consumer living with dementia. Understanding how the law valorises autonomy is therefore a crucial part of understanding the challenges facing consumers living with dementia.

The second understanding of autonomy is narrower and relates to the way in which consumers living with dementia see themselves. This is reviewed in **Section 3.4**. Many persons living with dementia feel strongly that despite the onset of the illness they wish to remain free make their own choices by making make decisions for themselves – in other words, they wish to retain a degree of autonomy. Used in this context, autonomy does not refer to the idea of the person who is self-reliant and independent in all aspects of their life, but rather considers only one facet of autonomy, that of making choices for oneself. The concept of relational autonomy is also explored to show how autonomy need not be seen as being in opposition to vulnerability but how both concepts can accommodate each other.

Finally, **Section 3.5** summarises and concludes this chapter.

3.2 Vulnerability in law and practice

Vulnerability is a concept that has been defined both very narrowly and very broadly. At its most basic level, being vulnerable may be defined as being susceptible to harm. Yet this is broad enough to apply to anyone; as Fineman puts it, "*we are born, live, and die within a fragile materiality that renders all of us constantly susceptible to destructive external forces and internal*

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[2] Consumer Rights Act 2015, c15.

disintegration…" [3] Vulnerability can result through either internal factors, such as an individual's mental and physical features, or external factors, such as relationships with others (including an individuals' actual and perceived position within society in terms of power, financial security, education) or events such as *"disease, pandemics, environmental and climate deterioration, terrorism and crime, crumbling infrastructure, failing institutions, recession, corruption, decay, and decline"*. [4]

As Herring has noted, the disagreements about the definition of vulnerability primarily focus upon *who* should be regarded as being vulnerable; in essence, whether the focus should be on *"particular individuals or groups of individuals who suffer particular vulnerabilities"* or whether vulnerability is in fact *"universal and an inevitable part of the human experience"*. [5]

From one perspective, a consumer living with dementia might be seen as self-evidently vulnerable in the narrower sense, on the basis that the cognitive impairment that they may experience increases the likelihood of harm in their interactions with others. Persons living with dementia are often deemed vulnerable, due to the cognitive impairment that may arise as a result of their illness. [6] Dementia may lead to memory loss, a lack of understanding, brain

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[3] Fineman, M. (2008) 'The Vulnerable Subject: Anchoring Equality in the Human Condition' *Yale Journal of Law & Feminism* 20(1): Article 2, at 12.

[4] Ibid.

[5] Herring, J. (2016) *Vulnerable Adults and the Law.* Oxford University Press, at 5.

[6] O'Connor, D and Donnelly, M (2009). 'Confronting the Challenges of Assessing Capacity, Dementia in the Context of Abuse' in O'Connor D and Purves B (eds.) *Decision-Making, Personhood and Dementia, Exploring the Interface,* Jessica Kingsley Publishers, at 106; Alzheimer's Society (2011) *Short changed: Protecting people with dementia from financial abuse.* Available at https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/short_changed_-_protecting_people_with_dementia_from_financial_abuse.pdf, last accessed 16 October 2021; Social Care Institute for Excellence (2020). Safeguarding people with dementia. Available at https://www.scie.org.uk/dementia/after-diagnosis/support/safeguarding.asp, last accessed 16 October 2021; ACS (2020). *ACS Works with Alzheimer's Society to Support Vulnerable Customers.* Available at https://www.acs.org.uk/news/acs-works-alzheimers-society-support-vulnerable-customers, last accessed 16 October 2021.

fog or other symptoms that might make it more difficult to follow certain interactions, such as those relating to their consumer choices.

There are however potential problems in adopting a narrow definition of vulnerability in this context. First, as discussed in Chapter 2, dementia is itself complex and changing. If the justification for classifying persons living with dementia as vulnerable is because they no longer have capacity to make any decisions, that would limit the applicability of the concept to a sub-set of those living with dementia. It needs to be remembered that a diagnosis of dementia does not mean that a person is no longer *capable*. In fact, the test under the Mental Capacity Act 2005[7] is designed to ensure that a person retains capacity for as long as possible.

Despite being capable, such a person may nevertheless be at risk of harm, economic or otherwise. They may be "*capable but vulnerable*".[8] Hall highlights that such vulnerability may be due through "*both self-neglect and exploitation by others*".[9] If, however, the justification for classifying persons living with dementia as vulnerable is that their capacity may fluctuate, or that they may be at greater risk of making decisions that are not to their benefit, then that is a characteristic that will be shared with many others. Depending on where the line is drawn in making an assessment of capacity, similar cases on either side of the cut-off point will be dealt with in very different ways, whilst vastly different cases might fall within the same category. Foster and Herring point this out in relation to decision-making abilities and the question of mental capacity.

> *We know that really not all those who are deemed to have mental capacity under the Act have equal decision-making abilities, even though the law treats them as if they do. … The fiction might be*

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[7] Mental Capacity Act 2005, s. 3(1).

[8] Hall, MI (2009). 'Capacity, Vulnerability, Risk, and Consent' in O'Connor D and Purves B (eds.) *Decision-Making, Personhood and Dementia, Exploring the Interface,* Jessica Kingsley Publishers, at 119.

[9] Hall, MI (2009). 'Capacity, Vulnerability, Risk, and Consent' in O'Connor D and Purves B (eds.) *Decision-Making, Personhood and Dementia, Exploring the Interface,* Jessica Kingsley Publishers, at 119.

> *justified on the basis that we lack the time, sophistication and effort to make a more detailed inquiry*.[10]

Second, adopting a definition of vulnerability that applies only to certain types of persons, or requires individuals to meet particular criteria, will result in some individuals falling outside the defined parameters. This is a point that has been made by Brown in the context of financial services regulation, which:

> *relies on "boxing" vulnerability, into income, age, mental ability or particular life circumstances, such as illness. Wedded in fixed ideas of consumer need and persona, this entrenches constricted views of vulnerability, and undermines consumer protection in the credit market, by creating gaps in protection*.[11]

A third problem in adopting a narrow definition of vulnerability is that it may stigmatize those so labelled. As Brown has noted, if the concept of vulnerability is applied narrowly to a small group of individuals by a society that uses the term in a "*patronising, paternalistic and oppressive*" manner,[12] it is likely to have negative connotations. Where vulnerability is viewed as something exceptional and problematic, individuals may fear that acknowledging that they are vulnerable may lead to stigma and diminished standing in society. The resulting reluctance to disclose one's vulnerability can in turn negate the existence of any benefits (such as protection or services) that are available to the vulnerable.[13]

On the other hand, adopting the view that vulnerability is universal and part of the human condition might seem to pay insufficient attention to the differences between individuals. However, universality does not mean that all people are

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[10] Foster, C. and Herring, J. (2017) *Identity, personhood and the law.* Springer, at 25.

[11] Brown, S. (2019) 'Un-Boxing Vulnerability In Protection Of The Credit Consumer' *Journal of Business Law* 7: 511-533, at 511-12.

[12] Brown, K. (2011). *"Vulnerability": Handle with Care*. Ethics and Social Welfare, 313–321, at 313.

[13] Hall, M. (2019) 'Relational autonomy, vulnerability theory, older adults and the law: making it real' *Elder Law Review* 12, at 8.

vulnerable all the time. People are complex beings, and not easily defined in such binary manner. Rather than being either vulnerable or autonomous, people are both, constantly fluctuating between the two extremes, usually taking on characteristics of each to some degree and in some aspect of their lives.

Equally, it is recognised that not everyone is equally vulnerable at all times. In some situations, some persons will have heightened vulnerabilities due to the circumstances, internal or external, that they are facing. For example, MacKenzie highlights that some groups (such as for example children) will be considered as especially vulnerable.[14]

As Herring notes, the two different perspectives on vulnerability – the one emphasising the universality of vulnerability and the other emphasising particular vulnerabilities – can be reconciled *"once it is recognized that the second understanding is seeking to identify a category of people who are vulnerable in a way above and beyond the way we are all vulnerable"*. [15]

But the fact that the two perspectives can be reconciled does not mean that the difference between them does not matter. The difference between defining vulnerability as being characteristic of particular groups and defining particular individuals as being more vulnerable than others can be illustrated by recent publications from the Financial Conduct Authority.[16] It defined *"a vulnerable customer"* as *"someone who, due to their personal circumstances, is especially susceptible to detriment, particularly when a firm is not acting with appropriate levels of care"*.[17] Identifying that vulnerability may arise through low financial resilience, recent life events, low financial capability and

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[14] MacKenzie, C. (2014) 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in MacKenzie, C., Rogers, W. and Dodds, S. (eds) *Vulnerability. New Essays in Ethics and Feminist Philosophy,* at 33-59. Oxford University Press.

[15] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 7.

[16] Financial Conduct Authority (2017) *Understanding the financial lives of UK adults: Findings from the FCA's financial lives survey 2017.*

[17] Financial Conduct Authority (2015) *Occasional Paper No. 8 Consumer Vulnerability*, at 7.

relevant health issues,[18] it concluded that "*50% of UK consumers show one or more characteristics of potential vulnerability*".[19] As it summed up:

> *vulnerability can come in a range of guises, and can be temporary, sporadic or permanent in nature…. The clear message from the research carried out for this paper is that we can all* ***become*** *vulnerable*.[20] [emphasis added]

While from one perspective its approach seeks to normalize vulnerability by demonstrating the high percentage of the population who are either vulnerable or potentially vulnerable, there is a crucial difference between recognising that we can all *become* vulnerable and recognising that we *are* all vulnerable.

This recognition that we are all vulnerable, but that some may be more vulnerable than others at particular times, is important in terms of how those living with dementia are perceived. Once it is recognised that there is not a neat binary distinction between those who are vulnerable and those who are not, but rather different levels of vulnerability, it is clear that 'vulnerability' cannot simply be equated with 'lacking capacity'. Just as levels of vulnerability will differ between individuals, at different times, so too will the needs of the individuals involved.

As Fineman has argued, a universalist conception of vulnerability also raises questions as to how the law should treat vulnerability. As she explains, *"The solution devised by law and policy makers is one that will either bolster and increase an individual's autonomy, or grudgingly provide some meager, stigmatized support."* [21]

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[18] Financial Conduct Authority (2017) *Understanding the financial lives of UK adults: Findings from the FCA's financial lives survey 2017,* at 185.

[19] Financial Conduct Authority (2017) *Understanding the financial lives of UK adults: Findings from the FCA's financial lives survey 2017,* at 14.

[20] Financial Conduct Authority (2015) *Occasional Paper No. 8 Consumer Vulnerability*, at 8.

[21] Fineman, M.A. (2019). Vulnerability in Law and Bioethics. *Journal of Health Care for the Poor and Underserved 30*(5), 52-61, at 59.

If all are vulnerable, and if vulnerability is valorised rather than being stigmatised, then it is no longer right for a specific group to be protected only if they can show their vulnerability. Instead, all laws, rules and regulations should be drafted with a view that all may be vulnerable now or at some time in the future. In doing so, the stigma and difficulty to demonstrate vulnerability would be removed completely, unburdening those that might other otherwise have to provide evidence of their weakness, which is often a difficult task.

However, as the next section will discuss, the concept of autonomy remains an important one in understanding the assumptions on which the current law is built.

3.3 Autonomy in law and practice

As Fineman has noted, across disciplines, humans have been consistently presented as ideally autonomous, independent, rational, and fully functioning adults, removed from social relationships, structures and resources.[22] This is particularly true of law; Herring has described how the law has been constructed around the ideal of *"a man who is autonomous, self-sufficient, in control, capacitous, and independent"*.[23]

Classical contract law assumed an autonomous individual, at liberty to enter into contracts. As stated by Jessel M.R.:

> *If there is one thing which more than another public policy requires it is that men of full age and competent understanding shall have the utmost liberty of contracting, and that their contracts when entered into freely and voluntarily shall be held sacred and shall be enforced by Courts of justice. Therefore, you have this paramount public policy to*

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[22] Fineman, M.A. (2019). Vulnerability in Law and Bioethics. *Journal of Health Care for the Poor and Underserved 30*(5), 52-61, at 59.

[23] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 1.

> *consider – that you are not lightly to interfere with this freedom of contract.*[24]

As Kauffman and MacDonald explain, the "*'classical' view of contract was that the parties entered into an agreement or bargain freely, and therefore there should be as little state regulation or intervention as possible. It was not the task of the law to ensure that a fair bargain had been struck."* [25] Contractual transactions were seen as essentially private matters: parties had freedom *to* contract, that is, to decide whether to enter into a contract, and freedom *of* contract, to decide on what the terms of that contract should be.[26]

That is not to say that all individuals were regarded as able to enter into a contract. Certain individuals were identified as lacking capacity to contract. Where a lack of capacity was determined, as now set out in the Mental Capacity Act 2005, a person was prevented from making decisions. Instead decisions were made by others, based on the assessment of their best interests.[27] As Herring suggests, capacity is "*used by law as a key marker between the vulnerable and the non-vulnerable*",[28] with capacity being seen as a pre-requisite to the right to autonomy.[29]

It has been suggested that the classical principles of contract law, autonomy and the freedom to contract, remain relevant today, and "*can still be seen to cast its shadow over English law*". [30] Atiyah suggests it was revived in the 1980s.[31] Since then, autonomy has become a guiding principle both within society and within the law. For example, in Radmacher v Granatino,[32] which

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[24] Printing and Numerical Registering Co. v Sampson (1875) LR 19 Eq 462 at 465.

[25] Macdonald, E. and Atkins, R. (2018) *Koffman & Macdonald's Law of Contract* (9th ed), Oxford University Press, at 3.

[26] Smith, S. (2004) *Contract Theory*. Oxford University Press, at 59.

[27] Mental Capacity Act 2005, s. 4.

[28] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 45.

[29] Ibid.

[30] Stone, R. and Devenney, J. (2019). *The Modern Law of Contract (13th ed)* Routledge, at 7.

[31] Atiyah, P (1995) *Introduction to the Law of Contracts* (5th ed), Oxford University Press, at 27-34.

[32] Radmacher v Granatino [2010] UKSC 42.

considered contract law in relation to a family breakdown, the Supreme Court held that it would not interfere with the private contractual arrangement made between the spouses. Both parties, the court concluded in that instance, were independent, autonomous parties who could make decisions and be bound by them. This decision has been significant, in that it led to the strengthening of the position of autonomy as a leading principle. For example, Lord Phillips states in Radmacher that "*respect should be given to the individual's autonomy*".[33] In subsequent cases this was mirrored, with for example Charles J in V v V[34] in 2011, referring to Radmacher, highlighted the "*new respect for individual autonomy*".[35] Consequently, case law has embraced the notion that of the autonomous party.

The corollary of this is that a person who has capacity is able to decide whether to enter into a contract and what the terms of that contract should be. Yet many scholars have pointed out that individuals may be constrained in the choices that they can make. Harding, for example, highlights that "*there is little room in the legal imaginary for the complexities of relationships, or in the influence of social connection on decisions that people make*".[36] Together with Tascioglu, she argues that because

> *… everyone makes decisions in, by and through their relational contexts, then the fully autonomous end is but a fiction, which ignores the reality of decision-making support that we all draw upon.*[37]

MacKenzie and Stolja[38] further highlight the inconsistency between autonomy in its abstract form and the individual. Autonomy, in its purest form, is

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[33] Radmacher v Granatino [2010] UKSC 42 at 78.

[34] V v V [2011] EWHC 3230 (Fam).

[35] V v V [2011] EWHC 3230 (Fam) at 36.

[36] Harding, R (2018). *Duties to Care, Dementia, Relationality and Law*. Cambridge University Press, at 17.

[37] Harding, R. and Tascioglu, E. (2018) 'Supported Decision-Making from Theory to Practice: Implementing the right to enjoy legal capacity' *Societies* 8(25): 1-17, at 13.

[38] MacKenzie, C. and Stoljar, N. (2000) 'Introduction: autonomy refigured' in MacKenzie, C. and Stoljar, N. (eds) *Relational autonomy: feminist perspectives on autonomy, agency and the social self,* p. 3-31. Oxford University Press.

considered to be a theoretical concept.[39] This is because parties in any relational situation will only be truly autonomous if they are objectively (formally) and subjectively (in terms of knowledge, means and power) equal and independent. This, however, is rarely, if ever, achieved. [40]

Taking the example of a 'business to consumer' contract, this is an instance where the parties do not meet on an equal footing. The business is better equipped, with legal representation and knowledge, economic weight and the imposition of standard terms on the consumer. This is the concept of "*inequality of bargaining power*",[41] and was first identified in case law[42] and then recognised in legislation.[43] In light of this concept, the status of the contracting parties and their circumstances becomes relevant. Macneil highlighted this issue as early as the 1970s, referring to the "*economic and social power*" held by businesses and concluding that as a result businesses rely on "*objective manifestations of consent*", rather than on "*actual consent*".[44] Atiyah highlights this issue clearly, stating

> *It surely flies in the face of all reality to treat written or printed contracts as though they themselves have been gone through clause by clause, word by word, and thoroughly accepted and understood by both parties.*[45]

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[39] Fineman, M.A. (2017) 'Vulnerability and Inevitable Inequality' *Oslo Law Review* 4(3): 133-149, at 148.

[40] Harding, R (2018). *Duties to Care, Dementia, Relationality and Law*. Cambridge University Press, at 17.

[41] Furmston, M. (2017) *The Law Of Contract (6th ed)* Butterworth Common Law Series.

[42] e.g. Lowe v Lombank [1960] 1WLR196; Schroeder Music Publishing Co Ltd v Macaulay [1974] 1WLR1308.

[43] e.g. Rent Act 1977, c.42; Employment Rights Act 1996, c.18; Consumer Rights Act 2015, c.15.

[44] Macneil, I.R. (1978) 'Contracts: Adjustment of Long-Term Economic Relations under Classical, Neoclassical and Relational Contract Law' *Northwestern University Law Review* 72: 854-905.

[45] Atiyah, P. (1986) *Essays on Contract* Oxford, Clarendon Press, at 366.

In fact, most consumers today have simply resigned themselves to be bound by the terms the business imposes on them.[46]

There have been suggestions to move away from these classic contract law notions and consider alternative ways in which people within society can interact and transact with one another. A key component to such alternative path is Macneil's relational contract theory, [47] a social view of contract that places the person back in the centre of a contractual interaction.[48] Taking into account the situational relationship between any two parties, a relational approach to contract law would allow for the contract to be interpreted looking at "*the reality of the parties' relationship and actual intentions".* [49]

This involves recognising that contracts between persons involve important social issues and cannot be seen as purely private matters. Tan [50] highlights the macro- and micro-lenses of contractual agreements. At micro-level, the parties will have agreed to a set of rules that will govern only their relationship. At macro-level these contracts must be understood in the context of wider societal rules and principles of justice. This wider societal context is particularly important in relation to consumer contracts.

Along with the issue of inequality of bargaining power, there is also the question of the level of knowledge and understanding attributed to each of the contracting parties. Consumer law (a branch of contract law), today is built around the notion that the 'average consumer' is "*a consumer who is*

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[46] Obar, J.A. and Oehldorf-Hirsch, A. (2020) 'The biggest lie on the Internet: ignoring the privacy policies and terms of service policies of social networking services' *Information, Communication & Society* 23(1): 128-147.

[47] e.g. Macneil, I.R. (2000) 'Contracting Worlds and Essential Contract Theory' *Social and Legal Studies* 9(3): 431-438.

[48] More recently, see for example Thompson, S. (2018) 'Feminist Relational Contract Theory: A new model for family property agreements' *Journal of Law and Society* 45(4): 617-645, at 617.

[49] Gounari, Z. (2021) 'Developing a relational law of contracts: Striking a balance between abstraction and contextualism'. *Legal Studies.* 41(2): 177-193, at 181.

[50] Tan, Z.X. (2020) 'Where the Action Is: Macro and Micro Justice in Contract Law' *Modern Law Review* 83(4): 725-760.

reasonably well-informed, observant and circumspect".[51] However, this definition (which stems from European case law) does "*not fit easily*"[52] with the reality of consumers, as surveyed by the Commission's Consumer Conditions Scoreboard.

As Beale has argued, the idea of the well-informed consumer reflects an ideal rather than the reality: parties cannot consider every eventuality that may affect the contract, because contract law "*takes little account of the context in which it is made*".[53] More fundamentally, Herring has noted how changing the starting point means making a different set of assumptions about the parties to the contract:

> *If we are all vulnerable, then we start with a contracting party who is ignorant about many things, is open to emotional and physical pressures, who is best with the norms of human life, and short on time and energy to read mountains of paperwork. We could see contracts as designed to promote those things that are central to a good human life: mutuality, relationship and interdependence.*[54]

As emphasised by Leczykiewicz and Weatherill, how the protection of consumers is shaped will depend "*on whose needs, preferences, characteristics and relations are taken as the point of reference. What is at stake is not only the level of protection but also the contexts in which protection is offered*..." [55]

3.4 Autonomy as a positive value

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[51] Consumer Rights Act 2015 s. 64(5).

[52] Committee on the Internal Market and Consumer Protection (2021) *Report on a Strategy for Strengthening the Rights of Vulnerable Consumers,* at 5.

[53] Beale, H. (2013) 'Relational values in English contract law' in Campbell, D. et al. (eds) *Changing Concepts of Contract: Essays in Honour of Ian Macneil* Basingstoke: Palgrave Macmillan, at p 117.

[54] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 258.

[55] Leczykiewicz, D. and Weatherill, S. (eds) (2016) *The images of the consumer in EU law: legislation, free movement and competition law.* Hart Publishing, at 1.

Diduck likens the concept of autonomy to the positive side of the concept of individual liberalism[56] which has more negative connotations, often associated with selfishness at the detriment of others less fortunate.

This criticism is also highlighted by Wallbank and Herring,[57] who state that autonomy usually refers to the attributes afforded to a certain type of fictional person, removed from the experiences of the majority of the population. Instead, key values such as "*mutuality, interdependence, and relational responsibilities*" [58] define humans living in society.

Whilst autonomy in its purest sense may be a fiction, that does not mean that the idea of autonomy has no value. In reality, people, including those deemed vulnerable, wish to feel that they have the autonomy to make choices for themselves. As Hall has suggested, decision-making is closely associated with the concepts of personal identity, integrity and dignity.[59]

Rather than focusing on the individualistic interpretation of autonomy, implying self-sufficiency,[60] the United Nations Convention for the Rights of People with Disabilities ('CRPD') suggests that individual autonomy can be understood to mean "*the freedom to make one's own choices, and independence of persons*". [61]

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[56] Diduck, A., (2013) 'Autonomy and vulnerability in family law: the missing link' in Wallbank J. and Herring J. (eds) *Vulnerabilities, care and family law*. Routledge, 202-241, at 203.

[57] Wallbank, J. and Herring, J. (2013) 'Introduction: vulnerabilities, care and family law' in Wallbank, J. and Herring, J. (eds) *Vulnerabilities, care and family law*. Routledge, at 30.

[58] Herring, J. (2016) *Vulnerable Adults and the Law.* Oxford University Press, at 1.

[59] Hall, M. (2019) 'Relational autonomy, vulnerability theory, older adults and the law: making it real' *Elder Law Review* 12, at 6.

[60] Baumann, H. (2008) 'Reconsidering Relational Autonomy. Personal Autonomy for Socially Embedded and Temporally Extended Selves' *Analyse & Kritik* 30: 445-468, at 446.

[61] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD), Article 3, Principle (a)

Arduin [62] comments that the use of the concept of autonomy in this context is particular to the CRPD [63] because the principle of autonomy is not "*expressly referred to in the core UN human rights treaties*". [64] In the context of the CRPD however, autonomy is understood as including the freedom of making one's own choices. The Office of the UN High Commissioner of Human Rights explained that

> *respect for the individual autonomy of persons with disabilities means that persons with disabilities have, on an equal basis with others, reasonable life choices, are subject to minimum interference in their private life and can make their own decisions, with adequate support where required*. [65]

This reference to support indicates that it is possible to value autonomy while at the same time acknowledging vulnerability. Instead, Baumann suggests that autonomy must be "*reconceived in a relational or social way*". [66]

For Nedelsky, [67] autonomy must be revisited as relational, in that it requires one to consider the person in context and understand that a person is situated in a social field. Friedman further describes Nedelsky's work as highlighting that a relational approach means that people are "*interconnected and interdependent*".[68]

The need of persons to remain autonomous, free to make their own choices, and in control of their lives and decision-making must be viewed within the

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[62] Arduin, S. (2019) 'Art.3 General Principles' in Bantekas, I., Stein, M.A. and Anastasiou, D. (eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* Oxford University Press, 84-105.

[63] Ibid, at 93.

[64] Ibid, at 93.

[65] UN OHCHR, 'Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors' *UN 2010* 19.

[66] Baumann, H. (2008) 'Reconsidering Relational Autonomy. Personal Autonomy for Socially Embedded and Temporally Extended Selves' *Analyse & Kritik* 30: 445-468, at 446.

[67] Nedelsky, J. (1989) 'Reconceiving autonomy: sources, thoughts and possibilities' *Yale Journal of Law & Feminism* 1(7): 7-37.

[68] Friedman, M. (2013) 'Relational autonomy and Individuality' *the University of Toronto Law Journal* 63(2): 327-341, referring to Nedelsky, at 327.

wider context. Autonomy cannot be separated from the understanding of the interdependence of persons. Consequently, their autonomy is necessarily relational, i.e. taking into account the relationships, resources and all circumstances of the person. Harding refers to the "*interwoven dynamics of everyday life*" [69], clarifying that *"[a relational view] allows a focus of the embodied individual whilst being mindful of the interpersonal and structural contexts that shape lives".*[70]

Relational autonomy allows a person, to the best of their abilities given their circumstances (i.e. "*depending on situation-specific relationships between context and self*"),[71] to make decisions and choices that are theirs. This in turn allows the (potentially vulnerable) person to be self-empowered; their identify and dignity remain intact.

In other words, whilst autonomy in its purest sense is not achievable (and remains a fiction), relational autonomy allows for decision-making, including by persons deemed vulnerable. Hall points out that "*some matters may require a different kind and degree of autonomy than others*" [72] but this does not take away from the outcome that decisions can be made in the relevant context.

This is important for persons living with dementia, who may be vulnerable due to their fluctuating capacity, memory issues, their role as consumer and that of the weaker contractual counterpart. They do not wish the label of 'living with dementia' or 'vulnerable person' to diminish their standing or have others make decisions in their place. By having a dialogue and ensuring their 'will

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[69] Harding, R. (2017) *Duties to Care: Dementia, Relationality and the Law*. Cambridge University Press, at 22.

[70] ibid. at 26.

[71] Hall, M. (2019) 'Relational autonomy, vulnerability theory, older adults and the law: making it real' *Elder Law Review* 12, at 14.

[72] ibid, at 15.

and preference' [73] is at the forefront of the decision supporting process, their relational autonomy allows their choices to be central to their decision-making.

3.5 Concluding remarks

In this chapter, the concepts of autonomy and vulnerability have been considered. Autonomy, despite the criticisms that have been levelled at it, remains a useful one for understanding what the law is, whereas vulnerability is more about understanding individual's experiences, and possibly what the law should be.

By setting out these concepts, the flaws in applying these in a binary manner are highlighted. Instead, this chapter suggests that autonomy and vulnerability are in fact interwoven. This chapter has shown that when relying on rules that protect those that are deemed vulnerable, the law cannot accurately cover the range and breadth of persons with varying vulnerabilities. There is therefore a need for laws to be drafted to ensure that the inherently (actual or potential) vulnerable state of all persons is considered the norm and legislated for. Further, vulnerability must not prevent a person from remaining (relationally) autonomous in their decision-making. As a result, where the concept of autonomy is used in the empirical chapters, it is done taking into account the necessarily relational aspect of such autonomy.

In the next chapter, the methodology and the methods applied to this project are detailed. After a brief discussion of the methodology that underpins the project, the method used to set out the legal framework is discussed. Next the socio-legal aspect of the project is examined and explained, before exploring in detail how new data was collected and analysed. Ethical considerations as well as potential weaknesses and challenges of the project are also discussed in the next chapter.

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[73] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD), Article 12.4, this is further discussed in Section 7.3.

Chapter 4 Methodology and methods applied

4.1 Introduction

This thesis seeks to explore the issues that arise for *consumers* living with dementia, i.e. people living with dementia who transact with businesses. The goal of this thesis is therefore to research this specific aspect by asking the question about the consequences, both legal and practical, when a person living with dementia enters into a consumer contract with a business. To do so, the voices of those with lived experience must be heard and taken into account. It is only by finding out what their needs are that tools can be devised to answer those needs. Chapter 4 will present the methodology and methods used in this thesis to achieve these aims.

In **Section 4.2** the methodology underpinning the research is explained. By briefly setting out how the nature of reality and the nature of knowledge are understood in this research, context is provided for the chosen methodology. As a critical-realist post-positivist researcher, the aim is to seek the truth whilst being at all times aware of the various lenses through which each of us will view the world. Experiences of each are unique and provide insight into the various perspectives available for each situation.

Section 4.3 addresses the way in which some of the literature on consumers living with dementia was explored. A scoping review was selected, and this section describes the scoping protocol, its merits and limitations.

Section 4.4 then provides a brief overview of the legal research. This will include an explanation of how the black-letter law, parliamentary debate leading up to new legislation, case law and court decisions together allow for a comprehensive picture to be taken of the current legal framework.

This section also gives background information to empirical research and considers the reasons for engaging with empirical research, before focusing more specifically on socio-legal empirical research and the objectives within this discipline.

Section 4.5 sets out the method applied, namely interviews, in order to obtain new data for this research project. The section describes the challenges and consequences of interviewing on a sensitive topic and explains how care of the participants was a decisive factor when performing the interviews.

In addition, in this section, statistical details of the participants are provided (in line with confidentiality provisions) in order to convey the range of participants and their different approaches, experiences and opinions to the various topics. This section also sets out the questions asked, and the reasons for asking these particular questions. Details are provided of the distinctions made in interview questions depending on the type of participant, as well as an explanation of why the format of semi-structured interviews was deemed most appropriate in this context. Finally, this section also considers the methods used for interview analysis.

Section 4.6 describes the ethical challenges and the limitations to the research. This section explores self-reflection, as well as validity and replicability of the work. Concluding remarks are set out in **Section 4.7.**

4.2 Understanding the principles underpinning methodology

The ontological approach taken in this project is to acknowledge that one can only ever partially know the truth, due to the subjective and socially-situated position as researcher. The stance taken in this thesis is one of critical realism. As suggested by Braun and Clarke,[1] this means that

> *A pre-social reality exists but we can only ever partially know it.*[2]

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[1] Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: a practical guide for beginners*. Sage.

[2] ibid., at 26.

Taking as an example the situation of a consumer living with dementia and a business interacting and transacting together, it is suggested that there is a reality of that event, beyond individual perception. However, that reality can only be seen through the eyes of each of the parties, or through the observations of a third party. Each of them will see and recount a different reality.

Epistemologically, in looking to understand that nature of knowledge, a post-positivist stance is taken in this research. This signifies that the researcher must recognise that their values, experiences and context will taint what can be known. Whilst the positivist believes they can see beyond the subjective to find the objective truth, the post-positivist will see limitations in knowing the full picture. Hence a post-positivist stance suggests that knowledge cannot be independent of the human mind; in other words, our knowledge is tied to our perspectives.[3]

Depending on the epistemology and ontology underpinning the project, the methodology will vary significantly. A realist positivist approach is often linked to quantitative research, where a large sample of narrow (closed-questioned) data is taken and, using percentages or other metrics, a clear outcome is demonstrated. The critical-realist post-positivist model in contrast is more suited to a qualitative project where the researcher aims to delve into the depth of human experiences. A smaller number of participants providing rich data is in those circumstances more appropriate.

This research is not seeking to provide a single quantifiable answer (such as the number of people living with dementia who entered into consumer contracts in any given year). Instead, it asks the question of the consequences, legal and practical, when a person living with dementia enters into a consumer contract with a business. In doing so, the thesis is looking to understand the issues, challenges and opinions of a number of persons in different contexts. From these different experiences, various themes can be

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[3] Ryan, A.B. (2006) ‘Post-Positivist Approaches to Research’ in *Researching and Writing your thesis: a guide for postgraduate students*. MACE: Maynooth Adult and Community Education, 12-26, at 17, 18.

identified and explored. Different aspects will feed into the overall picture of what it means to enter into a consumer contract as a person living with dementia.

The methods chosen to complete such qualitative research are a combination of doctrinal legal review and the collection (and subsequent analysis) of new data through interviews. Both will be described in more detail next.

4.3 A scoping review to explore existing literature

The literature review in legal research is often an organic process, which starts with a review of the main texts and authors, and then grows as further studies and works are selected from relevant journals, books and collections. Footnotes and references provide further insight into possible areas of the academic field to examine and explore. Slowly, a complete picture is built on this basis.

In medical research, a more structured process is preferred, which allows for a systematic combing of databases to ensure no study is missed and all relevant works are taken into account. The *systematic* review[4] is often used in medical research with the goal to verify, over a number of reported projects, if a certain intervention (e.g. a form of treatment, medication) is consistently providing similar outcomes for patients. The systematic review is however also used beyond the medical realm in socio-legal qualitative projects.[5]

For this project, the challenge was to apply this more systematic approach to the interdisciplinary field of dementia and law. The goal was to find articles on published research projects involving people living with dementia when they were acting as consumers in order to identify a pattern in outcomes from a legal perspective.

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[4] Centre for Reviews and Dissemination, University of York (2009) *Systematic Reviews: CRD's guidance for undertaking reviews in health care***.** Centre for Reviews and Dissemination, University of York, available at https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf, last accessed on 14 February 2021.

[5] For example, Brooke, J., Diaz-Gil, A. and Jackson, D. (2018) 'The impact of dementia in the prison setting: A systematic review' *Dementia* (London) 19(5): 1509-1531.

An initial review of these specific criteria demonstrated a clear gap in the existing literature; no studies looked specifically at this topic.[6] Whilst this finding itself spoke to the originality of the current project, with nothing published on the topic, the search was broadened for the purposes of this review, in order to situate the concept of the consumer living with dementia within the wider field of financial decision-making.[7]

Consequently, another type of structured review, the mapping or scoping review,[8] was chosen and carried out in 2018/2019. This type review is specifically used to "*identify gaps in the evidence [and] clarify key concepts…*"[9] As such, the scoping review broadens the horizon of the review field, whilst still ensuring a reduction of the bias that might otherwise creep in unintentionally. This was achieved by reviewing all articles and other publications of research pertaining to the topic as identified using a number of selected databases, carefully removing only those that were not relevant to the subject and analysing and integrating all other findings into the final scoping review.

The research question for this scoping review aims to provide an overview of what has been discovered so far in relation to persons living with dementia when entering into contracts that have an economic impact on them.

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[6] For example, with the search terms 'consumers' and 'dementia', Google scholar provided articles in which 'consumers' were those that 'consumed' food or drink, consumers of health care provisions, consumers in relation to medical treatments or research trials, available at https://scholar.google.co.uk/scholar?start=10&q=consumers+dementia&hl=en&as_sdt=0,5 last accessed on 14 February 2021.

[7] In addition to consumer contracts, financial decision-making includes all unilateral and bilateral contracts that have a financial impact on the person living with dementia.

[8] Ehrich, K., Freeman, G.K., Richards, S.C. Robinson I.C. and Sheppard, S. (2002) 'How to do a scoping exercise: continuity of care. Research, Policy and Planning' *The Journal of the Social Services Research Group* 20(1): 25-29.

[9] Peters, M., Godfrey, C., McInerney, P., Baldini Soares, C., Khalil, H. and Parker, D. (2015) *The Joanna Briggs Institute Reviewer's Manual – Methodology for JBI Scoping Reviews*. The Joanna Briggs Institute, at 6.

“What experiences have been recorded in relation to people living with dementia when entering into contracts or making decisions that affect their financial situation?”

The question is wider than the over-arching research question of the thesis, as there is little, if anything, within the current literature on the specific topic of people living with dementia contracting with businesses as consumers. This wider question allows review of the experiences of decision-making in a financial setting. In doing so, areas of research such as decision-making in relation to medical treatment, end-of-life considerations, decisions around assisted living and assisted dying, and choice of residence at the later stages of the illness, have been excluded.

<u>Relevant studies identification</u>

The six databases that were searched electronically were Medline, Social Policy and Practice (‘SPP’), PsycINFO, International Bibliography of the Social Sciences (‘IBSS’), Applied Social Sciences Index and Abstracts (‘ASSIA’) and Westlaw UK. Search strategies were tailored for each database, the detail of which is set out in Table 4.1. below. The review process also included forward and backward citation searching, i.e. screening the reference lists of the identified papers, as well as checking what other journal articles had cited these identified papers.

The review of the databases took place in 2018, and was finalised in December 2018.

Search word	Medline ^	PsycINFO ^	SPP ^	ASSIA ^^	IBSS ^^	Westlaw ^^^
1 dementia	112240	65905	13967	9499	2008	210
2 Alzheimer*	142452	58607	3331	4566	1037	0
3 “decision	182671	110100	9392	28116	82475	4100

making”						
4 capacity	491265	80160	8134	18766	61785	3131
5 consumer	69084	55973	3131	14549	85182	16200
6 contract*	350763	26998	4878	8400	60701	53100
7 financial	96079	45343	11454	18766	218044	49400
(1 or 2) and (3 or 4) and (5 or 6 or 7)	177	150	64	32	12	136

^ Accessed through OvidSP on 05.12.18; search rules for OvidSP based searches: mp=abstract, title, publication type, heading word, accession number.

^^ Accessed through ProQuest on 10.11.18; search rules for ProQuest based searches: noft = key words searched anywhere (title, abstract, key words, subject) except in the full text.

^^^ Accessed through Westlaw UK on 11.11.18; search rules for Westlaw based searches: key words searched anywhere (title, abstract, key words, subject) except in the full text.

Table 4.1 Databases with number of articles identified by search term

Inclusion and exclusion criteria

Inclusion criteria were:

- studies presenting findings relating to persons living with dementia when making decisions that affect their financial situation, including entering into contracts with businesses or other parties as consumers,
- from 2005 (which is the year when the new Mental Capacity Act 2005[10] came into force),
- in the English language.

Exclusion criteria were:

- research pre-dating 2005,
- studies reviewing decision-making of persons living with dementia in relation to
    i. their care home setting,

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[10] Mental Capacity Act 2005, c.15.

    ii. end-of-life treatment or medical treatment options,
    iii. assisted suicide, assisted living, assisted dying,
    iv. consent to marriage or sexual activities, and
    v. consent to partaking in research,
- studies on criminal activity *by* people living with dementia.

Because of the nature of the scoping review, '*data from any type of evidence and research methodology… bringing together evidence from disparate or heterogeneous sources*'[11] was considered. Consequently, all articles setting out original findings were included. In relation to papers stemming from the social sciences (other than law), all papers presenting summaries, commentaries and editorials were excluded. For the papers stemming from the field of law, due to the nature of legal research, summaries and commentaries were included, and only editorials were excluded.

Study selection

At the start of 2019, the study selection was undertaken. All studies and articles identified in the six databases, using the formula *(Dementia or Alzheimer*) and ("decision making" or capacity) and (consumer or contract* or financial)* were listed together. These represented 571 articles. 128 duplicates were removed from the list. Thereafter, a review of the titles, dates, key words and abstracts allowed for the eligibility criteria to be applied to the remaining 443 articles. 127 articles were retained to be reviewed in greater detail. A fellow researcher, Debbie Kinsey ('DK'), was recruited as a second independent selector to further ensure a reduction in bias and increase in replicability. DK and I undertook the screening process independently of each other. Prior to the further selection process of titles and abstracts, DK and I discussed the eligibility criteria. Where there was disagreement after screening, we agreed on what the final selection should be. A flowchart of the selection process is depicted in Figure 4.1. below.

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[11] The Joanna Briggs Institute (2015) *Joanna Briggs Institute Reviewers' Manual: 15 editions/Supplement.* The Joanna Briggs Institute, at 8.

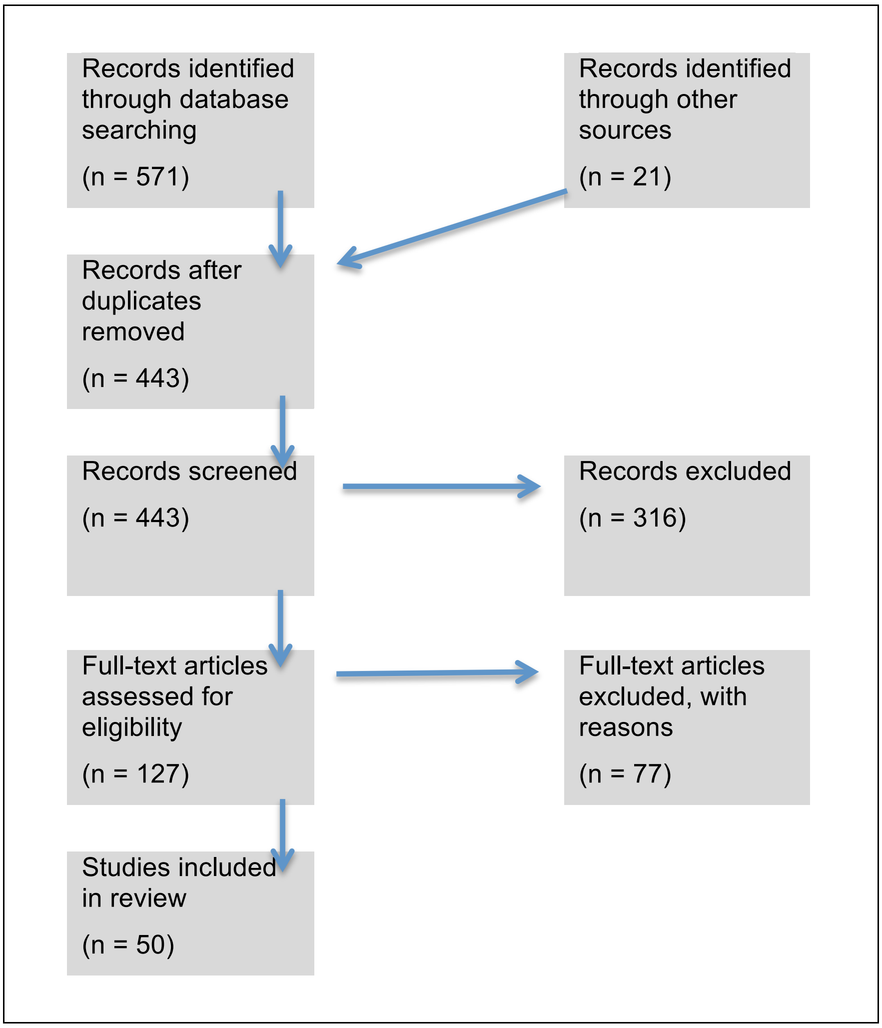

Figure 4.1.[12] Flowchart of scoping review records

Limitations of the scoping review

Whist this review provided an overview of articles on dementia and financial decision-making, there are clear gaps in using this form of review. Westlaw is a search engine that is relatively narrow in its scope, and it is likely that relevant literature was missed by not also including databases such as Hein Online and LexisNexis. For example, some socio-legal studies will have been omitted because they will not have been indexed on Westlaw. Whist the

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[12] Figure 4.1. PRISMA flowchart, adapted from Moher, D., Liberati, A. Tetzlaff, J., Altman, D.G. (2009) 'Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement'. *Annals of Internal Medicine* 151(4): 264-269, at 269.

literature review in Chapter 5 does provide information on financial decision-making by persons living with dementia, it is not a complete picture given the above-described limitations. However, this literature review choice has highlighted relevant literature that would not have been identified using only legal databases. This broader literature review aims to underpin the socio-legal nature of the thesis, in that it looks at law in the context of other disciplines.

4.4 Exploring the law from different angles

Arthurs[13] sets out a clear diagram of the different ways that law might be researched reproduced below in figure 4.2. Arthurs' analysis of legal research is depicted as a double axis and suggests four styles in which law might be researched:

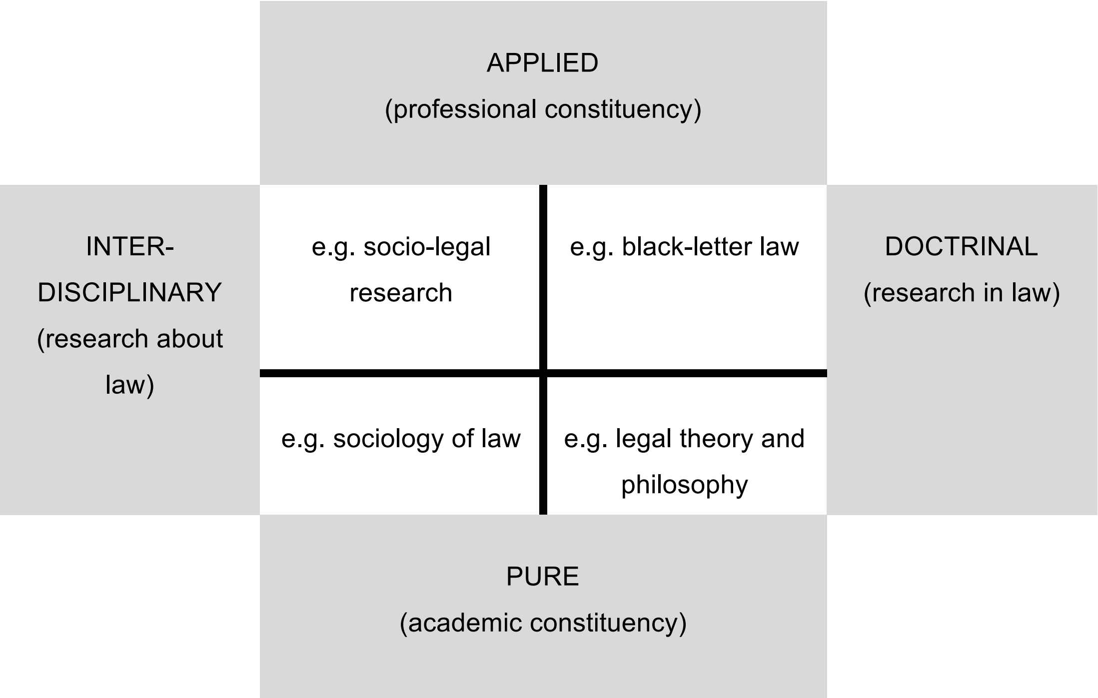

Figure 4.2. Arthurs' legal research styles[14]

On the first (vertical) axis, Arthurs differentiates between applied and pure research of the law; applied research is said to be for and by the professional

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[13] Arthurs, H.W. (1983) *Law and Learning: Report to the Social Sciences and Humanities Research Council of Canada by the Consultative Group on Research and Education in Law*, Information Division, Social Sciences and Humanities Research Council of Canada, Ottawa.

[14] ibid.

constituency, i.e. the group of legal professionals, and will include the research styles known as black-letter law and socio-legal studies. It asks the question of how the law is interpreted and applied to a concrete situation. Conversely, pure research relates to legal philosophy and legal theory, explored for and by the academic constituency. It questions, for example, the role and function of the law.

On a second (horizontal) axis, law can be viewed on the one hand as doctrinal methodology, which Arthurs refers to as research *in* law. This would involve research on the meaning of a specific rule of law. On the other hand, law can be researched in an interdisciplinary manner. Arthurs describes this as research *about* law, and the exploration of its place in the world and people's experiences.

This project aims to research the law both doctrinally and empirically. In Chapters 6 and 7 a doctrinal applied style of research of black-letter law is undertaken in order to assess if the law today sufficiently protects consumers living with dementia.

Indeed, doctrinal research is a traditional method of study of the law. Laws are for the most part set out in legislation and common law, as interpreted by the courts. Hence, the black-letter law approach is important, in that it allows for an understanding of what the law currently is, and how it is understood by those who enact it (the legislator) as well as those who interpret it (the judiciary). Analysis of the law allows us to identify how the law attempts to engage with those that are subject to it.

The law can be general in nature, covering all relevant issues, and allowing all parties, no matter their circumstances, to be provided for under the law. Alternatively, it might specifically deal with the issues of a certain group of people, for example when entering into contracts, groups such as minors or consumers are singled out and separate rules are provided for that group.

This thesis looks at consumers living with dementia, and therefore contract law generally, as well as related laws on consumers, capacity, equality and non-discrimination are applicable. To achieve a clear insight into the overarching concept of contract law, the black-letter study will involve reading the core textbooks on relevant law[15] to get a clear and detailed picture of the common law on contracts. In addition, the text of the relevant legislation [16] will be read in detail. In order to fully understand the aims and objectives of the relevant Acts of Parliament, it is important to also explore the debates preceding the legislative text,[17] to ask the question whether the law correctly reflects the intent of the legislators when it was first considered and formulated.

By reviewing the explanations of the relevant courts in relation to the contract law cases before them, a clear picture can start to emerge of the considerations that will sway the judges. In addition to the law, the circumstances of the parties to the contract, as well as the contracts themselves will be explored to consider whether these may be subject to interpretation by the judges, and what consequences these interpretations have on the validity of the consumer contract as a whole, or some of the clauses in particular.

Finally, insights, opinions and other teachings of academics will further inform the research of the law as it currently stands.

However, as pointed out by McConville and Chui,

> *Black-letter law' focuses heavily if not exclusively upon the law itself as an internal self-sustaining set of principles which can be accessed through reading court judgments and statutes with little or no reference to the world outside of the law.*[18]

This lack of connection between the law and what occurs in society can be problematic. Whilst the above described doctrinal analysis will give a clear

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[15] Peel, E. (2020) *Treitel on the Law of Contract* (15th ed.) Sweet & Maxwell.

[16] e.g. Consumer Rights Act 2015, c.15, Mental Capacity Act 2005, c.9, Equality Act 2010, c.15.

[17] UK Parliament. *Hansard, the official report of all parliamentary debates,* available at https://hansard.parliament.uk, last accessed on 14 February 2021.

[18] McConville, M. and Chui, W.H. (2017) *Research methods for law, 2nd ed*. Edinburgh University Press, at 1.

picture of the rules and regulations that currently govern a legal topic, this method does not look directly at what occurs in practice, for example when a person living with dementia enters into a contract.

Cotterrell[19] points out that therefore, compared to socio-legal studies, a purely doctrinal analysis of the law might produce "*less valuable knowledge about what the law is as a social phenomena and what it does*".[20]

In this thesis the law will therefore be reviewed and understood beyond the text of doctrine, legislation and court judgments that form the basis of our common law. Instead the law must be seen as "*a component part of the wider social and political structure … and can therefore only be properly understood if studied in that context*."[21]

It is said that socio-legal research is "*the study of law, legal processes and legal phenomena using social research methods such as interviews, observation and questionnaires*".[22] In order to understand whether the law serves the needs of the community generally and those within our society that need legal protection specifically, empirical research is a useful tool.[23] Consequently, this project considers the law using a socio-legal methodology, looking not only at what the law says, but also how those that are subject to it experience it.

Looking again at Arthurs' diagram, research about the law will be interdisciplinary in nature. Consequently, it is important to not only know the law, but also the world outside of the law, in order to see what occurs in practice when people in society live and interact with each other.

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[19] Cotterrell, R. (1995) *Law's Community*. Oxford University Press.

[20] ibid. Chapter 14, at 296.

[21] Harris, P. (1986) 'Curriculum Development in Legal Studies' *Law Teacher* 20(2):110-123, at 112.

[22] Burton, M. (2013) 'Empirical research' in Watkins, D. and Burton, M. (eds) *Research Methods in Law.* Routledge, at 55.

[23] ibid.

Smith suggests that "*The only way of knowing a socially constructed world is knowing it from within. We can never stand outside it*."[24] This thesis envisages looking at what is occurring in practice beyond the exploration of the text of the law. To do so, questions are asked of those that experience the application of the law first-hand in their daily lives.

The empirical approach, the findings of which are set out in Chapters 8, 9 and 10, allows for further questions to be considered, such as how the legal rules on contract law, consumer rights, capacity considerations and human rights are understood and experienced by specific groups such as people living with dementia, their family members and the advisers/charities/help groups that serve them. By looking at what happens in their "*everyday lives*",[25] new insights are provided into the experiences of people living with dementia and their family members when seeking legal protection. The empirical process allows for questions to be asked to find out if there are some rules that seem particularly helpful, whilst other rules may be identified as not working well in day-to-day situations.

As the overarching thesis research question[26] states, the interviews are aimed at looking at the experiences of those affected, when a person living with dementia enters into a contract as a consumer.

As Chapter 3 demonstrated, the debate concerning the protection of people living with dementia is fuelled by concepts such as vulnerability and autonomy.[27] This division of people according to arbitrary guidelines (determining who is vulnerable and to what extent) must be explored in order to determine if these rules are necessary, just and fairly applied.

One way in which the law might divide persons into autonomous and vulnerable groups is to identify people as either having capacity (in which case they are deemed to be autonomous and independent), or lacking

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[24] Smith, D. E. (1974) 'Women's perspective as a radical critique of sociology' *Sociological Inquiry* 44(1): 7-13, at 11.
[25] Ewick, P. and Silbey, S. (1998) *The Common Place of Law: Stories from Everyday Life*. London: Chicago University Press.
[26] See Chapter 1.
[27] See Section 3.2 and 3.3 for a detailed analysis.

capacity (in which case they fall into a specific category of persons in need to protect due to their vulnerability). However, people living with dementia are difficult to contain in one single category; they are neither all lacking capacity, nor all capable; neither all autonomous nor all vulnerable. The empirical data will demonstrate that their (degree of) ability and independence will vary not only from one person to another, but also within each person depending on *when* capacity is tested. A person may be confused at one point in time and lacking capacity as a result, but shortly thereafter might regain clarity, with capacity restored at that point.[28] This is significant, when considering the legal consequences that arise for consumers living with dementia.

Co-production: designing the interviews

As stated in NHS guidance,[29] co-production is a way of trying to ensure that the research is "*grounded in the lived reality of ordinary folk*".[30] This is achieved by researchers not working alone, but rather working together with health professionals and the public.[31] This relates not only to the collection of the data but to the design of the research. It was therefore important for this research to work closely with others who have lived experience, and incorporate their ideas, knowledge and opinions.

This also reflects the aims of Alzheimer Europe, who are

> *keen to promote the involvement of people with dementia in research, not only as participants but also in the context of PPI, by generating*

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[28] See Section 9.3 for examples of this fluctuating capacity.

[29] National Institute for Health Research (2018) *Guidance on co-producing a research project.* Involve, available at https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf, last accessed on 14 February 2021.

[30] ibid.

[31] National Institute for Health Research (2015) *Going the Extra Mile*. NHS available at https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf, last accessed on 14 February 2021, Recommendation 6.

> *ideas for research, advising researchers, being involved in consultations and being directly involved in research activities.*[32]

In summary, the steps taken in this collaborative process were therefore to

- identify a group of participants to fine-tune the list of questions and provide advice and guidance not only on what questions would be most relevant, but also how to ask the questions in the most effective manner;
- listen to all opinions and together agree on the most important topics and issues to be addressed as part of the research; and
- ensure that every participant was respected and their voice heard in terms of the direction the project took.

For this project, co-production for the design of interview questions took place in the following ways.

Collaborative meeting

A meeting with a group of carers and persons living with dementia was organised through collaboration between University of Exeter and Innovations in Dementia.[33] In the setting of an informal Patient Public Involvement ('PPI') focus group,[34] the need for research into various aspects of dementia was considered. In this context those present were asked to give their feedback on the validity of the premise and research question, their personal experiences and their thoughts generally on the topic.

The outcome was very useful and together the most important issues were explored. In total three people living with dementia and nine carers and family

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[32] Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., Øksnebjerg, L. and The European Working Group of People with Dementia (2018) 'Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement)' *Aging & Mental Health* 22(6): 723-729, at 723.

[33] Innovations in Dementia, http://www.innovationsindementia.org.uk, last accessed on 14 February 2021.

[34] The meeting took place in a community hub in a church in the centre of Exeter.

members were present, as well as two university researchers and a coordinator from Innovations in Dementia.

This focus group assisted greatly in shaping the interview questions to ensure they focused predominantly on the issues deemed most important by the group. The meeting also reaffirmed the need to consider the topic of ‘consumers living with dementia’, as all participants, carers and persons living with dementia alike, had stories to tell of sales of goods or services that had caused problems subsequently. Between them, they had experience of sales being conducted by telephone, by post, on the doorstep or following an advertisement on television. Overall participants felt that huge sums were paid in these ways each month to charities and businesses.

For example, many participants reported that their family members living with dementia would no longer understand that leaflets and flyers delivered by post were advertisements, but instead thought that these were mandatory forms to be completed. This led to a significant increase in direct debits and purchases. Another common feature was that, overwhelmed by events, participants often did not try to cancel the contracts or return any of the goods received.

The discussion also turned to the issue of banks and their responsibilities. The participants commented that some banks were very helpful, agreeing to check with carers when a person living with dementia asked for money, whilst other banks did not have any verification process in place. Consensus was that much of this might be related to issues such as legal capacity, powers of attorney and how closely the bank employees knew the person living with dementia and their family.

The issue of whether banks should verify a person’s spending with family members lead to the topic of independence and self-determination, alongside the need to protect the person living with dementia. A participant questioned if it mattered how a person living with dementia spent their money, as long as they felt connected to others in doing so. Others thought the issue was that often the person living with dementia could not afford the money spent and that they could not remember what they had done. All agreed there was a fine line between caring/supporting and taking away a person's right to choose.

Many participants thought businesses should bear some financial risk, even if they had unknowingly entered into a contract with a person with dementia, rather than the risk lying with the individual living with dementia. The concept of social corporate responsibility was touched upon in this regard.

The issue of stigma was also raised. It was felt that there was still some stigma attached to a diagnosis of dementia. Consequently it was a very personal decision to disclose a diagnosis, with some people happy to mention it, whilst others thought it was an invasion of their privacy. The issue of confidentiality was raised in this respect.

The issue of stigma was one that had not been considered in detail at the outset of the project. The focus group was instrumental in demonstrating how stigma might affect not only the response by the business counterpart, but also the willingness of the person living with dementia to disclose either their diagnosis or any difficulties in understanding a contract to the business in the first place. As a group, it was concluded that people living with dementia were worried about being labelled by their illness, and about what the admission of the disease might do to their consumer-business relationship. Consequently, the issue of stigma was added to the list of interview questions for all participants.

The participants were also very helpful in highlighting exactly what outcomes they would find most useful. There was consensus that a change in the law to reflect the situation of those living with dementia might be helpful, although at this stage no concrete ideas on what that change might look like were discussed. Other requested outcomes were to provide persons living with dementia and their family members with practical advice when issues arose regarding contract and consumer law.

4.5 Collecting new data through interviews

In considering qualitative research, Flick[35] suggests a range of method choices, from verbal data collection methods, such as interviews and focus groups, and 'multifocal data' collection techniques,[36] including ethnographies, visual data or case studies. Due to practical considerations involving time spent, the range of persons that were to be approached, as well as ethical concerns as further discussed below in Section 5.5 below, the focus was on verbal data collections, and in particular on data collection through interviews.

The aim of interviews as a research method is to gain new data that is rich, complex and allows participants to express their thoughts and share their experiences in detail. Participants all have lived experience of situations relating to consumer contracts. Interviews in this context allow participants to recount specific events relating to the person living with dementia and consumer matters that might not occur daily.[37] The dialogue allows for the participant and interviewer to explore various themes in a direct and non-intrusive way.[38] In that regard, interviewing as a method provides further information, which would not be apparent through observation alone.[39]

Following the collaborative PPI process, participants were recruited and interviewed, enabling them to share their thoughts, experiences and questions in a way that allows for the data to be "*textually rich*".[40] This new data stems from interviews with people living with dementia, as well as their family

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[35] Flick, U. (2014) *An Introduction to Qualitative Research* (5th ed.) London: Sage.
[36] ibid., at 39.
[37] Hockey, J. and Forsey, M. (2012) 'Ethnography Is Not Participant Observation: Reflections on the Interview as Participatory Qualitative Research' in Skinner, J. (ed) *The Interview: an Ethnographic Approach.* Bloomsbury Academic, 69-87, at 84.
[38] ibid.
[39] ibid.
[40] Kelly, S.E. (2010) 'Qualitative interviewing techniques and styles' in Bourgeault, I.L., de Vries, R.and Dingwall, R. (eds) *Handbook of Qualitative Health Research*, Thousand Oaks: Sage, at 307.

members and carers. In addition, representatives from charities working with persons living with dementia were also interviewed.[41]

In doing so, this research aimed to access knowledge of the types of contract concluded, the circumstances in which the contracts were formed, but also gain an understanding of the thoughts and feelings of the some of the participants involved in the consumer transactions.

To ensure this was the case, a mutually trusting and friendly atmosphere was created in the interviews, allowing for interviewees to speak freely and openly about the various topics. The aim was to ask open-ended rather than binary 'yes/no' style questions.

Considering the varied data expected from the interactions, and taking into account the fact that the sample group was diverse in nature, a rigidly structured set of questions would not achieve the variety, "*thickness*"[42] and richness of data that is key to the project. Consequently, the aim was to apply semi-structured interview techniques,[43] consisting of a formal interview guide,[44] which set out a list of themes and questions. The guide allowed for flexibility as to the order, and let interviewees select which themes were most significant or meaningful to them. It also allowed the inclusion of new elements where relevant.

The main criticisms of interviewing as a research tool relate to challenges regarding scale, as well as difficulties in translating individual narratives into broader social patterns.[45] However, whilst these difficulties are acknowledged,

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[41] Details of sampling and of how the interviews were conducted are set out below in this section.

[42] Bryman, A. (2015) *Social Research Methods* Oxford University Press, at 384, referring to Geertz, C. (1973) 'Thick Description: Toward an Interpretive Theory of Culture' in Geertz, C. *The Interpretation of Cultures*. Basic Books, Perseus Books Group.

[43] Bryman, A. (2015) *Social Research Methods* Oxford University Press, at 201.

[44] See Appendix 3.

[45] Lamont, M. and Swidler, A. (2014) 'Methodological Pluralism and the Possibilities and Limits of Interviewing' *Qualitative Sociology* 37(2): 153-171, at 162, 163.

this method allows for the identification of many experiences that arise when people living with dementia enter into consumer contracts.

A further recognised limitation of interviews that must be considered when analysing the results, is that the picture painted in recalling past events is often incomplete and sometimes tainted by later thoughts, opinions and views. Contrary to case studies or ethnographies, interviews rely on the participant's "*self-report".*[46] Closely linked is the notion of self-censorship, be it consciously and unconsciously. In relation to this research, it was noticed that participants would in some cases censor themselves. For example, in some instances participants were reluctant to share significant events because they considered their experiences not to be important or interesting enough. It was only through thorough and careful questioning and encouragement that the relevant information came to light.

However, while interviews are by their nature delayed in time and tainted by the encounter with the interviewer, as well as by the questions asked and themes covered, they do provide the researcher with access to the otherwise private thoughts of the participant, always to the extend they are willing to share these. Interviews occur after the event, and participants are able to digest the events and subsequent consequences.[47] As a result, participants can reflect on the different aspects of the consumer transaction, be it the parties' roles, the contractual document, or the (intended and unintended) outcomes. Simply observing consumer-business transactions would not provide any insight into such reflections.[48] It is only through qualitative interviewing that access to the knowledge and perspective of the participants can be gained. [49]

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[46] Bryman, A. (2015) *Social Research Methods* (5th edition) Oxford: OUP, at 493.

[47] Lamont, M. and Swidler, A. (2014) 'Methodological Pluralism and the Possibilities and Limits of Interviewing' *Qualitative Sociology* 37(2): 153-171, at 160, 161.

[48] ibid.

[49] Kelly, S.E. (2009) 'Qualitative interviewing techniques and styles' in Bourgeault, I.L., de Vries, R.and Dingwall, R. (eds) *Handbook on Qualitative Health Research*, Thousand Oaks: Sage, at 309.

Sensitivity of topic

The issues discussed in the interviews relate to dementia, family dynamics, personal financial matters and consumer decision-making. All of these topics fall into the category of sensitive issues.[50]

Dempsey et al point out that sensitive issues are further heightened when the interviews are conducted within a "*population at risk*".[51] As a result, it is important for the interviewer, in relation to all participants, but even more so for participants living with dementia, to monitor both their verbal and nonverbal responses for signs of distress throughout the interview.[52]

Furthermore, Zgoda et al[53] talk about the trauma that is created through grief or diagnosis. This trauma might still be fresh in the minds of those interviewed, be it persons living with dementia, or family members and other loved ones. There is a real risk of "*re-traumatisation*"[54] through the re-experiencing of the initial trauma in interview. In order to prevent this as much as possible, the questions focused on concrete and often positive steps taken, such as whether a lasting power of attorney was put in place, how the participants interacted with their bank or utility providers, and who was helping with day-to-day matters.

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[50] Braye, S. and McDonnell L. (2013) 'Balancing powers: University researchers thinking critically about participatory research with young fathers' *Qualitative Research* 13(3): 265-284.

[51] Dempsey, L., Dowling, M., Larkin, P. Murphy, K. (2016) 'Sensitive Interviewing in Qualitative Research' *Research* 13(3): 265-284 *in Nursing & Health* 39(6): 480-490, at 482.

[52] Berghmans, R.L.P. and Ter Meulen, R.H.J. (1995) 'Ethical issues in research with dementia patients' *International Journal of Geriatric Psychiatry* 10: 647-651, at 651.

[53] Zgoda, K., Shelly, P. and Hitzel, S. (2016) 'Preventing Retraumatization: A Macro Social Work Approach to Trauma-Informed Practices & Policies' *The New Social Worker,* available at https://www.socialworker.com/feature-articles/practice/preventing-retraumatization-a-macro-social-work-approach-to-trauma-informed-practices-policies/, last accessed on 14 February 2021.

[54] ibid., at 1.

As such it is important to consider the topics carefully to assess, and reduce as much as possible, the risk of harmful consequences [55] for all participants. In addition to being mindful of the questions asked, all interviewees were told at the start of the interview, and reminded during the meeting, that breaks were possible and that they could stop the whole process at any time if requested.

However, whilst an interview can lead to distress, for which the interviewer must be prepared and ready to intervene to alleviate any upset, it was generally the case in this study that participation was experienced positively. For many participants, there is a sense of relief or clarity that derived from reviewing the past. [56] Further, the fact that the research aimed to shine light on some of the challenges faced and ultimately improve matters, was often of comfort to those who felt they might not have benefitted themselves, but who hoped that their stories would allow for positive change in the future. [57]

Indeed, sharing an experience can contribute to healing, providing interviewees with a sense of self-determination.[58] This was echoed by Moore and Hollett who found that

> *many persons living with dementia value the opportunity to be heard and to contribute to a research effort and that they wish to continue speaking about their experiences even when strong emotions surface*.[59]

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[55] Sieber, J. E., and Stanley, B. (1988) Ethical and professional dimensions of socially sensitive research *American Psychologist* 43(1): 49–55, at 49.

[56] Carter-Visscher, R.M., Naugle, A.E., Bell, K.M. and Suvak, M.K. (208) ‘Ethics of asking trauma-related questions and exposing participants to arousal-inducing stimuli’ *Journal of Trauma & Dissociation* 8: 27-55, at 51.

[57] Jaffe, A.E., DiLillo, D., Hoffman, L., Haikalis, M. and Dykstra, R.E. (2015) ‘Does it hurt to ask? A meta-analysis of participant reactions to trauma research’ *Clinical Psychology Review* 40: 40-56, at 52.

[58] Block, L. and Leseho, J. (2005) ‘Listen and I tell you something: Storytelling and social action in the healing of the oppressed’ *British Journal of Guidance & Counselling* 33(2): 175-185, at 184.

[59] Moore T.F. and Hollett J. (2003) ‘Giving voice to persons living with dementia: the researcher's opportunities and challenges’ *Nursing Science Quarterly* 16: 163-167, at 165, 166.

Sample

A total of 31 persons were recruited to take part in the interviews. This group was made up of 6 people living with dementia, 21 family members and 4 charity representatives working or volunteering as advisers within the relevant information and advice departments of dementia or age-related charities. The deliberate choice was made to not approach businesses, the contractual counterparts to the consumer, but instead to focus on giving a voice to those who often do not have the power, time or energy to speak up.

Ensuring the participation of persons living with dementia is a relatively new occurrence, but one that is increasingly sought to ensure all voices are heard and deemed of value.[60] Whilst many researchers welcome the participation of those with lived experience of dementia, the validity and authenticity of individuals living with dementia is sometimes queried, and their right to speak up about their experiences is challenged. For example, in 2017, Howard [61] asked if those persons living with dementia who stepped forward to partake in research were indeed representative of the population living with dementia and as such if their input was valid and useful. Underlying Howard's query was the thought that anyone able to take part in research as an active participant in dementia research could by the very nature of the role not be considered to be a person living with dementia.

This point of view is an attempt to put all persons living with dementia into a single category. The root belief in this case is that all persons living with dementia can be regarded as identical and therefore all those that do not fit a certain image of what a person living with dementia should *be* like, *look* like, *sound* like, or *act* like, must be removed from the representative group. In doing so, the status of those living with dementia who are keen to partake and shape research is undermined and their standing diminished. Their

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[60] e.g. Proctor G. (2001) 'Listening to older women with dementia: relationships, voices and power' *Disability & Society* 16: 361-376, at 374; Reid D., Ryan T. and Enderby P. (2001) 'What does it mean to listen to people with dementia?' *Disability & Society* 16: 377-392, at 389.

[61] Howard, R. (2017) 'Doubts about dementia diagnoses' *Lancet Psychiatry* 4(8): 580-581.

personhood is questioned on the basis of someone else's idea of what it means to live with dementia.

Hu's response [62] to Howard is thoughtful. He confirms that indeed dementia advocates, i.e. persons living with dementia who partake in research, are often younger, better educated, in better health and better off both financially and socially than the average person living with dementia. This does not however mean that their diagnosis of dementia is to be questioned and that therefore their right for their lived experiences to be shared should be rejected. Hu calls this form of diagnosis based on the abilities demonstrated in a person's advocacy role as "*diagnosis-by-sound-bite*".[63]

Hu also considers the stigma[64] faced by people living with dementia regarding their "*reliability and trustworthiness*". Rather than question those that speak up about their experiences, their strength in coming forward to give first-person accounts of how dementia affects their lives should be applauded.

In this research, the interviewees who were living with dementia all had valuable contributions to make and their participation was gratefully received. As a result of their participation, the project has been more wide-reaching and inclusive. Their reflections have provided insight into their lived experiences, their frustrations, their doubts, but also their hopes and suggestions for the future.

Whilst Moore and Hollett[65] also advocate the inclusion of the voices of persons living with dementia in research, they recognise the challenges associated with such participation

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[62] Hu, W.T. (2017) 'No doubts about dementia advocacy' *Lancet Psychiatry* 4(11): 830.

[63] ibid.

[64] Stigma was also a topic that was discussed in interviews, see Section 9.4. Many participants felt strongly that there was still today much stigma associated to a diagnosis of dementia. As a result of their fear of stigma, many felt fearful to speak up about their disease.

[65] Moore T.F. and Hollett J. (2003) 'Giving voice to persons living with dementia: the researcher's opportunities and challenges' *Nursing Science Quarterly* 16: 163-167.

> *With increasing recognition of the importance of the voice of persons living with dementia, there is also a need and opportunity to acknowledge the unique challenges that such research presents and to offer strategies for dealing with the methodological challenges. In particular, the researcher needs to consider issues related to consent/assent, sample size, facilitating communication, and making the most of the data.* [66]

How these challenges were tacked in this project is described below.

Participating persons living with dementia

In total 6 persons living with dementia took part in the research. These participants were recruited through a variety of avenues. Through the initial PPI meeting, two persons living with dementia agreed to take part in this research study. Next, through contacts in the University of Exeter Medical School, one research-active person living with dementia, who was interested in partaking in research, was introduced to the project. In addition, through contacts made at the charity Alzheimer's Society, a call for participation was sent out by post to a number of persons living with dementia and their family members. Six people responded and subsequently took part in this research, of whom three were living with dementia.

In preparation for the interviews, information on the research, consent forms and the type of questions that would be asked was submitted to the potential interviewees. A copy of that information sheet and consent form is attached at Appendix 2.[67] In accordance with sections 30-34 of the Mental Capacity Act 2005, persons living with dementia who lacked capacity to consent to participate were not included in the empirical study.

Goldsmith[68] presents three principles to ensure successful interviews with persons living with dementia; the interviewer must (1) listen attentively to the

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[66] ibid., at 164.

[67] See Appendix 2.

[68] Goldsmith, M. (1996) *Hearing the voice of people with dementia: Opportunities and obstacles*. London: Jessica Kingsley, at 159-165.

person living with dementia, (2) accept that person fully as they are, and (3) remain open throughout to what the person is intending to share. To achieve such effective communication, Goldsmith recommends making the participant feel comfortable through tone of voice, eye contact, smiles and the sharing of emotions, acceptance of long pauses in the conversation, remaining respectful, and being aware of the value of the experiences they are generously sharing. These principles were adhered to throughout the project. The project was also guided by Hillman's suggestion that interviews with persons living with dementia must not be seen as "*confessional[s] but rather as an outcome of social interaction*".[69] The interviews with persons living with dementia were interactive discussions, rather than a probing of their past recollections and statements of fact.

To ensure that all participants could give informed consent, the guidelines of the Mental Capacity Act 2005 were observed. Participants had to be able to understand the study information (provided both in written format and then further explained verbally in advance to the interview). All participants were able to understand the aim of the research and of the interview, retain that information, weigh it up and communicate their decision about participation. At several instances throughout the interview, the participants were asked whether they remained happy to proceed.

Participating family members and carers

In this project, the term 'carer' is used to identify a person who is informally caring for the person living with dementia, rather than a professional (paid) carer. In all cases in this research, carers were family members of the person living with dementia. Some were happy to refer to themselves as carers, while others preferred the terms 'family member', 'spouse', 'son', or 'daughter', explaining that 'carer' denoted a medical or clinical element to them.

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[69] Hillman, A., Jones, I.R., Quinn, C., Nelis, S.M., Lamont, R.A., and Clare, L. (2020) 'All the world's a stage: accounting for the dementia experience - insights from the IDEAL programme' *Qualitative Research* 20: 703-720, at 704.

In total 21 family members took part in the research. These participants were identified through a variety of means. Some were identified through the initial PPI meeting, resulting in the participation of four spouses or adult children of a person living with dementia. Using snowballing, nine further participants were identified. An invitation to attend a dementia-specific carers' respite group led to a further five participants coming forward. Finally, through contacts at the charity Alzheimer's Society, a call for participation resulted in a further three spouses or other family members of persons living with dementia offering to take part.

All participants were given the information sheet and consent form in advance to the meeting. This information was also explained verbally prior to the start of the interview, ensuring participants were happy to proceed. All participants were keen to take part and happy to share their experiences, thoughts and advice.

Participating charity representatives

Alzheimer's Society, Exeter Dementia Action Alliance and Age UK are active in assisting people living with dementia and their families. They do so through advice centres, meetings, workshops, events and activities. Consequently, these charities were chosen because it was considered likely that people living with dementia, their spouses or other family members might contact them when a consumer issue arose. It was their experience in dealing with such matters that was of interest. Four representatives took part in the interviews.

Demographic data

The aim of this research was not necessarily to constitute a representative sample, but to meet a broad range of participants. The following tables set out some of the demographics of the group of participants.

Table 4.2 sets out the gender split within different groups of participants.

	Persons living with dementia	Family member/carer	Charity representative
Total	6	21	4
Gender			
Women	2	14	4
Men	4	7	0

Table 4.2 Participant numbers and gender split

Table 4.3 highlights that in this study all participating persons living with dementia lived independently in their own homes with their partners. For other persons living with dementia whose family members were interviewed, the picture was more varied, with 9 living at home with a partner, 2 living at home with family members (such as grown-up children), 8 living alone and 2 living in a nursing home.

Living arrangements	**Participating persons living with dementia**
Living with partner	6
Living alone	0
Living arrangements	**Persons living with dementia discussed by family members**
Living with partner	9
Living with family members	2
Living alone	8
Living in a nursing home	2

Table 4.3 Living arrangements of people living with dementia

Table 4.4 identifies the split within the group of family members, both by position within the family (spouse of grown-up child) as well as by gender.

Relationship of the participating family members to person living with dementia

Spouse	9
Wife	7
Husband	2
Adult child	12
Daughter	7
Son	5

Table 4.4 Relationship of family members to the person living with dementia

Table 4.5 sets out the roles of the participants within their charity organisation.

Role in charity	**Charity representative**
Information and advice	2
Legal department	1
Management	1

Table 4.5 Role of charity representatives within their organisation

Interviews

The interviews were semi-structured and a topic guide was followed. Three interview guides[70] were devised for the different categories of interviewees, namely people living with dementia, carers and family members, and charity representatives. The guides were thematically divided into four distinct groups of questions. Generally, participants were asked about the following topics: decision-making, capacity issues, lasting powers of attorney and dementia awareness. These topics were then adapted as necessary to the relevant category of participants. Whilst the interview guides were broadly followed, interviews were flexible, depending on the interviewee's developments, and participants were invited to add whatever information they found relevant.

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[70] See Appendix 3 for the complete interview guides.

- For example, for the **person living with dementia**, the guide focused on their attitude and experience generally to making decisions. Together, the difficulties in accepting other people's advice were explored. The person living with dementia was asked about their perception of dementia and to what extent, and to whom, they might talk about their diagnosis of dementia. In this context, the topic of stigma was discussed. In addition, the interviews also focused on various possible ways in which the person living with dementia might be assisted, be that through informal advice given by a family member or carer, or through a more formal process, such as a lasting power of attorney.
- For **carers and family members**, the guide sought information on their role in relation to the person living with dementia, and any changes that might have occurred after the onset of symptoms. The participants talked about decision-making before and after the diagnosis and issues that arose because of the illness. Participants also discussed how, why and when they may have curtailed the freedom to choose of the person living with dementia, and what resistance by the person living with dementia, if any, they had experienced. The relevance of lasting powers of attorney was explored, looking at the frequency with which they were established and then later used. In this context participants also considered the issue of assessing capacity in practice, either through a doctor, solicitor or other party, such as a family member.

- In the case of **charity representatives**, the focus was on experiences they had been asked to advise on, and (practical) solutions they offered. Participants spoke of challenges and difficulties experienced by people living with dementia and their family members. Issues of capacity assessment were discussed in the context of the lasting powers of attorney, including the difficulties encountered when seeking professionals who would assist in certifying capacity.

In most cases, participants were interviewed individually, although in some cases, the person living with dementia and the family member remained together throughout the interview and were interviewed as a couple. In one instance, two participants, both spouses of people living with dementia, decided they wanted to do a group interview. All the interviews were conversational in style and participants could introduce new areas of interest to be discussed if they wished.

For each interview, the aim was to build a relationship with the interviewee through active listening, reading body language and responding appropriately and sensitively, as well as through sharing information. When interviewing, my insider-status was shared, with information about my mother who had dementia, or about the challenges faced as a family member in trying to assist her with consumer matters. This was in some ways a shortcut that identified me as a person with similar experiences and who might therefore find it easier to understand the experiences shared in the interview.[71]

All interviews but one were audio-recorded and transcribed. The interview that was not recorded was transcribed using extensive notes taken during the session. The interviews ranged in length from 10 min[72] to 1 hour and 50 minutes. The mean length was 42 minutes.

Analysis process

Following the interviews, the data was organised and reviewed. Thematic analysis was used to identify and explore patterns of meaning within the data.[73] The aim in doing so was to compare "*the views and experiences of respondents… to illuminate potentially important differences and similarities*"[74] experienced by different interviewees.

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[71] See Section 4.6 for reflections on the limitations this 'insider-status'.

[72] A participant living with dementia had asked at the outset to limit the conversation to just ten minutes, as she felt that her concentration faded after that time.

[73] Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: a practical guide for beginners*. Sage, at 223.

[74] Joffe, H. (2012) 'Thematic Analysis' in Harper, D. and Thompson, A.R. (eds) *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*. John Wiley & Sons, Ltd, pp.209-223, at 214.

The thematic analysis followed the guidelines of Braun and Clark.[75] In the first phase of analysis, the interviews were transcribed, and transcriptions were then read several times. Margin notes made at this stage gave details of initial reflections and generated a preliminary overview of interesting aspects of the data. It was noted that towards the end of the interviews, data saturation was reached, as few new themes emerged from the analysis.

Braun and Clarke[76] describe the identification of themes or patterns within data as being either achieved through inductive 'bottom up' or theoretical, deductive 'top down' analysis. Specifically,

> *inductive analysis is a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions. In this sense, this form of thematic analysis is data-driven*.[77]

Here an inductive data-driven approach was chosen.

Thomas describes

> *the primary purpose of the inductive approach is to allow research findings to emerge from the frequent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies*. [78]

Thomas points out three main purposes for using an inductive approach:

> *(1) to condense extensive and varied raw text data into a brief, summary format;*

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[75] Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: a practical guide for beginners*. Sage.

[76] Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101, at 83.

[77] ibid.

[78] Thomas, D.R. (2003) *A general inductive approach for qualitative data analysis*. School of Population Health University of Auckland, New Zealand*,* at 2.

> *(2) to establish clear links between the research objectives and the summary findings derived from the raw data [...]; and*
>
> *(3) to develop a model or theory about the underlying structure of experiences or processes which are evident in the text (raw data).* [79]

Having read the interviews multiple times, the main points made were summarised and labelled. This allowed the raw interview data to be condensed and clarified, in order to determine themes emerging from the text. A list of themes was created which was then refined, identifying themes and sub-themes. For example, in relation to the theme of awareness of dementia by the person living with dementia, different sub-themes emerged to capture data on the person having no awareness of their own diagnosis, having awareness but refusing the acknowledge their diagnosis to others, acknowledging the illness but refusing to share the diagnosis with others, being aware and open about their diagnosis, and wanting to share and educate others about dementia to increase their awareness. These groupings of sub-themes allowed for links to be drawn between the findings from the data and the research question. Organising themes and sub-themes in this way allowed for further development to identify broader patterns of meaning. A codebook setting of the main themes and sub-themes is attached as Appendix 6.

Initially there were many different categories/themes, but through repeated review and analysis, these were reduced and organised from 19 (including knowledge, awareness, disclosure, stigma, education, capacity, assessment of dementia, lasting powers of attorney, costs, financial matters, power, powerlessness, businesses, cold calling, abuse, among others) to the key categories of capacity, knowledge and actions. These key themes reflect the more general categories within which other sub-themes where placed, but also represent the main weighting of the subjects discussed in the interviews. This development of the data into a coherent whole sets out the significant experiences of the participants. The aim of the analysis was to "*tell a*

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[79] ibid.

convincing and well-organised story about the data and topic” with a “*good balance between analytic narrative and illustrative extracts*”.[80]

Throughout the results and analysis section, full “*attention to reflexivity and subjectivity*”[81] was given, to provide results in qualitative research that reflect the data gathered, as well as the questions that remain unanswered.

4.6 Ethics, reliability and validity

Ethics

Prior to approaching the first participant, ethics approval was obtained from the University of Exeter. In turn, each participant was shown the ethics certificate,[82] as well as an information sheet with consent form,[83] which was signed and returned before the interview.

The information sheet and consent form were carefully designed to ensure that the information was clear and consent could be given by all participants without excessive effort. For example, at first the ethics board had asked that on the consent form participants provide their initials next to each statement, as well as their signature at the bottom of the page. In order to facilitate giving consent for some participants, such as persons living with dementia, I persuaded the ethics board to allow for participants to either initial or tick each statement. In all cases the individual statements in the consent form were ticked rather than initialled by participants living with dementia. This was also the case for most family members, with only a few taking the time to initial the consent form. In all cases the form was signed. This seemingly small change allowed for a more smooth start to the interview and removed a potential stumbling block for some participants.

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[80] Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101, at 96.

[81] Kelly, S.E. (2009) ‘Qualitative interviewing techniques and styles’ in Bourgeault, I.L., de Vries, R.and Dingwall, R. (eds) *Handbook on Qualitative Health Research*, Thousand Oaks: Sage, at 309.

[82] See Appendix 1.

[83] See Appendix 2.

Prior to the interview, the interviewer used the test in the Mental Capacity Act[84] to assess if the participants had capacity to consent to participation in the research project. In relation to participants living with dementia, all participants were able to give informed consent in line with the Mental Capacity Act. As a result, those persons that would have lacked capacity to consent to participate were excluded from the data corpus.

Interviews were recorded and transcribed. All participants were offered the opportunity to see a copy of the transcript and invited to make any changes they wished, and in all but three cases participants took up this offer to review the interview transcript. In eight cases, participants asked for the transcript to be amended to tidy up grammar, syntax or clarify certain points they made.

Anonymity was essential to safeguard the privacy of both the interviewees and of others discussed (such as a relative living with dementia). All transcripts were anonymised and identifying information was removed.

Reflection, reliability and reproducibility

In order to be reflexive in this research, it was important for me to recognise my role and perspective throughout the project, and acknowledge my personal investment in the project as the daughter of a person living with dementia.[85] Whilst I have not used my personal experience in the data that appears in this thesis, the interest in the topic and the drive to pursue this project results directly from my experiences.

At all stages, be it at the initial co-production stage, as well as in all interviews, I disclosed my experience as a family member of a person living with dementia to the interviewees. This was done to clarify my position, but also to build rapport with the participants by explaining how I also had first-hand experience of the highs and lows, the hopes, challenges and issues many of them faced. The discussion in the interviews with participants would often include my personal thoughts, drawn from my experiences.

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[84] Mental Capacity Act, s. 3.

[85] A short description of my personal experience is attached in Appendix 6.

As a result, it must be acknowledged that the content of the interviews, as well as the subsequent evaluation of the interviews and analysis resulting thereafter will have been shaped to some extent also by my status and experience. However, by remaining reflexive of this and keeping a broad and open mind of all experiences discussed, the aim is to counter any bias arising from this "*insider status*".[86]

Interviews took place at different times of the day and in different settings. Most interviews were conducted in the privacy of the participants' homes, but others took place either in a semi-private setting, for example in a meeting room off the main hall of a carers' support group, or in a public space, such as a café or bistro. Many external factors will influence the interviewee and interviewer at that moment, and the data gathered will be informed by these external aspects, as well as by the internal feelings of the participants at that time.

Mishler describes this, highlighting the fact that our story telling will not always be a uniform and objective account.

> *The problem is that the retellings are often quite different from each other. People story their lives differently depending on the occasion, audience, and reason for the telling.*[87]

Taking this into account, the recounted events, thoughts, ideas and concerns by persons living with dementia and their families, remain important aspects of the experiences of consumers living with dementia.

Whilst the interview guide was followed as much as possible, in each instance the guide was adapted to some extent to cater for the specific situation the interviewee was describing. As a result, the interviews did not necessarily

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[86] Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: a practical guide for beginners*. Sage, quoting Demetriou (2011) *Instead of dad coming out of the closet, I guess we all jumped in with him: A qualitative analysis of the experience of adult children of lesbian, gay and trans parents.* Dissertation. University of the West of England, at 303, 304.

[87] Mishler, E.G. (2004) 'Historians of the Self: Restorying Lives, Revising Identities' *Research in Human Development* 1(1-2): 101-121, at 101.

cover all of the questions or follow the specific order of questions. In addition, the time spent with each interviewee varied significantly, with the shortest interview lasting just 10 minutes and the longest discussion taking close to two hours. This more naturalistic method, typical in semi-structured interviews, may reduce the possibility of replicating the study exactly and obtaining identical data in a different study,[88] but it is suggested that the in-depth, rich data achieved through this method counter-balances the lack of reproducibility[89] of the research.

Validity

Methods to determine validity include "*triangulation, use of contradictory evidence, respondent validation, and constant comparison*."[90]

Triangulation was achieved by getting the views of different groups, namely persons living with dementia, family members, carers and relevant charities. Further, to ensure validity of the data, this research relied on respondent validation, inviting participants to review and, if desired, amend the transcripts of the interviews to ensure they reflected exactly what they wanted to say. The aim was to "*empower the respondents*" [91] by allowing interviewees to review and amend the interview transcripts in a more collaborative role, [92] increasing the confidence in the validity of the data obtained.

4.7 Concluding remarks

This chapter has highlighted the socio-legal approach selected, the aim of which is to review and understand the impact of the law on those who living with dementia as well as their carers. This is important to critically understand their needs and assess whether/how the law meets those needs. To do so,

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[88] Long, T. and Johnson, M. (2000) 'Rigour, reliability and validity in qualitative research'. *Clinical Effectiveness in Nursing* 30: 30-31.

[89] ibid., at 31.

[90] Anderson, C. (2010) 'Presenting and Evaluating Qualitative Research' *American Journal of Pharmaceutical Education* 74(8): Article 141, at 2.

[91] Mishler, E. G. (1986) *Research Interviewing: Context and Narrative*, Harvard: Harvard UP, at 118.

[92] ibid., at 126.

questions were asked of those that experience the application of the law first-hand in their daily lives.

As a consequence, throughout the process, this thesis has sought to put the everyday life experiences of people centre-stage; this is why the voices of persons living with dementia and their families are most important to this research. As a result, participation has been active and collaborative. The initial collaborative process of the PPI shaped the project, by providing advice and guidance on the nature of the issues encountered. In addition, with the selection of participants representing different stakeholder groups, the data provided is fruitful and depicts vividly the challenges, issues and events encountered. It is these experiences that are at the heart of the research.

This chapter has also examined the ethical dimensions of the project, such as compliance with formal ethical requirements (prior ethical approval at university level, individual consent forms and authorisations by participants to include their interviews in the final analysis), and less formal but equally important ethical aspects, such as interview sensitivity. Given the area of research and the traumatic nature of a diagnosis of dementia, it was highly important to broach the subject carefully and sensitively to ensure no re-traumatisation. This was achieved through carefully selected questions and topics, but also by being aware and alert to any possible upset and planning for that possibility.

The weaknesses and limitations of the project were also set out in this chapter. Due to the nature of semi-structured interviews and my experience as a daughter of a person living with dementia, the interviews are not necessarily replicable. However, there were recurring themes within the interviewed group and it is thought likely that similar topics would be reproduced in similar research projects.

Whilst the number of the participants is relatively small, saturation was reached and many of the themes and topics were repeated by many of the participants. The empirical research can therefore be said to have clearly brought a number of common experiences and challenges to the forefront.

This chapter has also considered the scoping review, the process applied and its intended aim, and as well as its limitations and challenges. The next chapter will set out the results of the scoping review focusing on financial decision-making by the person living with dementia.

Chapter 5 Financial decision-making in literature

5.1 Introduction

Having explored the methodology and method in the previous chapter, in this Chapter 5 academic literature on dementia and financial decision-making is considered. The aims of Chapter 5 are to examine some of the literature relating to consumers living with dementia, and identify the gaps in research on dementia in the context of contract and consumer matters, focusing on the decision-making ability of this group of consumers.

When deconstructing the research question, which looks at the consequences, legal and practical, that arise when a person living with dementia enters into a contract with a business as a consumer, it is clear that there are many elements that co-exist in the proposed question.

The literature reviewed and explored in this chapter must therefore concern *persons living with dementia*, as opposed to the ageing population more generally, or those more specifically with mild cognitive impairment. In addition, these persons must be making decisions of a contractual nature and their decisions will have a *financial or economic impact*. This is in opposition to other decision-making that might be relevant predominantly in relation to either day-to-day activities (such as getting dressed, selecting meals, choosing activities) or the 'fundamental liberties'[1] of a person, which will often have an emotional, physical or intellectual aspect, such as a person's health or well-being. Finally, not all decisions that will financially impact the person with dementia are to be considered in this literature review. It is only those that relate to bilateral contracts, namely those where a contractual counterpart, the *business or trader*, engages in the contractual process.

Section 5.2 explores decision-making in the context of cognitive impairment. This is then further broken down into sub-themes, with the academic field providing insight into the topic of *capacity* in the context of decision-making,

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[1] See Section 2.3 for an explanation of what is included in the term 'fundamental liberties'.

financial decision-making in contrast to other decision-making, and the *role of the carer* in decision-making.

In **Section 5.3** assessment of financial capacity is examined, looking at the justification of attempting to assess such capacity (i.e. asking *why* financial capacity should be assessed), considering the question as to *who* is best placed to carry out such assessment, and *how* such financial assessment might be undertaken.

The third emerging theme from the scoping review, in **Section 5.4**, is concerned with issues surrounding the potential abuse or neglect of persons with cognitive impairment and consequential difficulties relating to (financial) decision-making. This section explores the *greater risk* of fraud or abuse to such members of the population due to their circumstances, and then looks at suggested ways in which that group may be *protected*. Finally, in **Section 5.5**, concluding remarks will draw the outcomes of the scoping review together in a short summary.

5.2 Financial capacity and decision-making

Decision-making and capacity

For the consumer living with dementia, each contract they enter into is in response to a series of decisions they have taken, namely to purchase (or hire) certain goods, services or digital content, as well as the decision to select a certain business and their offer over all other offers in the market place. Where those decisions are later questioned, it is often done so by suggesting that the person living with dementia might not have had the capacity to enter into the contract. Decision-making and capacity are closely linked.

The reviewed literature considers decision-making as a fundamental aspect to a person's well-being in life,[2] and is to be encouraged wherever possible. As

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[2] The link between decision-making and well-being is also explored in Section 2.3.

pointed out by Samsi et al, "*Exercising choice and control over decisions is central to quality of life*".[3]

However, with (gradual) cognitive impairment, a person's decision-making faculties become more stretched. Consequently, there are greater risks of decisions being made where it is not clear if the person could fully understand all the implications of a decision, or if that person was able to remember the context within which a decision might be made.[4] Further challenges may relate to weighing up the pros and cons of a choice, as well as taking into account their personal or financial situation as a whole. This can lead to decisions with outcomes that are detrimental to the person whose cognitive functions are impaired. These are named 'unwise' decisions in the legislation,[5] although no further mention (or definition) of the term 'unwise' is included.

Capacity issues will also affect a person's ability in relation to accuracy and speed. Studies have shown that both of these skills will deteriorate with the onset of dementia when contemplating choices regarding financial or other daily activities.[6] For example, Lassen-Greene et al. demonstrate that memory loss and cognitive impairment led to "*reduced accuracy on measures of everyday function, … [and reduced] speed of performing instrumental activities of daily living*". [7] However, accuracy and speed are crucial attributes when a sales person is pressing for a sale and the consumer living with dementia feels obliged to react swiftly.

Financial matters require financial capacity

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[3] Samsi, K. and Manthorpe, J. (2013) 'Everyday decision-making in dementia' *International Psychogeriatrics* 25(6): 949-961, at 949.

[4] See Section 9.2 on the concerns participants expressed of a lack of understanding in contractual matters by the person with dementia.

[5] Mental Capacity Act 2005, s. 1(4).

[6] Okonkwo, O.C., Wadley, V.G., Griffith, H.R., Ball, K. and Marson, D.C. (2006) 'Cognitive Correlates of Financial Abilities in Mild Cognitive Impairment' *Journal of the American Geriatrics Society* 54: 1745-1750.

[7] Lassen-Greene C.L., Steward K., Okonkwo O., Porter E., Crowe M., Vance D.E., et al. (2017) 'Mild Cognitive Impairment and Changes in Everyday Function Over Time: The Importance of Evaluating Both Speed and Accuracy' *Journal of Geriatric Psychiatry & Neurology* 30: 220-227, at 220.

In addition to capacity in relation to decision-making generally, researchers have also focused specifically on *financial* capacity; that is to say the ability to deal with financial matters. For the consumer living with dementia, financial capacity is important, as their decisions and actions will have an impact on their financial and economic situation. This in turn can determine their independence and their quality of life.

This is a consumer society, and therefore financial capacity is deemed to be "*one of the instrumental activities of daily living considered the single best predictor of capacity for independent living in older adults*".[8] This "*knowledge and reasoning ability needed to manage one's finances*" is, as Hsu eloquently describes it, "*a form of human capital*".[9]

Typical errors in financial management by persons living with dementia were identified as including those in relation to "*financial knowledge, understanding of checkbooks and banks statements, and includes specific financial tasks*".[10] This was determined in research that considered the deterioration of financial skills over a longer period of time, during which participants with mild cognitive impairment[11] expected to evolve into a form of dementia,[12] were tested at regular intervals.

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[8] Caboral-Stevens M. and Medetsky M. (2014) 'The construct of financial capacity in older adults' *Journal of Gerontological Nursing* 40: 30-37, at 30.

[9] Hsu J.W. and Willis R. (2013) 'Dementia Risk and Financial Decision Making by Older Households: The Impact of Information' *Journal of Human Capital* 7(4): 45, at 1.

[10] Ghesquiere A.R., McAfee C. and Burnett J. (2017) 'Measures of Financial Capacity: A Review' *Gerontologist* 59(2): 109-129, at 124.

[11] Alzheimer's Research (2019) *Mild cognitive impairment*, available at https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/mild-cognitive-impairment/, last accessed on 14 February 2021.

[12] ibid.; see also Triebel K.L., Martin R., Griffith H.R., Marceaux J., Okonkwo O.C., Harrell L. et al. (2009) 'Declining financial capacity in mild cognitive impairment: A 1-year longitudinal study' *Neurology* 73: 928-934; and Mitchell, A.J. and Shiri-Feshki, M. (2009) 'Rate of progression of mild cognitive impairment to dementia – meta-analysis of 41 robust inception cohort studies' *Acta Psychiatrica Scandinavica* 119: 252-265.

These errors in relation to financial matters can often have "*devastating personal and family consequences*"[13] because of the essential nature of economic resources in order to remain independent. Edersheim et al. further highlight the negative impact unwise financial decisions can have, listing that these can "*adversely affect patients, their families, and society*".[14] Indeed, in many cases the person living with dementia is part of a couple, and the other spouse will be equally affected by any loss in resources due to any contracts entered into 'unwisely'.[15] Where the person or couple can no longer live financially independently, the state might need to step in. Alternatively, family members, and in particular adult children of people living with dementia, may feel obliged to intervene and pay off debts, again affecting them and their own families.

Chiong et al. see dementia and financial decision-making as so closely related that whilst, on the one hand, a diagnosis of dementia will usually lead to an assessment of financial capacity, on the other hand, "*the frequency and functional importance of financial errors*" can be seen "*as symptoms*" of various forms of dementia.[16] For the consumer living with dementia, the lack of financial clarity when making decisions will have significant effects.

Decision-making, capacity and the carer

Whilst some people living with dementia may not have any support, others will have access to carers who are willing and able to assist in their daily lives, including in their financial decision-making. These can be either family members, such as spouses, adult children or other relatives, or non-family carers and supporters (including professional carers, nurses, home help

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[13] Chiong W., Hsu M., Wudka D., Miller B.L. and Rosen H.J. (2014) 'Financial errors in dementia: testing a neuroeconomic conceptual framework' *Neurocase* 20: 389-396, at 389.

[14] Edersheim J., Murray E.D., Padmanabhan J.L. and Price B.H. (2017) 'Protecting the Health and Finances of the Elderly With Early Cognitive Impairment' *Journal of the American Academy of Psychiatry & the Law* 45(1): 81-91, at 81.

[15] This effect on family members is also discussed in Section 2.2.

[16] Chiong W., Hsu M., Wudka D., Miller B.L. and Rosen H.J. (2014) 'Financial errors in dementia: testing a neuroeconomic conceptual framework' *Neurocase* 20: 389-396, at 389.

providers or informal carers such as neighbours, friends or volunteers). These carers can become both facilitators and barriers to the decision-making process.[17] In doing so, they shape the decision-making of the person living with dementia. This will also impact their decision-making as a consumer, and result in specific financial, emotional and physical consequences in relation to their consumer transactions and other financial activity.

Assisting with the finances for the person living with dementia can take many forms and often involves a gradual process for the carer. The research of Samsi and Manthorpe[18] demonstrates that over time the roles of the person living with dementia and the carer will evolve, as the illness reduces financial decision-making capacities. Their research shows that at the outset of the illness, a family member would often look to provide support in decision-making, be it by providing a second opinion, offering a simplified choice and assisting the person living with dementia in coming to a decision by weighing up the pros and cons as they see them. As the illness progresses further, the carer's role changes, resulting in the substitution of the carer's decisions for those of the person living with dementia.[19] Where financial decisions were taken by the carer on behalf of the person living with dementia, there was still reliance on "*providing cues, reducing options, using retrospective information and using the best interests principle*"[20] in order to achieve an outcome most likely in line with the views and values of person living with dementia. These additional measures sought by carers to identify a person's 'best interests'[21] show that where financial decision-making is deemed no longer possible, a wide variety of factors will be significant (such as historical, personal, social

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[17] This statement is reflected in the experiences shared by participants, as set out in Sections 8.2 and 8.3. Whilst all family members acted out of love and concern, this translated into a range of different outcomes, from supporting the person living with dementia in making whatever choices they wanted, to restricting their decision-making and taking full control of their finances.

[18] Samsi, K. and Manthorpe, J. (2013) 'Everyday decision-making in dementia' *International Psychogeriatrics* 25(6): 949-961.

[19] This role reversal over time is also something that was identified in the interviews, see Chapter 8, Sections 8.2 and 8.3.

[20] Samsi, K. and Manthorpe, J. (2013) 'Everyday decision-making in dementia' *International Psychogeriatrics* 25(6): 949-961, at 949.

[21] Mental Capacity Act 2005, s. 4.

factors relevant to the person living with dementia) and will play a part in determining the outcome of any financial decision to be taken.[22]

The fact that such an eclectic range of factors must be considered when making a decision is in line with research[23] that suggests that financial decision-making is not purely a matter of cognitive reasoning. Other factors will also have a significant impact on the outcome of any financial decision. An important social factor is the influence of those close to the decision-maker. For example, in married couples, Boyle found that the spouse of the person living with dementia would be highly influential in assisting decision-making of the spouse living with dementia. The research demonstrates the importance of "*social factors in influencing the involvement of people with dementia in financial management and decision-making*".[24] In relation to these social factors, gender is significant and the roles within the couple prior to the illness will often have an influence on how actively a person living with dementia will engage in the decision-making process.[25]

The issue of decision-making being influenced not only by family members and carers, but also by other external elements was further highlighted by Darby and Dickerson, stating that in addition to a person demonstrating that they still have "*the capacity for complex reasoning and executive functions, … motivational and metacognitive processes are also important*".[26] In other words, decision-making will always be based on a wide range of internal and external circumstances. This wide range of factors responsible for taking a decision highlights the challenge of understanding how decisions are reached.

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[22] On the tension between substituted decision-making and supported decision-making, see Section 7.3.

[23] Boyle G. (2013) 'She's usually quicker than the calculator: financial management and decision-making in couples living with dementia' *Health & Social Care in the Community* 21(5): 554-562.

[24] ibid., at 554.

[25] This was highlighted, for example, by Irvin in Section 8.2, talking about his parents' entrenched roles and the consequences for his mother following her dementia diagnosis.

[26] Darby R.R. and Dickerson B.C. (2017) 'Dementia, Decision Making, and Capacity' *Harvard Review of Psychiatry* 25: 270-278, at 270.

Whilst it is clear that capacity (and financial capacity) of the person living with dementia is difficult to capture and identify, numerous attempts have been made to do so through the various assessment methods available.

5.3 Financial capacity assessment

Capacity assessment is crucial for the consumer living with dementia. How, when and by whom capacity is determined will be one of the factors that will determine the validity to the consumer contracts entered into.[27] Questions around capacity assessment will also be relevant to the person living with dementia and their families when setting up support structures, such as for example the lasting power of attorney.[28]

As described above, capacity can generally be described as the ability to choose or decide for oneself. The Mental Capacity Act defines capacity,[29] as well as the lack of capacity.[30] Whilst there is a presumption of capacity,[31] capacity testing is required in situations where there is a doubt in relation to the ability of a person to make their own decisions. In addition to capacity testing in light of the Mental Capacity Act, the need to assess *financial capacity* is suggested to provide insight of a person's ability to make decisions that will affect their financial situation.

The difficulty in assessing financial capacity is three-fold and relates to (1) the justification for the need of financial capacity assessment, (2) the assessment tool itself, and (3) the assessor. As a consequence in the literature, questions are raised regarding *what* that assessment should cover, *how* to best identify financial capacity, and *why* assessment is necessary. The topic of financial assessment further invites the question as to *who* should provide such an assessment and *if* objectivity and accuracy of the assessment can be

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[27] See Section 7.2 for a detailed discussion of the impact of capacity assessment on contract validity.

[28] See the challenges faced by participants in entering into lasting powers of attorney, as described in the new data, in Section 10.5.

[29] Mental Capacity Act 2005, s. 2 and s. 3.

[30] Mental Capacity Act 2005, s. 3.

[31] Mental Capacity Act 2005, s. 1(2).

guaranteed. The review considers the identified articles in light of these sub-themes.

Justification for assessing financial capacity

The reasons for testing for capacity generally are numerous. Capacity testing is usually undertaken to determine the welfare of a person living with dementia.[32] In particular, testing of capacity aims to determine if the person living with dementia is able to make decisions in relation to treatment, advance directives, end-of-life decisions, hospital or care home admission, in relation to sexual activities, marriage, or consent to partaking in research.[33] In addition, capacity may need to be ascertained in relation to dealing with financial matters, including a person's ability to negotiate and enter into contracts, powers of attorney, wills and testaments.

Being capable of dealing with one's financial matters means that that person has the ability to manage their financial affairs in line with their own values and interests.[34] It differs greatly from, for example, the capacity to drive or the capacity to make everyday decisions because of the complexity of the subject matter. The skill set required is different and requires numerous abilities, both at basic level (e.g. arithmetic) and conceptual level (e.g. understanding of the banking system).[35] The person living with dementia will expect to continue to undertake their daily activities for as long as possible. A typical daily activity will involve them acting as a consumer. In their role as consumer, it is essential that they still can understand financial transactions and deal with relevant financial matters that arise routinely, if they wish to continue to live independently.

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[32] for example, Astell H., Lee J.H. and Sankaran S. (2013) 'Review of capacity assessments and recommendations for examining capacity' *New Zealand Medical Journal* 126(1383): 38-48.

[33] Bhattacharyya, S. and Burns, A. (2008) 'Practice of competence assessment in dementia: UK' in Stoppe, Gabriela (ed) *Competence assessment in dementia*. Springer Publishing Co, US, 175-180.

[34] Gardiner P.A., Byrne G.J., Mitchell L.K. and Pachana N.A. (2015) 'Financial capacity in older adults: a growing concern for clinicians' *Medical Journal of Australia* 202(2): 82-85, at 82.

[35] ibid., at 83.

Financial decision-making is a specific skill, which may be reduced for people living with dementia.[36] An inability to make financial decisions (reasonably) wisely can consequently lead to a reduction of independence. This may be either because personal funds are depleted leading to economic dependence, or because family members, in an attempt to protect the person living with dementia, enforce restrictions on their ability to spend or live independently.[37] It can also result in the person becoming more vulnerable to financial abuse or exploitation. There is therefore a real risk that a reduction of capacity to make decisions affecting their financial affairs will impact adversely that person's (and their family's) overall quality of life.[38]

Marson[39] questions the usefulness of performing specific tests relating to financial capacity, especially for people at early or medium stage dementia, because financial capacity (like capacity more generally) may fluctuate and the tests used may not be relevant to the decision contemplated at that time. However, Marson concludes that a valid reason to perform such tests of financial decision-making ability may be to ensure that family members and carers of people living with dementia "*proactively engage in financial and legal planning*", in light of the future risk of loss of financial capacity.[40] With dementia being a neuro-degenerative disease with no current cure in sight, the need for others to support the planning for a future time were the person living with dementia no longer is able to care for themselves is important.[41]

Even if assessment of financial capacity is deemed helpful, the question remains as to who should be performing these assessments to ascertain if a

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[36] ibid., at 84.

[37] In Section 8.3, new data is presented on such restrictions on spending.

[38] Arcara G., Burgio F., Benavides-Varela S., Toffano R., Gindri P., Tonini E. et al. (2019) 'Numerical Activities of Daily Living - Financial (NADL-F): A tool for the assessment of financial capacities' *Neuropsychological Rehabilitation* 29(7): 1062-1084, at 1063.

[39] Marson D.C., Martin R.C., Wadley V., Griffith H.R., Snyder S., Goode P.S. et al. (2009) 'Clinical interview assessment of financial capacity in older adults with mild cognitive impairment and Alzheimer's disease' *Journal of the American Geriatrics Society* 57: 806-814.

[40] ibid., at 806.

[41] See Section 10.5 on participants' thoughts on lasting powers of attorney and other mechanisms to plan ahead.

person has the capacity to make decisions that will affect their financial situation.

Assessors of financial capacity

In most of the literature, the suggested assessors are within the health community, be they doctors or nurses. This is because for most family members, the family doctor or health professional that first identified the loss of cognitive function is the natural person to turn to for guidance and advice on capacity matters generally.[42] However, for many health professionals, this additional responsibility is not something they are necessary familiar or comfortable with.[43] Many "*do not understand their role or know how to help*".[44] As a result, there is in the literature a call for further training to provide this relatively new, and steadily increasing, demand of financial capacity assessment. For example, Astell et al. suggest that *"Training for capacity assessment is not usually included in most medical or nursing qualifications. As such, many medical professionals lack training to perform capacity assessments"* and that *"there is a need a need for general practitioners to be trained in this assessment*."[45]

Bhattacharyya et al. suggest that it should be the responsibility of practitioners to provide this service, and that therefore practitioners should be at the forefront of financial capacity testing. *"All clinicians should ensure sufficient familiarity with current legal and ethical concepts and how these concepts might be applied*."[46] This is echoed by much of the literature. Most papers all

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[42] Widera E., Steenpass V., Marson D. and Sudore R. (2011) 'Finances in the older patient with cognitive impairment: He didn't want me to take over' *Journal of the American Medical Association* 305: 698-706.

[43] In Section 8.5, the difficulties faced in trying to find a (healthcare) professional willing to assess capacity is discussed.

[44] Widera E., Steenpass V., Marson D. and Sudore R. (2011) 'Finances in the older patient with cognitive impairment: He didn't want me to take over' *Journal of the American Medical Association* 305: 698-706, at 698.

[45] Astell H., Lee J.H. and Sankaran S. (2013) 'Review of capacity assessments and recommendations for examining capacity' *New Zealand Medical Journal* 126(1383): 38-48, at 43.

[46] Bhattacharyya, S. and Burns, A. (2008) 'Practice of competence assessment in dementia: UK' in Stoppe, Gabriela (ed) *Competence assessment in dementia*. Springer Publishing Co, US, 175-180, at 180.

suggest that practically, clinicians, general practitioners[47] and mental health practitioners[48] are most often approached to assess capacity, including financial capacity, by family members, the legal profession and other third parties. Gardiner[49] recommends that any such assessment tool must be easy to use by clinicians, including "*non-specialist clinicians*". Guidelines for financial capacity testing that are familiar to general practitioners and readily practicable are therefore overdue.

However, the issue is also that most forms of assessment are to some extent subjective. Werner[50] considered the motivation of family physicians in recognising capacity and the lack thereof and found that much related to the physicians' perception of the person living with the dementia and the decisions they were facing. Issues of safety and danger, as well as perceived responsibility for the person living with dementia, were significant. However, other seemingly unrelated matters, such as the "*percentage of patients aged 65+ with cognitive deterioration in the physician's practice*"[51] had impact on the physician's assessment. Again, this shows the difficulties in performing a reliable, accurate assessment of capacity, including financial capacity.

Rabin et al. focused on whether the assessors themselves were confident with the tests they were administering. Of those clinicians surveyed, "*61% of respondents were slightly confident, and only 23% were very confident, in their ability to assess a patient's judgment skills with their current tests. The*

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[47] Astell H., Lee J.H. and Sankaran S. (2013) 'Review of capacity assessments and recommendations for examining capacity' *New Zealand Medical Journal* 126(1383): 38-48; Bennett H. & Hallen P. (2005) 'Guardianship and financial management legislation: what doctors in aged care need to know' *Internal Medicine Journal* 35: 482-487.

[48] Sousa, L.B., Simoes, M.R., Firmino, H. and Peisah, C. (2014) 'Financial and testamentary capacity evaluations: Procedures and assessment instruments underneath a functional approach' *International Psychogeriatrics* 26: 217-228.

[49] Gardiner P.A., Byrne G.J., Mitchell L.K. and Pachana N.A. (2015) 'Financial capacity in older adults: a growing concern for clinicians' *Medical Journal of Australia* 202(2): 82-85.

[50] Werner P. (2007) 'Family physicians' perceptions and predictors regarding the competence of a person with Alzheimer's disease' *International Journal of Geriatric Psychiatry* 22(4): 320-326.

[51] ibid. , at 321.

overwhelming majority (87%) of respondents perceived a need for improved measures."[52]

An assessment tool may therefore be needed that can assist those asked to test for financial capacity. However, no such definitive test exists.

Assessment of financial capacity

Whilst diagnosis of dementia is difficult, especially in the early stages of the illness, assessments to assist in the diagnosis of dementia do exist. The most well known such test is the MMSE.[53] Other neuro-psychological tests include WAIS[54] (as revised, most recently in 2008)[55] and COGNISTAT.[56] However, whilst these assessments can detect cognitive impairments, they do so without determining if that diagnosis also means a loss of capacity.[57] Consequently, it is important to note that a diagnosis of dementia or cognitive impairment does not automatically result in a verdict of incapacity.

This was highlighted by Matsuda[58] who researched whether such psychological tests could assist in identifying financial capacity or incapacity.

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[52] Rabin L.A., Borgos M.J. and Saykin A.J. (2008) 'A survey of neuropsychologists' practices and perspectives regarding the assessment of judgment ability' *Applied Neuropsychology* 15: 264-273, at 264.

[53] Mini Mental State Examination (MMSE), the form of which can be accessed at https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/mini-mental_state_exam.pdf, last accessed on 14 February 2021.

[54] Wechsler Adult Intelligent Scale (WAIS), as initially set out in Wechsler, D. (1955) *Manual for the Wechsler Adult Intelligence Scale.* Oxford, England: Psychological Corporation.

[55] Wechsler Adult Intelligent Scale – Fourth Edition (WAIS-IV), as set out in Wechsler, D. (2008) *Wechsler Adult Intelligence Scale-Fourth Edition: Administration and scoring manual*. San Antonio, TX: Psychological Corporation, the form of which can be accessed at https://www.pearsonclinical.com/psychology/products/100000392/wechsler-adult-intelligence-scalefourth-edition-wais-iv.html?Pid=015-8980-808, last accessed on 14 February 2021.

[56] a commercial tool for cognitive testing, accessed at https://www.cognistat.com, last accessed on 14 February 2021.

[57] Alvaro L.C. (2012) 'Competency: general principles and applicability in dementia' *Neurologia* 27: 290-300.

[58] Matsuda, O. and Saito, M. (2013) 'Advocacy of elderly persons with dementia and evaluation of their mental capacity: Consistency between results of intelligent and cognitive tests and capacity to perform financial and

The findings show that "*financial capacity did not correspond with [either] [above average (89/90)] IQ scores, or [above the cut-off point (23/24)] MMSE scores. Approximately 80% of the patients whose IQ was above average did not have enough capacity to manage their finances.*"[59] Consequently, other assessment forms are required to determine financial capacity.

Similarly, whilst Alvaro states that whilst "*capacity is directly related to the level of cognitive deterioration*", [60] this cannot usually be determined through the MMSE or similar cognitive tests designed to identify dementia. In the UK, more generally, the Mental Capacity Act makes it clear that cognitive impairment is not a determining factor in whether or not a person has capacity.[61] Instead, assessment of a person's capacity to make decisions will be based on that person's inability to understand and process relevant information (information that may be complex or relatively basic).

The level of capacity that the person living with dementia needs in order to successfully make a decision depends on what the decision relates to. Indeed, Alvaro explains that the "*level of required capacity depends on the decision: higher for critical ones, lower for low-risk decisions*".[62] Capacity cannot be considered a binary choice. A decision about relatively mundane daily activities, such as what to wear, will require a lesser level of capacity than the level of capacity needed to decide if a financial investment is advantageous or detrimental to that person's financial well-being. Consequently the same person may have capacity to choose their clothing, but lack capacity to make financial decisions. This gradation of capacity makes assessment more difficult.

Skills required for financial capacity

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everyday activities' in Boutros, Nash (ed) *The international psychiatry and behavioral neurosciences yearbook - 2012, Vol 2* Nova Biomedical Books, US 127-144.

[59] ibid., at 127.

[60] Alvaro L.C. (2012) 'Competency: general principles and applicability in dementia' *Neurologia* 27: 290-300, at 290.

[61] Mental Capacity Act 2005, s. 3.

[62] Alvaro L.C. (2012) 'Competency: general principles and applicability in dementia' *Neurologia* 27: 290-300, at 290.

In order to ascertain whether a person still has financial capacity, it is necessary first to identify what financial skills are usually present in someone who is deemed to have financial capacity.

Gerstenecker[63] sets out four skills that together cover the full spectrum of financial capacity. These are (1) basic monetary knowledge and calculation skills, (2) financial judgment, (3) financial conceptual knowledge, and, finally, (4) financial procedural knowledge.[64]

Whilst these skills are all relevant to ascertain the overall understanding of finances and therefore establish financial capacity, it is prudent to remember that different situations will require only some of these skills. For example, financial conceptual and procedural knowledge may be important for some decisions with on-going obligations such as a mortgage, these skills may be less significant where a person makes a financial decision relating to the purchase of goods or services for a moderate amount of money in a shop.

Gerstenecker states that for people living with dementia in the early stages, changes might be identified in some but not all of the above listed skills.[65] Consequently, the assessment of financial capacity must be tailored to the decision that the person with cognitive impairment is about to make.

Marson[66] concurs that the skills required to manage one's financial affairs must be considered in light of different levels of decision-making. Consequently, Marson proposes that the concept of managing financial matters be divided into "*three levels: specific financial abilities, broad domains of financial activity, and overall financial capacity*".[67]

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[63] Gerstenecker A., Triebel K., Eakin A., Martin R. and Marson D. (2018) 'Exploring the Factor Structure of Financial Capacity in Cognitively Normal and Impaired Older Adults' *Clinical Gerontologist* 41(1): 33-41, at 36.

[64] ibid., at 36.

[65] ibid., at 39.

[66] Marson, D. (2001) 'Loss of Financial Competency in Dementia: Conceptual and Empirical Approaches. Aging, Neuropsychology, and Cognition' *Journal on Normal and Dysfunctional Development* 8(3): 164-181, at 166.

[67] ibid., at 166.

Whilst determining the level of capacity in managing financial matters will vary from person to person, in more general terms it may be said that in the early stages of dementia, capacity would usually only be determined at the first level, namely focusing on specific financial abilities, rather than providing a blanket assessment of overall financial capacity. This means that for each transaction undertaken by the person living with dementia, capacity (and financial capacity) is presumed. Only where there is doubt, a specific test on their ability to perform a specific financial task might be undertaken.

In the medium term, it may at some point become apparent that a consumer living with dementia, whilst still capable of making decisions regarding everyday matters, no longer has financial capacity because broad domains of financial activity no longer make sense to them. This is a difficult interim phase where capacity will still be available in some instances, whilst in other circumstances, the person living with dementia is deemed no longer to have capacity for more complex decision-making, and their family members or attorneys will need to support them more actively.

Finally, at a later stage in the illness, financial capacity is often lost. At this stage, the person living with dementia will depend on their family members, attorneys and carers to act in their best interests for their financial affairs, such as the payment of bills. Whilst financial capacity may be lost, capacity to make other decisions, including decisions regarding fundamental liberties, may still be intact or at least fluctuating. Whilst financial capacity may no longer be questioned at the last stage of the illness, capacity more generally will still need to be considered for some decision-making affecting the person living with dementia.

Different ways to assess financial capacity

Another difficulty is that a lack of financial ability is not necessarily based purely on cognitive decline; a wider range of factors will have bearing on any decision-making. The choices made will also be due to “*various cognitive, psychiatric, social, and cultural factors that potentially contribute to* *financial incapacity in older adults*",[68] making a single test to determine capacity more difficult. Where the perceived lack of capacity is due to social, cultural or educational factors, as well as cognitive impairment, it is difficult to assess how these different factors should be taken into account, if at all. For example, in the context of spouses living with dementia, Boyde[69] demonstrated that non-cognitive social factors such as gender played an important role when testing the financial capacity of those living with dementia. As Werner highlights, "*The assessment of competence in persons with [dementia] is a subtle and complex process*."[70]

There is currently no agreed-upon standard for evaluating financial capacity.[71] Instead, tests described in the literature range from new models devised by the authors[72] to more established tests,[73] reviewed and in some cases updated or combined with further tests[74] in the relevant research projects. Overall, all tests aim to assist in determining the capacity of a person to make decisions that will have an impact on their financial situation.

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[68] Pinsker, D.M., Pachana, N.A., Wilson, J., Tilse, C., and Byrne, G.J. (2010) 'Financial Capacity in Older Adults: A Review of Clinical Assessment Approaches and Considerations' *Clinical Gerontologist* 33(4): 332-346, at 333.

[69] Boyle G. (2013) 'She's usually quicker than the calculator: financial management and decision-making in couples living with dementia' *Health & Social Care in the Community* 21(5): 554-562, at 558, 560.

[70] Werner P. (2007) 'Family physicians' perceptions and predictors regarding the competence of a person with Alzheimer's disease' *International Journal of Geriatric Psychiatry* 22(4): 320-326, at 320.

[71] Pinsker, D.M., Pachana, N.A., Wilson, J., Tilse, C., and Byrne, G.J. (2010) 'Financial Capacity in Older Adults: A Review of Clinical Assessment Approaches and Considerations' *Clinical Gerontologist* 33(4): 332-346, 333, 338.

[72] e.g. Arcara G., Burgio F., Benavides-Varela S., Toffano R., Gindri P., Tonini E. et al. (2017) 'Numerical Activities of Daily Living - Financial (NADL-F): A tool for the assessment of financial capacities' *Neuropsychological Rehabilitation* 1-23.

[73] e.g. Lui V.W., Lam L.C., Chau R.C., Fung A.W., Wong B.M., Leung G.T., Leung K.F., Chiu H.F., Karlawish J.H. and Appelbaum P.S. (2013) 'Structured assessment of mental capacity to make financial decisions in Chinese older persons with mild cognitive impairment and mild Alzheimer disease' *Journal of Geriatric Psychiatry & Neurology* 26(2): 69-77.

[74] e.g. Kirshner H.S. (2013) 'Determination of mental competency, a neurological perspective' *Current Neurology & Neuroscience Reports* 13(6): 356.

Their methods will vary significantly and, broadly speaking, the tests approach the assessment of financial capacity in one of three ways: These are (1) clinical interviews, (2) reports of observation (of the person living with dementia or their carers), or (3) performance-based measures,[75] where the person whose financial capacity is questioned will be asked to perform a series of tasks simulating various financial tasks and transactions.

Clinical interviews will focus on a discussion between a clinician and the person to be tested. This type of assessment allows for direct interaction and therefore can be tailored to the specifics of the person to be assessed. In doing so, details of any transaction that requires the capacity assessment can form part of the interview. For example, in the sale of a house (in the event of down-sizing or the move to a nursing home), the person living with dementia can discuss directly with the physician how, if at all, they understand the transaction they are about to enter into. Clinical interviews are also often used to assess capacity to sign specific legal documents, such as lasting powers of attorney or wills.

Results of clinical interviews tend to declare a substantial number of persons with mild or moderate dementia as lacking in financial capacity. It is thought that this may relate to the weight of the responsibility the practitioner perceives when performing the assessment. For example, Marson's research indicated that 82% of persons with mild cognitive impairment were deemed capable, compared to only 26% for persons with mild Alzheimer's disease, and 4% for persons with moderate Alzheimer's disease.[76] This may potentially demonstrate heightened concern for those with a diagnosis of dementia.

Reports of observation are similar to the clinical interview in that they rely on a discussion with a clinician, although significantly that interview might not be

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[75] Hebert, K.R. and Marson, D.C. (2007) 'Assessment of financial capacity in older adults with dementia' in Qualls, S.H. and Smyer, M.A. (eds) *Changes in decision-making capacity in older adults: Assessment and intervention*. Hoboken, NJ, US: John Wiley & Sons Inc, US; 237-270.

[76] Marson D.C., Martin R.C., Wadley V., Griffith H.R., Snyder S., Goode P.S. et al. (2009) 'Clinical interview assessment of financial capacity in older adults with mild cognitive impairment and Alzheimer's disease' *Journal of the American Geriatrics Society* 57: 806-814, at 806.

with the person living with dementia themselves, but could be with a family member or carer. Even where the person living with dementia does the reporting, this form of assessment looks back at past behaviour, rather than at current ability. For example, Sousa suggests using not only the "*traditional neuropsychological and functional assessment but also forensic assessment instruments (FAIs). FAIs are the only specific instruments intended to provide a specific and direct answer to the assessment of financial capacity based on legal systems*".[77] Sousa's forensic methods rely on reports of past behaviour and ability.

In some cases a combination of different methods is sought. Kishner[78] suggests that "*The determination of competency for a general medical patient may be assessed by a combination of a bedside mental status examination such as the MMSE and a questionnaire such as the Aid To Capacity Evaluation (ACE 1999)*".[79] Whilst the MMSE is a performance-based test used to identify cognitive impairment rather than capacity (financial or otherwise), the ACE 1999 relies on reports from carers or the person living with dementia to determine capacity.

However, some academics question the reliability of the reports by the person with cognitive impairment or their carers, because it remains "*unclear whether patients with mild cognitive impairment are fully aware and provide reliable estimates of their functional status*".[80] Okonkwo et al.[81] revealed that there was indeed a difference between what the person with cognitive impairment had reported and how they fared in objective performance tests relating to "*checkbook management, bank statement management, and bill payment,*

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[77] Sousa, L.B., Simoes, M.R., Firmino, H. and Peisah, C. (2014) 'Financial and testamentary capacity evaluations: Procedures and assessment instruments underneath a functional approach' *International Psychogeriatrics* 26: 217-228, at 218.

[78] Kirshner H.S. (2013) 'Determination of mental competency, a neurological perspective' *Current Neurology & Neuroscience Reports* 13(6): 356.

[79] ibid., at 1.

[80] Okonkwo O.C., Wadley V.G., Griffith H.R., Belue K., Lanza S., Zamrini E.Y. et al. (2008) 'Awareness of deficits in financial abilities in patients with mild cognitive impairment: going beyond self-informant discrepancy' *American Journal of Geriatric Psychiatry* 16:650-659, at 650.

[81] ibid.

and on overall financial capacity". More surprising was that persons with mild cognitive impairment "*were better at estimating their financial abilities than their informants*", i.e. their carers and family members.[82] This shows the subjective element that will factor in any test relying on self- or carer-reporting of issues.

Finally, from the literature available, it appears that **performance-based measures** are most often applied in order to assess financial capacity. Examples of these performance-based tests include Arcada et al.[83] who provided a new tool, "*the Numerical Activities of Daily Living - Financial (NADL-F) test*", the aim of which was to assess if a person has capacity to make financially sound decisions. This short test focuses on being able to perform basic financial activities, such as arithmetic and basic financial, budgeting and economic concepts.

Sherod devised a different tool, the Financial Capacity Instrument (FCI), using "*arithmetic skills, simple visuomotor sequencing, and immediate story recall*".[84] Stoeckel[85] reviewed the reliability of the FCI, by combining that test with a magnetic resonance imaging (MRI) of the brains of the participants. Stoeckel's research demonstrates that financial capacity will indeed deteriorate as the illness progresses.[86] Niccolai, using the FCI, highlighted that "*Semantic arithmetic knowledge, and to a lesser extent visual memory*

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[82] See also Chapter 8 where family members described their concerns and worries for their relatives living with dementia.

[83] Arcara G., Burgio F., Benavides-Varela S., Toffano R., Gindri P., Tonini E. et al. (2017) 'Numerical Activities of Daily Living - Financial (NADL-F): A tool for the assessment of financial capacities' *Neuropsychological Rehabilitation* 1-23, at 1.

[84] Sherod M.G., Griffith H.R., Copeland J., Belue K., Krzywanski S., Zamrini E.Y. et al. (2009) 'Neurocognitive predictors of financial capacity across the dementia spectrum: Normal aging, mild cognitive impairment, and Alzheimer's disease' *Journal of the International Neuropsychological Society* 15: 258-267, at 258.

[85] Stoeckel L.E., Stewart C.C., Griffith H.R., Triebel K., Okonkwo O.C., den Hollander JA., Martin R.C., Belue K., Copeland J.N., Harrell L.E., Brockington J.C., Clark D.G. and Marson D.C. (2013) 'MRI volume of the medial frontal cortex predicts financial capacity in patients with mild Alzheimer's disease' *Brain Imaging & Behavior* 7(3): 282-292.

[86] ibid., at 282.

and attention, are key longitudinal cognitive predictors of financial skill decline" concluding that "*neurocognitive abilities of written arithmetic, visual memory, and processing speed*" were key to assessing financial capacity.[87]

Another performance-based capacity test is the 'Assessment of Capacity for Everyday Decision-Making' ('ACED'). This test was devised by Karlawich and Lai[88] after Lai contended that "*current approaches to making this assessment are incomplete*",[89] and therefore needed improving. The ACED test was reviewed subsequently by other academics. For example, Lui et al. applied the ACED test within their project and concluded that it "*provided a reliable and clinically applicable structured framework for assessment of mental capacity to make financial decisions*."[90] Their results showed that 53.5% of those with mild Alzheimer's disease were capable (using the ACED test), compared to 94.6% of those with mild cognitive impairment.[91] These figures show a different outcome to that produced by Marson et al.[92] using the clinical interview to assess financial capacity. No further research has been published on the discrepancy in outcome.

From all the above, it is clear that there is no consensus as yet over the best manner to assess financial capacity. Indeed, given that capacity is governed not only by an ability to make decisions using cognitive function, but is also

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[87] Niccolai L.M., Triebel K.L., Gerstenecker A., McPherson T.O., Cutter G.R., Martin R.C. et al. (2017) 'Neurocognitive Predictors of Declining Financial Capacity in Persons with Mild Cognitive Impairment' *Clinical Gerontologist* 40: 14-23, at 14.

[88] see https://www.ono.ac.il/wpcontent/uploads/The_Short_Portable_ACED.pdf, last accessed on 14 February 2021.

[89] Lai J.M. and Karlawish J. (2007) 'Assessing the capacity to make everyday decisions: a guide for clinicians and an agenda for future research' *American Journal of Geriatric Psychiatry* 15: 101-111, at 101.

[90] Lui V.W., Lam L.C., Chau R.C., Fung A.W., Wong B.M., Leung G.T., Leung K.F., Chiu H.F., Karlawish J.H. and Appelbaum P.S. (2013) 'Structured assessment of mental capacity to make financial decisions in Chinese older persons with mild cognitive impairment and mild Alzheimer disease' *Journal of Geriatric Psychiatry & Neurology* 26(2): 69-77, at 69.

[91] ibid.

[92] Marson D.C., Martin R.C., Wadley V., Griffith H.R., Snyder S., Goode P.S. et al. (2009) 'Clinical interview assessment of financial capacity in older adults with mild cognitive impairment and Alzheimer's disease' *Journal of the American Geriatrics Society* 57: 806-814.

ruled by social, cultural and other factors, often individual to the specific person whose capacity is being questioned, the task seems monumental. Nevertheless, "*national guidelines for the evaluation of task-specific decision-making capacities to reduce the variability of outcome and improve quality of evaluations found among medical professionals, forensic evaluators, and legal actors*"[93] would be a helpful step to clarify matters further.

For the consumer living with dementia, assessment of financial capacity may be a useful guide of future behaviour. However, no matter the form such assessment takes, it is too cumbersome to be applied in a consumer setting when the consumer is faced with a possible transaction with a business counterpart.

In contrast to the financial capacity assessments, the proposed test as set out in the Mental Capacity Act 2005 is clear and straightforward in its application, but in practice the issue of evidence is its stumbling block.[94] In order to ensure that the contract or signed document will not be contested, further assessments are often sought. As a consequence, parties are reluctant to rely on the legislative test of the Mental Capacity Act 2005[95] without further assessment by a medical or legal professional. Consequently, current legislation is not helpful in many instances.

However, even if national (unified) guidelines were put in place that were easy to apply by medical and legal professionals alike, and that were both accurate and objective, the moment in time when the assessment would be carried out, as well as the frequency of such testing, would also need to be reviewed carefully.

Frequency of assessments

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[93] Edersheim J., Murray E.D., Padmanabhan J.L. and Price B.H. (2017) 'Protecting the Health and Finances of the Elderly With Early Cognitive Impairment' *Journal of the American Academy of Psychiatry & the Law* 45(1): 81-91, at 81.

[94] See Section 8.5 where participants express their difficulties in ensuring the assessment of capacity is done in a way that can be subsequently evidenced if required.

[95] See Chapter 6, Section 6.3 on the capacity test as set out in the Mental Capacity Act 2005, s. 3.

Fundamentally, the concern with assessment of financial capacity, like other forms of capacity, is that it is likely that capacity will vary for each tested person over time. To counter this, Gerstenecker[96] suggests that "*[c]linicians working with older adults should **routinely** examine for potential changes in … financial function*."[97] The question therefore arises of what 'routinely' means.

For practical reasons such as time and money constraints, many of the assessments suggested above are often only performed once, or at best infrequently. Whilst the trend regarding the loss of capacity by persons living with dementia is usually irreversible in the long-term, their short- and medium-term prospects are more positive and capacity, including financial capacity, may come and go on a daily or even hourly basis.[98]

5.4 Financial capacity and risks of abuse

Finally, many of the articles on financial decision-making focused on the risks associated for persons living with dementia. A lack of financial capacity can lead to a greater risk of financial fraud, abuse or exploitation of that person. However, knowledge of reduced capacity can ensure that protective measures are put in place.

For the consumer living with dementia, there is also a risk of abuse or fraud perpetrated by the business they are interacting with.

A greater risk of abuse

Generally, with the loss of capacity due to cognitive impairment, there is an increased risk of abuse and neglect. More specifically, where there is financial incapacity, there is in addition the risk of financial abuse, exploitation and

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[96] Gerstenecker A., Triebel K., Eakin A., Martin R. and Marson D. (2018) 'Exploring the Factor Structure of Financial Capacity in Cognitively Normal and Impaired Older Adults' *Clinical Gerontologist* 41(1): 33-41.

[97] ibid., at 33.

[98] This was also described by participants in interviews for this project. See for example, Section 9.3 for examples of this fluctuating capacity.

fraud.[99] It is well documented[100] that financial exploitation of older adults is a significant challenge that has grown steadily in the last decade.[101] In fact, psychological abuse and financial exploitation are today the most common form of elder abuse.[102]

As discussed above, financial capacity is essential in continuing to lead an independent life. However, over time, dementia will render the ability to make sound financial decisions more and more difficult. As a result, there is a real risk for people living with dementia of falling victim to financial fraud, abuse and exploitation. These risks are also on the minds of carers and family members[103] when talking about their experiences of living with, or caring for, a person living with dementia.[104]

Martin highlights that research into the speed of deterioration showed that financial capacity is likely to diminish quickly and significantly in as little as one year for people living with mild dementia, although differentiation must be done depending on the specific financial tasks undertaken.[105] Martin concludes that this decline in financial judgement is of both "*clinical and public*

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[99] Manthorpe J., Samsi K. & Rapaport J. (2012) 'Responding to the financial abuse of people with dementia: a qualitative study of safeguarding experiences in England' *International Psychogeriatrics* 24(9): 1454-1464.

[100] Wood, S. and Lichtenberg P.A. (2017) 'Financial Capacity and Financial Exploitation of Older Adults: Research Findings, Policy Recommendations and Clinical Implications' *Reviews in Clinical Gerontology* 40(1): 3-13.

[101] Lichtenberg P.A. (2016) 'Financial exploitation, financial capacity, and Alzheimer's disease' *American Psychologist* 71(4): 312-320.

[102] Peisah C., Bhatia S., Macnab J. & Brodaty H. (2016) 'Knowledge translation regarding financial abuse and dementia for the banking sector: the development and testing of an education tool' *International Journal of Geriatric Psychiatry* 31(7): 702-707; Sooryanarayana R, Choo WY, Hairi NN. (2013) 'A Review on the Prevalence and Measurement of Elder Abuse in the Community' *Trauma, Violence, and Abuse* 14(4): 16-25.

[103] These concerns were highlighted by nearly all participants in this study. Consequently, safety and security of their loved ones living with dementia were often placed above concerns about capacity and freedom of choice.

[104] Benbow, S.M. and Kingston, P. (2017) 'Spontaneous concerns about risk and abuse reported by people with dementia and their carers' *The Journal of Adult Protection; Brighton* 19(2): 92-99.

[105] Martin R.C., Gerstenecker A., Triebel K.L., Falola M., McPherson T., Cutter G. et al. (2018) 'Declining Financial Capacity in Mild Cognitive Impairment: A Six-Year Longitudinal Study' *Archives of Clinical Neuropsychology* 27(6): 81-90.

policy interest" because it heightens the risk of people living with dementia being taken in by "*simple fraud schemes*".[106] Fraud will take place in many different ways and persons living with dementia can be subjected to financial abuse through third parties, as well as family members or friends of a person living with dementia.[107]

This research project specifically excludes fraudulent behaviour by businesses when transacting with consumers living with dementia. Nevertheless, the decline in financial judgement might lead to situations that remain legal, but do not take into account the more vulnerable position of the consumer.

Protection from risk

The literature highlights that financial decline means that "*financial supervision and planning for patients newly diagnosed*" with dementia must be provided.[108] Indeed, many suggest that "*early detection and new interventions to reduce exploitation risk*"[109] are essential.

The question however must be *who* should bear responsibility for assisting with such supervision and planning. Furthermore, it must be identified *how* these interventions might reduce the risk of financial fraud and abuse.

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[106] Martin R., Griffith H.R., Belue K., Harrell L., Zamrini E., Anderson B. et al. (2008) 'Declining financial capacity in patients with mild Alzheimer disease: a one-year longitudinal study' *American Journal of Geriatric Psychiatry* 16: 209-219, at 209.

[107] Tayton, S. (2016) 'What morals?' *Private Client Adviser* 21(5): 34.

[108] Martin R., Griffith H.R., Belue K., Harrell L., Zamrini E., Anderson B. et al. (2008) 'Declining financial capacity in patients with mild Alzheimer disease: a one-year longitudinal study' *American Journal of Geriatric Psychiatry* 16: 209-219, at 209.

[109] Spreng R.N., Karlawish J. and Marson D.C. (2016) 'Cognitive, social, and neural determinants of diminished decision-making and financial exploitation risk in aging and dementia: A review and new model' *Journal of Elder Abuse & Neglect* 28: 320-344, at 320.

Mechanisms to protect people living with dementia from abuse or exploitation are limited in law, although some options are available. These focus mainly on the official route of the Court of Protection and Office of Public Guardian.[110]

On a practical level, local adult safeguarding systems and social care can also assist the person living with dementia by reviewing the safety and financial provisions of the person with cognitive impairment.[111] Charities and voluntary organisations can provide advice and some assistance, although their role is often limited to sign-posting to the relevant authorities.[112] Legal advisers are urged to be aware of the issues and assist their clients by protecting their assets.[113] Finally, the private sector is becoming involved and, for example, research is seeking to educate banking staff to alert them to fraud and financial abuse schemes to look out for.[114]

Again, assessment is thought to be a key element in risk prevention. The best way to combat financial abuse is seen to be the ability to accurately assess financial capacity. Lichtenberg suggests, that financial assessment is "*the cornerstone assessment needed in cases of financial exploitation*".[115]

The question remains however, if a financial capacity assessment can overrule the legal test set out in the Mental Capacity Act 2005. If the assessment of financial capacity is an infrequent event, could it be argued that the presumption of capacity overrides any earlier assessment, unless a

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[110] Cooper, C. (2015) 'Protecting the vulnerable from financial exploitation' *Trusts and Estates Law and Tax Journal* 165(Apr): 22-25.

[111] Manthorpe J., Samsi K. & Rapaport J. (2012) 'Responding to the financial abuse of people with dementia: a qualitative study of safeguarding experiences in England' *International Psychogeriatrics* 24(9): 1454-1464.

[112] Samsi K., Manthorpe J. and Chandaria K. (2014) 'Risks of financial abuse of older people with dementia: findings from a survey of UK voluntary sector dementia community services staff' *Journal of Adult Protection* 16(3): 180-192.

[113] Withers, D. (2015) 'A ticking time bomb' *Private Client Adviser* 20(6): 21-23.

[114] Peisah C., Bhatia S., Macnab J. & Brodaty H. (2016) 'Knowledge translation regarding financial abuse and dementia for the banking sector: the development and testing of an education tool' *International Journal of Geriatric Psychiatry* 31(7): 702-707.

[115] Lichtenberg P.A. (2016) 'Financial exploitation, financial capacity, and Alzheimer's disease' *American Psychologist* 71(4): 312-320, at 312.

more recent test as set out in the Mental Capacity Act determines a lack of capacity. Arias points out that "*[a]* ***legal*** *determination of incompetency is a prerequisite to a judicial order appointing a guardianship or other protective mechanism.*"[116] The consequence of this requirement is that these legal means to protect may not always be available, especially given the period within which a person living with dementia is often still legally capable, but practically no longer able to successfully deal with financial choices.[117]

Consequently, most suggestions to protect the person living with dementia from fraud, abuse or exploitation, as well as generally any unwise decisions, rely on families, spouses[118] or adult children, to step in and intervene. For example, much emphasis is placed on the need to "*educate older adult patients and their families about the need for advance financial planning*".[119] Effectively, this means considering the use and usefulness of a form of power of attorney granted to carers or family members.[120] However, recent data shows that the majority of financial exploitation was perpetrated by someone known to their victim, be it a service provider (13.7%), or more likely someone else known to the older person, such as a family member, friend, acquaintance or neighbour (66%).[121] Given that research has shown that financial abuse will stem not only from strangers, but also from family

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[116] Arias J.J. (2013) 'A time to step in: legal mechanisms for protecting those with declining capacity' *American Journal of Law & Medicine* 39(1): 134-159, at 134.

[117] ibid.

[118] Hsu J.W. and Willis R. (2013) 'Dementia Risk and Financial Decision Making by Older Households: The Impact of Information' *Journal of Human Capital* 7(4): 45.

[119] Widera E., Steenpass V., Marson D. and Sudore R. (2011) 'Finances in the older patient with cognitive impairment: He didn't want me to take over' *Journal of the American Medical Association* 305: 698-706, at 698.

[120] Bennett H. & Hallen P. (2005) 'Guardianship and financial management legislation: what doctors in aged care need to know' *Internal Medicine Journal* 35: 482-487; Routh R., Mcneill C. & Jackson G.A. (2016) 'Use of power of attorney in Scotland' *Scottish Medical Journal* 61: 119-123.

[121] NHS Digital (2018) *Safeguarding Adults England, 2017-18, Experimental Statistics. Health and Social Care Information Centre*, available at https://files.digital.nhs.uk/33/EF2EBD/Safeguarding%20Adults%20Collection%202017-18%20Report%20Final.pdf, last accessed on 14 February 2021.

members,[122] the risk of fraud and exploitation remains relevant even where relatives of the person living with dementia step in to help.[123]

5.5 Concluding remarks

This review shows first that there is a gap in existing research regarding the issue of the *consumer* living with dementia. This is surprising as a person living with dementia will still be taking part in consumer transactions on a regular basis. Recognising that such a gap exists is important and highlights the need for this current project. More broadly however, this thesis is situated in the field of research on financial decision-making by the person living with dementia.

This chapter has demonstrated that capacity is a fluid concept; different choices by people living with dementia require different levels of capacity. For example, where the decisions taken relate to their financial affairs, a person needs to be able to use different skills in order to successfully understand a financial question. However, financial skills alone will not fully determine how a financial decision is reached. Social, cultural and historical factors play an equally significant part.

The level of ability applied to tackle financial tasks will impact on their financial situation and consequently on their ability to live independently and without intervention. Intervention is likely to be provided by family members and partners, who can act both as facilitators as well as barriers from making any financial decisions. This in turn is likely to have an effect more generally on the confidence, well-being and quality of life of the person with dementia.

A further insight from this review is the question of whether there is a need to assess financial capacity in certain circumstances. This is particularly controversial, as legislation already provides guidance on how to tackle

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[122] Wood, S. and Lichtenberg P.A. (2017) 'Financial Capacity and Financial Exploitation of Older Adults: Research Findings, Policy Recommendations and Clinical Implications' *Reviews in Clinical Gerontology* 40(1): 3-13.

[123] I wish to make it clear that in relation to this research project it was clear that all who partook had the best interests of their loved ones living with dementia at heart.

capacity more generally. The test spelt out in the Mental Capacity Act should be sufficient to ascertain a person’s financial capacity when faced with a specific choice. The research demonstrates that rather than superseding the general test, various studies show that a financial assessment of capacity can be useful in assisting the person living with dementia and their families when considering if financial planning and some protective steps are appropriate to protect the person living with dementia from losing their financial independence due to unwise decisions resulting from their lessened financial skills. Whilst various models have been suggested that can ascertain the level of financial skill and ability of a person living with dementia, just like for the more general test, questions remain as to when, and by whom, the assessment of financial capacity should be carried out.

Finally, much of the literature on financial decision-making focuses on the risk of abuse and exploitation of the person living with dementia. The risks arise from the person’s inability to understand financial choices clearly, but also when others act illegally or unethically. Risk is sought to be mitigated through education and awareness. This means that both people living with dementia as well as their family members must become aware of the lessened financial ability of the person living with dementia in certain circumstances. In addition, external bodies, such as safeguarding agencies need to be informed and aware of those that may need additional protection and care. Next, tools that can alleviate the risks must be explained and put in place, such as financial planning tools, lasting powers of attorney, or other structures that allow for the assistance of family members to help where needed. All this highlights the complexities associated with dementia and financial decision-making and the need for further legal protection for the consumer living with dementia.

In the next two chapters, the law as it stands today is reviewed in detail. First, in Chapter 6, the legal categorisation of the consumer living with dementia will be examined.

Chapter 6 The legal status of the consumer living with dementia

6.1 Introduction

The previous chapter explored the methodology and methods that are used in this project to examine the consequences, legal and practical, when a person living with dementia, as a consumer, enters into a contract with a business. In the next two chapters, the legal framework within which such a consumer will operate is reviewed in detail. Beyond a descriptive review, this thesis makes a contribution to doctrinal analysis through thorough examination of the law to highlight both the protections and the gaps in legislation that will affect the consumer living with dementia.

This chapter and the next will consider if and how the law, as it stands today, protects the consumer living with dementia. A multitude of rules come into play when a person living with dementia enters into a consumer contract. In this chapter, relevant laws are analysed to explore the legal status and standing of a consumer living with dementia. In the next chapter, the remedies available to that person will then be examined.

There is currently no specific protection for consumers living with dementia. Instead, a number of different rules must be considered. As this thesis considers people living with dementia when they act as consumers, *consumer* legislation is relevant. As explained in Chapter 2, where a consumer is living with dementia, the neuro-degenerative effect of dementia may affect their cognitive ability, which in turn may lessen their *capacity* to understand the complex deals offered by businesses, as well as their ability to make decisions on whether to enter into a contract on the offered terms. In addition, the cognitive impairment may lead to a person being classified as having a disability[1] and *non-discrimination* law, *equality* principles and *human rights* more generally, may also be relevant. Finally, the relationship between business and consumer is contractual in nature. Hence, *contract* law is

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[1] Mental Health Foundation (2015) *Dementia, rights and the social model of disability, policy discussion paper*, available at https://www.mentalhealth.org.uk/sites/default/files/dementia-rights-key-summary.pdf, last accessed on 14 February 2021.

relevant and the contract's validity might be questioned, either at the time of entering into the contract, or after the contract was concluded.

These different areas of the law need to be examined in order to assess how the law considers the person living with dementia when acting as a consumer. Ideally, the relevant areas of law would be complementary to each other, protecting consumers living with dementia by ensuring that they are interconnected and interdependent. In reality, as will be demonstrated in this chapter and the next, whilst there is some interaction between certain areas of law,[2] there is currently little coherence between all the relevant different laws that look at the person from different angles, depending on the status they attach to them.

As demonstrated in Chapter 5, the specific topic of the *consumer living with dementia* has not been explored in research. Much has been written about capacity and decision-making by persons living with dementia in medical settings,[3] on vulnerable consumers and their interaction with companies,[4] and on the Mental Capacity Act.[5] This interconnection of consumer, contract,

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[2] See Chapter 7, Fig. 7.1.

[3] for example recently: Wright, M.S. (2020) 'Dementia, Healthcare Decision Making, and Disability Law' *The Journal of Law, Medicine and Ethics* 47(4): 25-33; Lamahewa, K., Mathew, R., Iliffe, S., Wilcock, J., Manthorpe, J., Sampson, E.L., Davies, N. (2018) 'A qualitative study exploring the difficulties influencing decision making at the end of life for people with dementia' *Health Expectations* 12(1): 118-127; Dening, K.H., King, M., Jones, L., Sampson, EL (2017) 'Healthcare decision-making: past present and future, in light of a diagnosis of dementia' *International Journal of Palliative Nursing* 23(1): 4-11.

[4] for example recently: Riefa C, Saintier S (eds) *Vulnerable Consumers and the Law – Consumer Protection and Access to Justice*, Routledge; Mulder, J. (2019) 'Comparing Vulnerability: How Can EU Comparative Law Methods Shed Light on the Concept of the Vulnerable Consumer' *Journal of International and Comparative Law* 6(2): 209-231: Rosenbaum, M.S., Seger-Guttmann, T. and Giraldo, M. (2017) 'Commentary: vulnerable consumers in service settings' *Journal of Services Marketing* 31(4/5): 309-312.

[5] for example recently: Kong, C. and Ruck-Keene, A. (2018) *Overcoming Challenges in the Mental Capacity Act 2005: Practical Guidance for Working with Complex Issues*. Jessica Kingsley Publishers; Marshall, H. and Sprung, S. (2016) 'Community nurse's knowledge, confidence and experience of the

capacity, and disability law in this research has not been explored before and adds to current literature in its analysis.

This chapter will examine the ways in which persons are categorised in order for the law to apply to them. Whilst such classification is useful for understanding the law, it is important to be aware of its limitations. Indeed, it must be pointed out that any categorisation of persons is not a precise science.

Foster and Herring set out the limitations of placing individuals into a unifying threshold category by explaining that

> *…all who fall in the category are deemed equal regardless of the extent to which they qualify. For example the individual awaking with the most dreadful hangover on the morning of their eighteenth birthday is as much of an adult for the purposes of the law as the person excitedly reading a telegram from the Queen congratulating them on their one hundredth birthday… many of the legal categories which adopt the threshold category are to an extent based on a fiction, devised for bureaucratic convenience.*[6]

In addition to such threshold categories that may be very broad, other categorisations in law will set out strict criteria for categorisation resulting in that group being extremely narrow and specific. As pointed out by Brown, in this event, persons might be "*boxed*"[7] out of a category despite, for example, a vulnerability, because they do not meet the strict requirements of adhesion. Brown explains that *"[t]his compartmentalisation of vulnerability produces consequences contradictory to the overall aim—that is, it creates potential*

Mental Capacity Act in practice' *British Journal of Community Nursing* 21(12): 615-622.

[6] Foster, C. and Herring, J. (2017) *Identity, personhood and the law.* Springer, at 25.

[7] Brown, S. (2019) 'Un-Boxing Vulnerability In Protection Of The Credit Consumer' *Journal of Business Law* 7: 511-533.

exclusion of opportunity, yet does not provide a comprehensive system of protection." [8]

Whilst these limitations of any categorisation are taken into account, the law however uses this device regularly as a tool to provide clarity in its application. In this chapter, the person and their circumstances, both external and internal, will be considered.

First, the *external* aspects that influence the status of the person when entering into a contract will be examined in **Section 6.2**. External factors may relate to their economic or social standing within the community, such as their position of wealth, education or power. This section will analyse how over time the law has conceded that persons entering into contracts are not always on an equal footing due to their external circumstances. This examination will be undertaken by looking at the special rules created to protect certain groups, such as consumers.

However, not all factors influencing the law are external to the person. Consequently, **Section 6.3** will also look at attributes *internal* to the person that will affect their status and standing. These include aspects of the person relating to their health, age, and mental ability. Internal attributes will be analysed in this section by considering rules, the aim of which is to protect persons with disability, or where capacity is lessened or lacking due to cognitive impairment, mental health issues or learning difficulties.

Next, in **Section 6.4**, the meaning of these external and internal factors relative to the person, and the consequences drawn, will be explored. These categorisations raise the question of vulnerability and whether a person is, or should be, deemed vulnerable where relevant internal or external factors impact on them or their circumstances. Finally, **Section 6.5** draws the chapter together with concluding remarks.

Case law on the status of the person and the remedies available

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[8] ibid., at 521.

To illustrate the various legal points throughout this chapter and the next, two key court decisions[9] are analysed in detail. These cases were chosen for the following reasons. First, both decisions demonstrate the courts' position when persons living with dementia enter into contracts. Next, these cases demonstrate how the process of entering into the contract may differ, with one party relying on experts to assist in the negotiations and formation of the contract, whilst the other entered into the contract unaided. Finally, despite diverging outcomes for the individuals involved, the underlying principles are nevertheless complementary and consistent. Below is a brief description of the facts in these two cases, as these will be key to later discussion.

The Privy Council decision of *Hart v O'Connor*[10] concerned the selling of a farm by Mr O'Connor, a farmer living with dementia. It was Mr O'Connor, on the basis of his expert's valuation and after legal advice, who suggested a price which the other party, Mr Hart, a neighbouring farmer, accepted. It was only after the sale was completed that family members of Mr O'Connor became aware that the agreed price was in fact not market value (undervalued by approximately 10%) and that the terms of the agreement (including a two-year delay to make all required payments) were more favourable to the buyer. The family therefore sought to void the contract on the basis of 'mental incapacity'. The other party, Mr Hart, argued that he had not been aware of any cognitive impairment and had accepted the price suggested by Mr O'Connor's experts.

The Privy Council was asked to decide whether the contract had been validly entered into, or whether in fact it was void due to a lack of capacity that rendered Mr O'Connor's consent to contract invalid.

In *Ayres v Hazelgrove,*[11] Lady Ayres was a widow, living independently at home with her grown-up son. In the 1970s she developed dementia (the court described her diagnosis as "*senile dementia*"). Russell J explained that Lady Ayres' son and daughter, as well as her doctor, all provided statements that:

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[9] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1; Ayres v Hazelgrove (QB, 9 February 1984, unreported).

[10] O'Connor v Hart [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.

[11] Ayres v Hazelgrove (QB, 9 February 1984, unreported).

> *By January 1980, …Lady Ayres had reached the stage when her mental faculties were grossly impaired. She was, … confused, disorientated as to time, forgetful, lacking in insight into her condition, incapable of making rational judgments. …*

It was in 1980 that the events occurred. Lady Ayres was at home alone when she met Mr Hazelgrove, a bric-a-brac dealer, going from house to house, looking to purchase second-hand and antique items. He entered Lady Ayres' home and chatted to her for 40 minutes. She sold him some jewellery and a number of paintings valued at between £6000-£7000. He paid the much smaller sum of £40 for all of the items. When her son returned home, he was shocked at the removal of the chattels and could not find the £40 that Mr Hazelgrove had said to have paid for them.

Mr Hazelgrove denied all knowledge of 'mental incapacity' and explained that he and Lady Ayres had spent some time together before the sale of paintings and jewellery had been agreed. In that time, he felt she had "*behaved perfectly normally*" and that he had acted throughout "*honestly in the belief that this was a transaction freely entered into by somebody suffering from no disability*".[12]

Here again, the court was asked to decide whether a contract had been validly entered into.

Over the course of this chapter and the next, these decisions will be discussed to assess the adequacy of the law in protecting the consumer living with dementia.

6.2 External circumstances affecting the status of the person

To fully appreciate the impact that external factors may have on contractual relationships, it is important to step back and consider the building blocks that make a contract. Once these have been determined, the classical position of contract law is presented. Having established these fundamentals of contract

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[12] ibid.

law, next the external circumstances that will alter such classical contract law position will be reviewed.

Prerequisites for contracts

For a contract to validly be entered into, four conditions must be met. These are analysed below by reference to the issues that may arise when a consumer living with dementia enters into a contract.

Offer and acceptance

For a contract to be validly concluded, there must be an offer and acceptance and those must clearly and evidently match up, i.e. there cannot be any uncertainty as to whether the parties both agree to the same terms. For the consumer with dementia, there is a possibility that in some cases the terms offered are misunderstood. However, as most consumer contracts, especially for larger or more costly transactions, are adhesion contracts that are fixed in writing, it may be difficult for the consumer living with dementia to provide evidence suggesting that the contract was not accepted on the terms offered by the business. A signature on the contract demonstrates at least a formal acknowledgement of the offer made, and an indication to be bound by the terms of the offer.[13] This contract law principle, with its primary focus on the terms of the agreement rather than on the person, is not helpful to the consumer living with dementia.

Intention

The question of certainty of contract may also arise in relation to a party's intention to so be bound. The principle is that each party must intend to enter into the contract and be bound by its terms for the contract to be validly formed. Where a person thought they were only making a non-binding remark, this should not bind them to legally enforceable obligations. However, the intention is assessed objectively. Not by asking whether a person did not in fact subjectively intend to be bound by contract, but by considering whether "*a reasonable man would believe that he was assenting to the terms*

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[13] L'Estrange v Graucob Ltd [1934] 2 KB 394.

proposed by the other party and that that other party upon that belief enters into a contract with him".[14] Provided that this objective assessment is met, a valid contract is concluded. The court in Smith v Hughes[15] felt that the principle of certainty was too important to allow more flexibility. Later case law clarified further that whilst there is the presumption in social and domestic transactions that the parties did not intend to be legally bound by the arrangements,[16] in a commercial context such intention is presumed.[17]

For the consumer with dementia, as demonstrated in Chapters 2,[18] 8[19] and 9,[20] it may occur that they are confused and will complete a form or sign a document without fully understanding or wanting to be bound by a contract.[21] Whilst the presumption of intention can be rebutted, that evidence might be difficult to produce by the person living with dementia. In addition, once the parties in a business-to-consumer setting have agreed to acquire goods, services or digital content (subject to consumer legislation, as set out in more detail below), those parties are usually bound by that contract, whether it was concluded online, in a shop, by telephone, by post or on the door step. In law, the parties' intention or precise understanding is of lesser importance that the objective formation of the contract.[22]

Consideration

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[14] Smith v Hughes (1871) LR 6QB 597 at 607.

[15] Smith v Hughes 1871 LR 6QB 597.

[16] Jones v Padavatton [1969] 1 WLR 328.

[17] Esso Petroleum v Customs & Excise [1976] 1 WLR 1.

[18] See Section 2.4 on the consequences of dementia and its effects when entering into a contract.

[19] See Section 8.2 where participants describe the confusion of their loved ones with dementia that may lead to contracts being entered into without understanding the consequences.

[20] See Section 9.2 on a lack of knowledge of a contract being entered into.

[21] See, for example, Section 8.2 and Mary's account of her mother entering into a contract with a book club without the understanding that it would lead to the monthly sale of (unwanted) books.

[22] Peel, E. (2015) *Treitel on the Law of Contract (14th ed.)* Sweet and Maxwell at 1-001 – 1-005.

Consideration in contract law relates to the value provided under the contract.[23] Both parties to the agreement must provide consideration in some form, be it a benefit received or a detriment suffered. In consumer contracts, the consideration of the business will usually be in the form of goods, services or digital content provided to the consumer, whilst the consumer's consideration is habitually the price paid to the business. However, the courts will not be arbiters of whether the parties struck a *fair* deal between them, and they will not usually look at market value in a contractual exchange. Case law suggests that even "*used chocolate bar wrappers*",[24] required as part of a consumer promotion to purchase a record, have value and can form part of the consumer's consideration.[25] It is therefore said that consideration must simply have "*some value in the eyes of the law*".[26] Consequently, the courts are generally not concerned with whether the parties have made a good or bad bargain.

The amount paid under a contract will be further considered below.[27]For the person living with dementia and their families, a bad bargain is often the reason why a contract will subsequently be questioned, with the aggrieved party often wishing to void the contract altogether. Swain suggests that there is "*a very real tension between, on the one hand, disallowing someone to escape from a bad bargain and threatening the stability of the bargaining process [and] on the other, recognising that autonomy can be impaired*..."[28]

This issue of impairment of autonomy in turn leads to the fourth prerequisite, capacity.

Capacity

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[23] Consideration and the notion of value are further explored in empirical Chapter 8.

[24] Chappell v Nestle [1960] AC 87.

[25] ibid.

[26] Patteson J, in Thomas v Thomas (1842) 2 QB 851, at 859. In this case a payment of rent of £1 per year was sufficient consideration, even if it was well below market value.

[27] See Chapter 7 on legal remedies.

[28] Swain, W. (2020) 'Without the power to drink or contract' *Edinburgh Law Review* 24(1): 26-48, at 48.

Capacity is the fourth condition that needs to be met when entering into a contract. Whilst the Mental Capacity Act 2005 has to some extent superseded capacity at common law,[29] common law identifies two distinct categories of persons that are protected when entering into contracts due to a lack of capacity. These are minors and those defined as 'mentally incapacitated'. The 'mentally incapacitated' are a broad category and will include those that are lacking in capacity, either temporarily or permanently, through cognitive impairment, mental health or learning difficulties. Impairment may be due to illness or accident, or might be self-inflicted through drug or alcohol abuse.[30] As capacity, and the lack thereof, is usually due to factors internal to the person, these will be explored in more detail in Section 6.3.

Parity of parties to a contract, a classical position

Under contract law in its classical interpretation as devised in the 18th and 19th centuries, the identity of the persons, or the context within which they were contracting, was of no importance. In other words, the attributes or circumstances of the parties to a contract were deemed irrelevant.[31] Instead, under the classical position of contract law, it was the agreed terms of the contract, and only those terms, that determine the arrangements between the parties. This is because, as discussed in Chapter 3, classical contract law was premised on the existence of an autonomous individual deemed to be self-sufficient and independent and therefore free to make whatever choices they wished. Be they natural persons, i.e. human beings entering into a contract, or artificial persons, i.e. companies, trusts or charities with legal personality, they are understood to have full autonomy, and it is assumed that they will seek

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[29] Mental Capacity Act 2005, c.9.

[30] Although remedies for drug or alcohol related incapacity are significantly reduced and generally only available when considered together with other circumstances (see Swain, W. (2020) 'Without the power to drink or contract' *Edinburgh Law Review* 24(1): 26-48).

[31] Friedman, L.M. (1965) *Contract Law in America*. Madison: Wisconsin University Press, as referred to by Atiyah, P. (2003) *The Rise and Fall of Freedom of Contract.* Oxford University Press, at 405.

out the best bargain for them. Consequently, the parties to a contract are considered equals for the purposes of contract law.[32]

As a result, a fundamental principle of contract law is that all contracts validly entered into (objectively assessed) are enforceable.[33] Contracts will only be void for formal irregularities.[34] This is because in classical contractual relationships, under common law, the principle of certainty of contract is essential. It is both the sanctity of contract, as well as the notion of freedom to contract that informs the parties' rights and obligations.[35] "*My word is my bond*" represents the contractual promise that the parties make to each other.[36]

Deviations from classical contract law: external circumstances

Whilst it remains the case that the "*classical theory, and its model of the typical contract, can still be seen to cast its shadow over English law*"[37] and that in contract law generally, "*two linked principles remain of fundamental importance, viz the principles of freedom of contract and of the binding force of contract*",[38] over time however it became apparent that parties to a contract are not always independent, autonomous or on an even footing. The concept of "*inequality of bargaining power*",[39] which arises every time two parties to a contract are not identical in terms of financial resources, legal representation, educational background, power and motivation when entering into a contract,

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[32] Atiyah, P. (2003) *The Rise and Fall of Freedom of Contract.* Oxford University Press, at 405.

[33] Peel, E. (2015) *Treitel on the Law of Contract (14th ed)* Sweet and Maxwell at 1-001 – 1-005.

[34] See the four formal conditions set out above.

[35] Atiyah, P. (2003) *The Rise and Fall of Freedom of Contract.* Oxford University Press, at 405.

[36] Fried, C. (2015) *Contract as Promise: A Theory of Contractual Obligation*. Oxford University Press.

[37] Stone, R. and Devenney, J. (2019). *The Modern Law of Contract (13th ed)* Routledge, at 7.

[38] Beale H.G. (ed) (2018) *Chitty on Contracts (33rd ed)* Thomson Reuters, at 1-030.

[39] Furmston, M. (2017) *The Law Of Contract (6th ed)* Butterworth Common Law Series.

was first identified in case law[40] and then recognised in legislation.[41] In light of this concept, the status of the contracting parties and their circumstances becomes relevant.

Indeed, more recent legislation on consumer, employee or tenant matters, have considered not only the contract that is entered into, but also the parties to the contract, resulting in a questioning of the principles of certainty, freedom to contract and autonomy.[42] By recognising the possibility of inequality between the parties to the contract (for example, if one of the parties is weaker than the other due to their position, capability or (financial) power), the conclusion must be drawn that the weaker party may not be acting freely and independently.

In order to combat some of the identified inequalities of bargaining positions, rather than review and revise the fundamental concept of the sanctity and stability of contract law, legislators have looked to redress the balance by imposing express regulations on the deemed stronger party in specific circumstances.

For example, consumers, tenants and employees are all groups that might find themselves in a weaker contractual position, and have therefore been specifically catered for through legislation.[43] The circumstances of these contracting parties are not weakened because of an internal aspect of their person. Instead, it is an external circumstance, the economically weaker position they find themselves in as tenant, employee or consumer, that triggers special laws to be applied. These special laws are essential in providing further protection for certain categories of persons and also demonstrate the legislators' willingness to interfere with classical contract law when deemed necessary.

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[40] e.g. Lowe v Lombank [1960] 1WLR196; Schroeder Music Publishing Co Ltd v Macaulay [1974] 1WLR1308.

[41] e.g. Rent Act 1977, c.42; Employment Rights Act 1996, c.18; Consumer Rights Act 2015, c.15.

[42] See also Chapter 3, Section 3.2 and 3.3 on the idea of the autonomous individual, and on arguments why this concept is debatable.

[43] Consumer Rights Act 2015, c.15; Landlord and Tenant Act 1985, c.70; Employment Rights Act 1996, c.18.

This evolution of the contract law position demonstrates that society, through its legislators, understands and agrees that in certain circumstances some identifiable groups may need additional protection in relation to contract law. The commonality between these groups of contracting parties is that they all are potentially at risk of harm due to their external circumstances. As Tan points out,

> *In practice, access to statutory intervention is often premised on contractors wearing certain hats – fairly uncontroversial examples include the definitions of 'consumer' under section 2(3) of the Consumer Rights Act 2015...*[44]

To clarify the change of approach, the nomenclature of the law was changed; rather than being described as 'contract law', more specific labelling is used, such as 'consumer law', 'land law', or 'employment law'. The focus here is on consumer law.

Consumer law

As set out above, contract law has adapted over time from its classical position of the 'freedom of contract' to address the issues that arise when two unevenly matched parties enter into a contract. One such area, of particular relevance in the context of this thesis, is the legislator's aim to protect the consumer, deemed the weaker party, from the business that usually will have the upper hand due to their economic advantage. Their stronger position is made clear by their ability to impose their standard terms and conditions on the consumer. In addition, in the rare cases that contracts may be negotiated, many businesses will have funds that allow for expert legal representation.

Previous regulations and laws have been amalgamated into the most recent consumer rights legal bundle, the Consumer Contracts (Information,

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[44] Tan, Z.X. (2020) 'Where the Action Is: Macro and Micro Justice in Contract Law' *Modern Law Review* 83(4): 725-760, at 741.

Cancellation and Additional Charges) Regulations 2013[45] and the Consumer Rights Act 2015.[46]

However, similarly to the objective approach adopted in contract law, consumer law has embraced an objective standard for the 'average' consumer. Indeed, the '*average*' consumer is defined in the Consumer Rights Act as "*a consumer who is reasonably well-informed, observant and circumspect*".[47] This demonstrates the legislators' understanding that even for these able and thoughtful consumers, external circumstances mean that they may be at risk of (economic) harm, and specific provisions are required to act as counter-balance to the position of strength of the business.

However, this does not take into account that a consumer living with dementia, or with any other form of cognitive impairment, mental disability or learning difficulty, might be even more vulnerable. Indeed, such consumer may not be as observant and circumspect because they cannot fully comprehend the complexities of the transaction, or may have difficulties retaining information pertaining to the contract. The categorisation as consumer alone is not enough to protect the consumer living with dementia.

In addition to these external factors, the internal attributes of the person will also be relevant to the rules that apply.

6.3 Internal attributes affecting the status of the person

Specific legal provisions also apply to those who are deemed in need of protection because of their internal attributes. Internal attributes are taken into account both within the law on capacity and within equality law, but in different ways.

<u>Common law on capacity</u>

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[45] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013 No. 3134.

[46] Consumer Right Act 2015, c.15.

[47] Consumer Right Act 2015 s. 64(5).

Within the common law of contract, two categories of persons can rely on special rules due to internally attributable factors: minors and those that are ‘mentally incapacitated’.

Minors

Whilst minors do not generally fall within the scope of this research, as dementia is a disease that affects overwhelmingly an older population, it is worth considering the contract law in relation to minors, as it mirrors some of the provisions applied to adults deemed lacking in capacity. However, other rules apply only to minors, and it is interesting to explore whether these are worth replicating for adults lacking capacity.

The category of the minor is easily established. In England and Wales a minor it is any person under the age of 18.[48] Minors may still enter into contracts, and in practice minors, especially in their later teens, will enter into contracts regularly and practice their interactions with the commercial world. Purchases of goods, services and digital content are common. Additionally, teenagers might need or want to earn money and enter into employment or gig economy (short-term or freelance work) contracts.[49] However, whilst the business counterpart is bound by all contracts, the situation is more nuanced with regards to the minor.

The general rule is that a minor will not be bound by the contracts they enter into. Only on becoming an adult at the age of 18 can they ratify a contract entered into as a minor, making it binding upon them.

To ensure that the business counterpart is not put in an excessively difficult (uncertain) position, exceptions exist in common law. Necessities,[50] such as food and drink, lodgings and educational services that are beneficial to the minor,[51] will be binding on the minor, although only a “*reasonable price*”[52] will

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[48] Family Law Reform Act 1969, c.46, s. 1.

[49] Moore, M. (2019) ‘The gig economy: A hypothetical contract analysis’ *Legal Studies* 39(4): 579-597.

[50] Chapple v Cooper (1844) 13 M&W 252.

[51] Nash v Inman [1908] KB 1.

[52] Sale of Goods Act 1979, s. 3(2).

need to be paid for these necessities. Similarly, employment contracts, if beneficial to the minor,[53] will be binding. Finally, some contracts relating to the purchase of land, shares, partnership or marriage settlements are binding but voidable by the minor either before reaching their majority or within a reasonable amount of time afterwards.[54] Whilst the cases that first introduced these rules in common law date back to the 19th century, the principles are still valid and applied today.

Interestingly, some of these provisions are mirrored in the Mental Capacity Act 2005 for those lacking capacity.[55] Indeed, as will be discussed in more detail below, there are some equivalent rules that are applied to consumers other than minors, if they find themselves in a situation where their contractual disadvantage as a consumer is compounded by cognitive impairment, mental disabilities or learning difficulties. Indeed, Section 7 of the Mental Capacity Act 2005 states that where an adult enters into a contract for necessities whilst lacking capacity, only "*a reasonable price*"[56] must be paid for them. What constitutes a necessity under the Mental Capacity Act 2005 is anything "*suitable to a person's condition in life and to his actual requirements at the time when the goods or services are supplied*".[57] This rule demonstrates a desire by the legislator to protect the person lacking capacity in an identical way to the minor. It seems to imply that, as necessities must be paid for, other contracts entered into will not be binding. However, in fact the situation is different for consumers lacking capacity under the Mental Capacity Act 2005, if the contract in relation to goods, services or digital content is not deemed a necessity. This will be further explored in Chapter 7 below.[58]

Mentally incapacitated

The common law notion of the 'mentally incapacitated' has to a large extent been superseded by the definition of the person lacking mental capacity under

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[53] De Francesco v Barnum (1890) 45 Ch D 430.
[54] Edwards v Carter [1893] AC 360.
[55] Mental Capacity Act 2005, s. 7.
[56] ibid.
[57] Mental Capacity Act 2005, s.7(2).
[58] See Section 7.2.

the Mental Capacity Act 2005 and proof of mental incapacity is now governed by the test as set out in the Mental Capacity Act 2005.[59] However, case law on mental incapacity is still relevant today in that it highlights the consequences that arise when a contract is entered into by a person lacking capacity to do so.[60]

Both cases referred to earlier, *O'Connell v Hart*[61] and *Ayres v Hazelgrove*[62] were determined using the common law concept of the mentally incapacitated, as they related to matters prior to the enactment of the Mental Capacity Act. Nevertheless, in both cases, one of the fundamental issues was to determine capacity or lack thereof. Both Mr O'Connell and Lady Ayres were held to have lacked capacity. In Chapter 7 on legal remedies, the court's conclusion as to what the lack of capacity means in terms of contract validity will be examined.

Mental Capacity Act on capacity

As explored above, general contract law relies heavily on the idea of the independent autonomous individual entering into agreements freely. Classical contact law presents the parties as able to decide whether to contract, and on what terms to contract. In addition, whilst recognising the economically weaker position of the consumer, consumer law refers to the average consumer as a person who is "*reasonably well informed, observant and circumspect*",[63] i.e. an able and independent person. It does not take into account those that might not be able to understand the terms, even when they are legible, clear and transparent. However, those that do not comprehend the terms of a consumer contract are not necessarily lacking capacity under the Mental Capacity Act 2005[64] and therefore might fall outside of any protective legislative measures. Indeed, the test to establish capacity or lack

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[59] Mental Capacity Act 2005, s. 3.
[60] See Chapter 7, Section 7.2 on remedies.
[61] O'Connor v Hart [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.
[62] Ayres v Hazelgrove (QB, 9 February 1984, unreported).
[63] Consumer Rights Act 2015, s. 64(5).
[64] Mental Capacity Act 2005, c.9.

thereof, and categorisation of a person as having or lacking capacity, is complex.

In order to understand it more fully, the presumption of capacity in law and the four-tier test in determining capacity are reviewed below. This analysis will assist in clarifying the category of persons that will be protected by the Mental Capacity Act 2005.

Presumption of capacity

Under the Mental Capacity Act, there is a presumption of capacity.[65] All persons are deemed to have capacity until it can be shown that they lack capacity. In other words, capacity is the 'default position' for all adults.

Nevertheless, where there is doubt, capacity needs to be determined for each decision. However, in contractual matters, it is often the case in practice that a blanket statement is made, saying a person (living with dementia, for example) either still has capacity, or now lacks capacity.

A relevant example is the lasting power of attorney, which provides a binary choice; the person signing the power of attorney (the donor) and transferring powers to their attorneys can do so either with immediate effect, or only once they lack capacity.[66] However, most businesses and organisations will accept the lasting power of attorney without further exploration of the state of capacity of the donor under the document at any point in time. In some cases a single statement by relatives on the capacity status of the donor under the lasting power of attorney will be deemed sufficient.[67]

Either when dealing with the consumer living with dementia directly, or when faced with a power of attorney, in practice the sales person will not often have

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[65] Mental Capacity Act, s. 1(2).

[66] Government guidance (2020) *Make, register or end a lasting power of attorney*, available at https://www.gov.uk/power-of-attorney, last accessed on 14 February 2021.

[67] For a more detailed analysis of the lasting power of attorney, see Section 8.4, which sets out the challenges faced by the interviewees in relation to the power of attorney, and Section 10.5, which suggests how these issues may be resolved.

the knowledge or ability to consider the concept of capacity in light of the four-tiered test[68] as set out in the Mental Capacity Act 2005. It is therefore usually at a later stage that the parties to the agreement (or their representatives or the court) will attempt to assess if the person living with dementia did or did not have capacity at that specific time.

Determining capacity

Section 1(4) of the Mental Capacity Act 2005 sets out that capacity cannot be brought into doubt ‘merely’ because the person made an ‘unwise decision’. However, for the person living with dementia or their family members, the question of capacity is often raised because of a decision to enter into a contract that subsequently is deemed ‘unwise’, i.e. is to the financial detriment of the person who made it. For the person living with dementia, the consumer contract may be unwanted, not needed or a transaction they cannot afford. It must be noted that the word ‘merely’ indicates that whilst it cannot be the only indicator of a lack of capacity, it can be taken into account with other factors[69], as set out in Section 3 of the Mental Capacity Act.[70]

The test for capacity

The lack of capacity must be due to an “*impairment of, or a disturbance in the functioning of, the mind or brain*”.[71] Dementia is specifically listed as an example of such a condition in the Mental Capacity Act Code of Practice.[72]

Section 3 of the Mental Capacity Act sets out the four-tiered test to establish capacity and by inference lack of capacity. A person has capacity if they can understand the information, retain it, weigh it up, and communicate their decision. These four aspects will be considered below in turn in relation to a

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[68] Mental Capacity Act 2005, s. 3.

[69] e.g. Savulescu, J. and Momeyer, R. (2007) ‘Should Informed Consent be Based on Rational Beliefs?’ *Journal of Medical Ethics*, 23: 282; Department of Constitutional Affairs (2007). *Mental Capacity Act Code of Practice*, para. 2.11.

[70] Mental Capacity Act 2005, s. 3.

[71] Mental Capacity Act 2005, s. 2(1).

[72] Department of Constitutional Affairs (2007). *Mental Capacity Act Code of Practice*, para. 4.12.

consumer living with dementia in order to ascertain the test's effectiveness in determining capacity to enter into complex consumer contracts.

Understanding

There is a difference between intending to enter into a contract and understanding what the contract means in terms of consequences for both parties.[73] In order the satisfy the test regarding capacity when making a decision to enter into a contract, a person must understand what the contract will mean to them in terms of immediate, future and on-going rights and obligations, financial or otherwise. This understanding will be easier for some decisions (e.g. one's choice of newspaper at the newsagents') than others (e.g. the complex standard terms and conditions of an insurance provider). The complexity of the specific decision is something that must be taken into account when considering capacity.

Retaining information

The Mental Capacity Act clarifies that information need only be retained for a very short period,[74] as long as it is long enough to consider it and weigh it up (see next point below). For the person living with dementia this can be problematic. Contracts may be entered into that are forgotten shortly afterwards, with the consequence that the benefits from the transaction are often not enjoyed or realised.

Weighing up information

Whilst in relation to simple transactions the pros and cons of the transaction can be weighed up relatively easily (e.g. when purchasing a newspaper, weighing up the parting of £1 in exchange for the paper and the enjoyment of reading it is a relatively simple calculation), where the transaction relates to

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[73] Ruck-Keene, A. (2016) *Re configuring contract law for purposes of the CRPD*, available at http://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2016/11/Reconfiguring-contract-law-for-purposes-of-the-CRPD-Paper-Discussion-Paper-for-ERC-Voices-Workshop-November-2016.pdf, last accessed on 14 February 2021.

[74] Mental Capacity Act 2005, s. 3(3), and Department of Constitutional Affairs (2007). *Mental Capacity Act Code of Practice*, para. 4.20.

more complex consumer matters, the weighing up of information is also more complicated. For example, entering into a contract for a new mobile phone with a two-year service contract may mean weighing up the pros and cons of a loan agreement to pay off the mobile phone during that (or a different) time period, penalty provisions on early termination, optional insurance, as well as considering other potential deals in the market. For a person with cognitive impairment (and for many people without such impairment), weighing up the various factors and coming to a conclusion will be challenging.

Communicating the decision

This is the least controversial element to the test and simply suggests that the decision must be communicated in any way available to the person be it by words, sounds, signs or other communication.

Evaluation of the four-tiered test

The assessment does not take into account the extent of the capacity displayed by the person tested. In order to be deemed to lack capacity, a particular threshold must be reached. As pointed out by Foster and Herring,

> *A person assessed under the Mental Capacity Act 2005 has mental capacity regardless of the extent to which they passed the capacity test. The law would simply be too complex for physicians to operate if they had to assess precisely the extent to which a person passed the mental capacity test… we know that really not all those who are deemed to have mental capacity under the Act have equal decision-making abilities.*[75]

For many, capacity is a fluctuating event. A person living with dementia may at one point in the day have capacity to make both simple and complex decisions, but a couple of hours later that decision-making capacity may be

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[75] Foster, C. and Herring, J. (2017) *Identity, personhood and the law.* Springer, at 25.

reduced to only a few basic matters.[76] The Social Care Institute for Excellence refers to "*fluctuating capacity*"[77] and recommends, where possible, going back to the person living with dementia at different times to check on their decision-making ability.

> *This means, if the person's capacity is sometimes better than at other times (known as 'fluctuating capacity'), the person should be enabled to make the decision when they are most able to do so.* [78]

This fluctuating capacity means that capacity cannot be seen as a binary state where a person either has or lacks capacity. Determining capacity must take place immediately before each decision to be made. In a consumer setting, where transactions are often done swiftly, this might not be easily achieved. Capacity assessment may not therefore be accurate, either in the moment when a deal is presented to the consumer, or if capacity is judged by looking at a person's ability to make decisions longer-term. Where the identification of capacity (or the lack thereof) is presented in such a binary way, capacity rules are not effective in protecting the consumer.

Mental Capacity Act's initial purpose

The aim of the test determining capacity under the Mental Capacity Act, as applied today, is to ensure that a person living with a cognitive impairment is able to make decisions affecting them for as long as possible. This was indeed the legislators' intention, although the scope of the test was initially narrower than applied now. At the outset, the goal of the law was to benefit vulnerable people in medical and caring matters specifically. This goal is still visible in the text of the legislation, as well as in the pre-enactment discussions in both the House of Commons and the House of Lords.

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[76] The experience of fluctuating capacity was also expressed in the interviews, as seen for example in Section 9.3. Both Eduard, who lives with dementia, and Nicole, talking of her mother living with dementia, discuss the fluctuating nature of a person's ability to speak, understand and make decisions.

[77] Social Care Institute for Excellence, available at https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/best-interest.asp, last accessed on 14 February 2021.

[78] ibid.

Section 4(5) of the Mental Capacity Act talks about "*life-sustaining treatment*" and indeed, when the bill was initially discussed in Parliament, it was that and other 'fundamental liberties'[79] relating to medical and social care that the legislature had in mind when devising the test.

This was made clear by the then Parliamentary Under-Secretary of State for Constitutional Affairs, Mr David Lammy, who introduced the Bill in the House of Commons and explained that "*the Bill provides a legal basis for a person to undertake acts in connection with* ***care and treatment*** *on behalf of an adult who lacks capacity*."[80] [emphasis added]

In the House of Lords, Lord Carter, chairman of the Joint Committee on the Draft Mental Incapacity Bill (as it was at first called), expressed his opinion (using the example of a woman living with Alzheimer's disease) that this Bill would provide help in decision-making in relation to "*decisions relating to her* ***health and welfare****, including the* ***choice of the right care home*** *for her*".[81] [emphasis added]

Similarly, Baroness McIntosh of Hudnall talked of how this decision-making would allow for "*opportunities to influence* ***the way their lives are ordered***".[82] Further, Lord Bishop of Worcester referred to the "*the right to refuse* ***burdensome treatment***."[83]

In fact, the entire preliminary discussion of the Mental Incapacity Bill demonstrates that the Mental Capacity Act and its test regarding (the lack of) capacity were designed to ensure that a person, even when they were reaching the end of their life and were no longer as readily able to communicate, would be afforded the opportunity to make all those decisions

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[79] See Chapter 2, Section 2.3.

[80] Hansard, House of Commons, 18 June 2004, Volume 422, at Column 68WS.

[81] Hansard, House of Lords, Mental Capacity Bill, 10 January 2005, Volume 668, at Column 44.

[82] Hansard, House of Lords, Mental Capacity Bill, 10 January 2005, Volume 668, at Column 52.

[83] Hansard, House of Lords, Mental Capacity Bill, 10 January 2005, Volume 668, at Column 55.

that might be considered fundamental to their dignity, i.e. giving them the right to choose the way in which to be treated and cared for, up until the end of life.

This ability to remain in control of one's life by making one's own decisions was indeed the guiding principle that drove the creation of the Mental Capacity Act 2005.

The idea of using such a test for all capacity questions, including those in relation to complex consumer contracts, was not in the minds of the legislators at the time. However, in its wording, the Mental Capacity Act was not specifically restricted to a list of such 'fundamental liberties' and consequently it applies to all persons, in all circumstances and all types of decisions relating to a multitude of situations, including consumer contracts, standard terms and conditions and all commercial practices.

However, for many consumers, including those living with dementia, the complexity of consumer contracts, and the variety of deals from which to select, is challenging. In a study for the European Commission,[84] the inherent complexity of consumer matters was clearly identified.

> *Consumer vulnerability is most frequent when consumers face complex marketing and are unable to select the best deals. For example, when presented with complex offers representing existing marketing practices in behavioural experiments, 37% of consumers are not able to select the best deal.*
>
> *A high share of consumers also experience difficulties buying, choosing and accessing suitable products. More than half of consumers say that they do not compare product deals in the financial sector and the energy sector, and a third of consumers say that they have problems comparing deals in the same sectors.* [85]

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[84] European Commission (2016) *Understanding consumer vulnerability in the EU's key markets*, available at https://ec.europa.eu/info/publications/understanding-consumer-vulnerability-eus-key-markets_en, last accessed on 14 February 2021.

[85] ibid.

This demonstrates the difficulty in understanding consumer contracts. It can be questioned whether the capacity rules as set out in the Mental Capacity Act should be applied beyond decision-making in care and health settings to these complicated and complex consumer matters.

Lock suggests that as a result of the capacity test under the Mental Capacity Act, a number of people fall into the category of "*technically hav[ing] decision making capacity but are in circumstances where they are de facto unable to exercise that capacity*".[86] Indeed, many consumers living with dementia will be capable as per the test in the Mental Capacity Act, but in practice will not be able to comprehend the complexity of the terms and conditions of a consumer contract.

A key factor is the presumption of capacity[87] in the Mental Capacity Act. Each time a person is faced with a decision, they are deemed to be able to understand, retain, and weigh up the information required to make a decision, and then be able to communicate their decision.[88] In Re L (Vulnerable Adults with Court's Jurisdiction) (No 2)[89] the Court of Appeal highlighted how the legislation resulted in some people being capable under the Mental Capacity Act whilst remaining vulnerable in practical terms. McFarlane LJ describes this very clearly as follows:

> *The issue does not concern those cases that fall within the Mental Capacity Act 2005 and which proceed in the Court of Protection. The question for consideration is whether, despite the extensive territory now occupied by the Mental Capacity Act 2005, a **jurisdictional hinterland** exists outside its borders to deal with cases of 'vulnerable adults' who fall outside that Act…*[90] [emphasis added]

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[86] Lock, D. QC (2015) 'Mental Capacity and Undue Influence: Action by Public Bodies to Explore the Grey Areas between Capacity and Incapacity' *Judicial Review* 20(1): 42, para. 5.

[87] Mental Capacity Act 2005, s. 1(2).

[88] Mental Capacity Act 2005, s. 3(1).

[89] Re L (Vulnerable Adults with Court's Jurisdiction) (No 2) [2012] EWCA Civ 253.

[90] ibid.

By asking this question, the court recognises that the Mental Capacity Act does not provide answers to all capacity considerations. This is also the case for consumers living with dementia. McFarlane LJ suggests that in such circumstances the court can step in. However, beyond this application of equitable principles by the court, this thesis suggests that further protections must be granted to those adults that would otherwise be trapped in such a "*jurisdictional hinterland*".[91] Herring and Wall refer to this 'gap' as meaning that "*people can be found to have capacity even though they are not acting autonomously*".[92]

The Mental Capacity Act will not provide sufficient protection to all vulnerable adults, such as consumers living with dementia. In fact it may lead to situations that are contrary to what the law intended.[93] Jonathan Herring expressed this particularly well:

> *To be clear, there are two terrible things that can go wrong in an assessment of capacity. First, you could be assessed to lack capacity when you do not. Others will make decisions on your behalf and set aside your own wishes based on what they think is in your best interests. You lose control over your life. … But second, you could be assessed to have capacity when you do not have it. You could suffer harms and injuries and you would be told that that was your choice, even though in fact that was not what you were choosing at all.*[94]

In addition to the challenges of assessing capacity, it must be emphasised that assessment is to some extent a subjective endeavour and will be dependent not only on the person being assessed, but also on the assessor.[95]

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[91] ibid.

[92] Herring, J. and Wall, J. (2015) 'Autonomy, capacity and vulnerable adults: filling the gaps in the Mental Capacity Act' *Legal Studies* 35(4): 698-719, at 704.

[93] Herring, J. and Wall, J. (2014) 'Understanding Capacity: The Heart May Easily Overrule the Head' *Elder Law Journal* 2014(2).

[94] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 54.

[95] Ruck-Keene, A. (2017) 'Is mental capacity in the eye of the beholder?' *Advances in Mental Health and Intellectual Disabilities* 11(2): 30-39.

Who undertakes the role of assessor is therefore significant in any assessment process.

Assessor of capacity

Even prior to the Mental Capacity Act, the question of the assessor was important. In O'Connor v Hart,[96] the buyer of the farm, Mr Hart, was unaware of any issue regarding capacity. The parties did not communicate directly with one another, and it was Mr O'Connor's lawyers who drafted the contract and Mr O'Connor's expert who valued the land. Assessing capacity was therefore not within the scope of Mr Hart at any time in the transaction.

This is in contrast to Ayres v Hazelgrove.[97] Mr Hazelgrove was also unaware of the issue of capacity, stating that Lady Ayres had acted in a capable manner throughout their meeting. He concluded that she was happy with the deal struck. However, the court considered that as he had spent 40 minutes alone with Lady Ayres, he would have been able, or ought to have been able, to assess her cognitive state and determine that she lacked capacity. The opportunity and duty to assess, as will be seen in the next chapter, is significant in determining if a contract can be voided.

The Mental Capacity Act does not provide clarification as to the identity of the assessor of capacity. Given this lack of guidance about the "*person making the determination*"[98] in terms of their expertise in making such capacity assessment, it would appear that the four-step test of capacity can be made at any time, before any decision, by whoever is asking the person to make the decision.

However, this does not take into account the relational aspect between the assessed and the assessor. Professionals, such as doctors or solicitors may not readily be to hand before each important decision. They will not provide their services for free. As a result, others might step in to fill the void. However, the identity of the assessor will be significant, especially if the

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[96] O'Connor v Hart [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.
[97] Ayres v Hazelgrove (QB, 9 February 1984, unreported).
[98] Mental Capacity Act 2005, s. 4(1).

assessor has an interest in assessing the situation one way or the other.[99] In other words, it must be questioned if the assessor can be a person who will benefit from the decision of the assessed person. For example, it is questionable whether it is reasonable for a business representative to assess the capacity of a person living with dementia before entering into a contract. The Mental Capacity Act does not refer to situations of conflict of interest. Nevertheless, in this case, questions might be asked about the validity of the assessment.

The question of capacity at common law and under the Mental Capacity Act will not resolve contractual issues satisfactorily in all circumstances where a person living with dementia enters into a contract as a consumer. In addition, categorising a person living with dementia as having or lacking capacity is difficult, given the fluctuating nature of capacity.

Next, non-discrimination law in relation to the consumer living with dementia will be considered. In this context, the question is whether categorisation as a person living with a disability may lead to protection in consumer matters.

Equality and non-discrimination provisions

In addition to being categorised, through external factors, as a contracting party and as a consumer, and, through internal attributes, as a person whose capacity is presumed unless they cannot make a decision, the person living with dementia may also be classified as a person living with a disability and may potentially be protected through equality and non-discrimination legislation. Indeed, for a person living with dementia there may be situations where they are faced with unequal treatment due to their neuro-degenerative disease. This may be the case in various spheres of life, but for the purpose of this thesis, focus will be on inequality experienced by consumers living with dementia, in contrast to other consumers.

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[99] Series, L. (2015) ‘Relationships, autonomy and legal capacity: Mental capacity and support paradigms’ *International Journal of Law and Psychiatry* 40: 80-91; Stefan, S. (1992) ‘Silencing the Different Voice: Competence, Feminist Theory and Law’ *Miami Law Review* 47: 763.

Principles of equality and non-discrimination are at the heart of the concept of human rights.[100] However, despite the various international treaties and national laws, there remain barriers for people with disabilities. In 2006 the United Nations Convention for the Rights of People with Disabilities ('CRPD') was agreed at international level, and later ratified by the UK in 2009. The CRPD defines 'persons with disabilities' in its Article 1(2) as

> … *those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*.[101]

It is estimated that around 13 million people in the UK fall into that definition;[102] this number will include persons living with dementia, where the illness has progressed.

The CRPD is a convention on disability rights, looking "*to drive forward real dignity, equality and inclusion for disabled people*".[103] Whilst its aim is not to create *new* rights for people with disabilities, its goal is to identify and then remove the obstacles that people with disabilities may still face, despite the human rights principle of equality. Its goal is therefore to harmonise equality principles by assisting domestic courts, where there is a lack of clarity, in the interpretation of national laws on equality, fairness and non-discrimination. Consequently, the Equality Act 2010,[104] the UK non-discrimination legislation, must be examined first.

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[100] Universal Declaration of Human Rights (1948); European Convention of Human Rights.

[101] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD), article 1(2).

[102] Equality and Human Rights Commission (2017) *The United Nations Convention on the Rights of Persons with Disabilities: What does it mean for you?*, available at https://www.equalityhumanrights.com/en/publication-download/united-nations-convention-rights-persons-disabilities-what-does-it-mean-you, last accessed on 14 February 2021.

[103] ibid.

[104] Equality Act 2010, c.15.

Under the Equality Act, unlawful discrimination, harassment and victimisation on the basis of disability is prohibited, be it in the spheres of employment, education, the exercise of public functions, or the provision of services. To fall within the scope of the Equality Act, a person will be deemed to have a disability if they have

> *a physical or mental impairment, and …the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities*.[105]

Dementia will result in cognitive impairment that, as the illness progresses, will be substantial and affect that person's ability to carry out day-to-day activities. Acting as a consumer is one of those habitual activities. As the illness advances, the consumer living with dementia will fall within the scope and can rely on the protection afforded therein. Whilst the consumer living with dementia will in certain circumstances be classified as falling with in the category of 'disabled', as will be demonstrated below in Chapter 7, the remedies available are however minimal.[106]

6.4 Vulnerability as legal tool

Vulnerability in law is not widely referred to and the definitions available are not always consistent. For example, under the Legal Aid, Sentencing and Punishment of Offenders Act 2012,[107] a "*vulnerable adult*" is defined as being "*a person aged 18 or over whose ability to protect himself or herself from abuse is significantly impaired through physical or mental disability or illness, through old age or otherwise".*[108] In this case, vulnerability is seen as the consequences of internal attributes of the person (i.e. their mental or physical frailty brought on by disability, illness or advanced age).

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[105] Equality Act 2010, s. 6(1).
[106] See Chapter 7.
[107] Legal Aid, Sentencing and Punishment of Offenders Act 2012, c.10.
[108] Legal Aid, Sentencing and Punishment of Offenders Act 2012, s. 3(5).

The Safeguarding Vulnerable Groups Act 2006[109] however considers vulnerability in a different manner. Following significant amendments to the Safeguarding Vulnerable Groups Act in 2012 by the Protection of Freedoms Act 2012,[110] "*vulnerable adults*" are not necessarily defined by the attributes internal to them (such as disability or age), but are instead considered vulnerable because of the external circumstances and situations they find themselves in. Consequently, any adult is deemed potentially vulnerable when receiving health care, personal care, attention by a social care worker, or assistance in the conduct of their own affairs.[111] It is only when finding themselves in the situation where for example a person assists with general household matters (which covers dealing with cash, paying bills and going shopping) that activities are deemed to be provided to a vulnerable person "*by reason of age, illness or disability*".

These examples of definitions of vulnerability in law demonstrate the difficulties encountered by the legislator in limiting and containing the category of those deemed vulnerable and in need of protection. In fact, vulnerability is wider reaching and dependent on *both* internal and external aspects to a person. This thesis argues for a wider application of Fineman's concept of universal vulnerability, and the understanding that all persons may at some time in their life experience vulnerability,[112] as described in Chapter 3.[113]

If vulnerability can be seen to be the norm for consumers, it must consequently be reflected in the law; a framework and tools are required to allow adequate protection.[114] As has been demonstrated above in Section 6.2 and 6.3, a consumer living with dementia is vulnerable, i.e. at risk of harm, because of both internal and external factors. In other words, vulnerability is compounded as both a *consumer* and a person *living with dementia*.

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[109] Safeguarding Vulnerable Groups Act 2006, c.47.

[110] Protection of Freedoms Act 2012, c.9.

[111] Safeguarding Vulnerable Groups Act 2006, Schedule 4, Part 2, s. 7(1)(a, b, c, e).

[112] Fineman, M.A. (2017) 'Vulnerability and Inevitable Inequality' *Oslo Law Review* 4(3): 133-149.

[113] See Section 3.3 for a detailed analysis of vulnerability.

[114] See Section 11.3.

However, the law does not recognise any such vulnerability until and unless the person with dementia falls within one of its prescribed "boxes".[115]

Vulnerability as an implied concept

Whilst common law on contracts does not refer to a *vulnerable* contracting party specifically, the exceptions provided to minors and mentally incapacitated persons indicated that there is an implied acceptance of the vulnerability of some parties to a contract. Their vulnerability, i.e. their risk of harm, stems from internal factors to the person, such as their age, or their lack of capacity due to permanent or temporary cognitive impairment, learning difficulties or mental health issues.

This vulnerability was implicitly recognised by the court in Ayres v Hazelgrove.[116] Russell J described that by all accounts, Lady Ayres was *"unable to have a rational conversation… quite incapable by reason of her mental condition of handling her own affairs*…".[117] He concluded that this internal factor, her dementia, would put her at a '*serious disadvantage*'. Without using the term, Russell J was describing a person at risk of harm, i.e. vulnerable, and in need of protection.

The need to protect those that have reduced capabilities is also the guiding purpose of the Mental Capacity Act 2005 and yet, vulnerability is not explicitly mentioned in the Mental Capacity Act. However, it can be argued that both when a person is given the opportunity to make decisions themselves, and when another person is designated to make decisions in the best interests of the person deemed to be lacking in capacity, the reason for doing so is the weighing up of their risk of harm, i.e. their vulnerable state.

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[115] Brown, S. (2019) 'Un-Boxing Vulnerability In Protection Of The Credit Consumer' *Journal of Business Law* 7: 511-533.

[116] Ayres v Hazelgrove (QB, 9 February 1984, unreported).

[117] Ayres v Hazelgrove (QB, 9 February 1984, unreported), Russell J, 2nd paragraph, official transcript, available at https://www.lexisnexis.com/uk/legal/results/, last accessed on 14 February 2021.

In addition to vulnerabilities that are implied because of internal attributes, there are those that are due to external circumstances (such as a person's economically weaker position). Whilst contract law does not explicitly acknowledge the notion of vulnerability, it does so implicitly in that those that are deemed vulnerable are protected through legislation. However, the protections focus on particular categories of persons. Where a person does not meet the specific criteria for that category (such as "*income, age, mental ability or particular life circumstances, such as illness"*), they are excluded and unable to rely on the legal protection that would otherwise be afforded to them. As Brown states, this boxing of persons by category is however a "*blunt tool*".[118]

For example, in consumer legislation, in order to attract the protection of the consumer, a person must be "*an individual acting for purposes that are wholly or mainly outside that individual's trade, business, craft or profession*".[119] By focusing on the consumer as a layperson with no professional expertise, this definition demonstrates the legislators' intention to protect not only the economically weaker, but also the less knowledgeable party in the consumer transaction. Beyond this criteria however, neither the Consumer Rights Act 2015, nor the Consumer Contracts (Information, Cancellation and Additional Charges) Regulations, cater specifically for consumers that are not "*well-informed, observant and circumspect"*[120] at all times. The above legislation does not use the word 'vulnerable' in its text to describe those that would not fall within the category of the 'average' consumer. In fact, all provisions are drafted to assist those who are deemed autonomous and self-determining and who have legal capacity to enter into a contract. Again, there is a clear gap in the legislation resulting in a lack of protection for those that do not fall within the above definition of 'average'.

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[118] Brown, S. (2019) 'Un-Boxing Vulnerability In Protection Of The Credit Consumer' *Journal of Business Law* 7: 511-533, at 516**.**

[119] Consumer Rights Act 2015, s. 2(3).

[120] Consumer Rights Act 2015, s. 64(5).

However, the existence of the legislation itself demonstrates the belief that being on an uneven footing in a contractual transaction can lead to a risk of harm for the weaker party.

Consumer legislation does not explicitly refer to vulnerability, instead it is it economic weaker position compared to the business that is at the origin of consumer law. It is likely that there was an assumption that other legislation[121] was in place to cover the situation where a person was not autonomous and self-determining because of their lack of capacity. However, as was discussed above,[122] there are situations where a person will be considered legally capable under the provisions of the Mental Capacity Act, but will in practice struggle to cope with the complex terms and conditions set out by a business.

For a person living with dementia, the requirements put in place under the Consumer Rights Act to counter any implied vulnerability, such as the obligation for transparency[123] and full financial disclosure, are not providing the help needed. Even in plain English,[124] the financial information provided to satisfy the Consumer Rights Act provisions often means that the volume of data can overwhelm consumers. For the person living with dementia, given the challenge of remembering all such financial information in order to weigh it up in any meaningful way, this protection is simply not effective.

In addition, the cooling-off period that is available under the Consumer Contracts (Information, Cancellation and Additional Charges) Regulations[125] may not be of use to the person living with dementia, who may forget either relevant terms of the contract or even the contract itself. In those circumstances, the right to rescind becomes meaningless.

Vulnerability explicitly recognised

Unfair practices legislation

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[121] such as the Mental Capacity Act 2005, c.9.

[122] See Section 6.3.

[123] Consumer Rights Act 2015, s. 68(1).

[124] Consumer Rights Act 2015, s. 68(2).

[125] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013, N.3134, Regulation 30.

The lack of mention of the vulnerable consumer in the Consumer Rights Act is particularly surprising, given that it is expressly considered in European law, as well as UK equivalent regulations. Whilst the Consumer Rights Act does not refer to the 'vulnerable' consumer, the Consumer Protection from Unfair Trading Regulations 2008,[126] which is the text with which the Unfair Commercial Practices Directive 2005 ('UCPD')[127] was transposed into UK Law in 2008, refers to the 'vulnerable' consumer. In Section 2(5) it states that consumers may be considered "***particularly vulnerable*** *to the practice or the underlying product because of their mental or physical infirmity, age or credulity in a way which the trader could reasonably be expected to foresee*". [emphasis added]

In May 2016, a study on consumer vulnerability in key markets across the European Union[128] was published, further clarifying the notion of the 'vulnerable consumer' as

> *A consumer, who, as a result of socio-demographic characteristics, behavioural characteristics, personal situation, or market environment:*
>
> - *is at higher risk of experiencing negative outcomes in the market;*
> - *has limited ability to maximise his/her well-being;*
> - *has difficulty in obtaining or assimilating information;*
> - *is less able to buy, choose or access suitable products; or*
> - *is more susceptible to certain marketing practices.*

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[126] The Consumer Protection from Unfair Trading Regulations 2008, N.1277.

[127] Directive 2005/29/EC of the European Parliament and of the Council of 11 May 2005 concerning unfair business-to-consumer commercial practices in the internal market and amending Council Directive 84/450/EEC, Directives 97/7/EC, 98/27/EC and 2002/65/EC of the European Parliament and of the Council and Regulation (EC) No 2006/2004 of the European Parliament and of the Council.

[128] European Commission (2016) *Understanding consumer vulnerability in the EU's key markets*, available at https://ec.europa.eu/info/publications/understanding-consumer-vulnerability-eus-key-markets_en, last accessed on 14 February 2021.

> *This definition takes into account that consumer vulnerability is situational, meaning that a consumer can be vulnerable in one situation but not in others, and that some consumers may be more vulnerable than others.*[129]

Here again, internal and external factors are identified that can result in further compounded vulnerability. The consumer living with dementia is likely to fall into one or more of these categories.

Interestingly, the study explains that

> *Most consumers show signs of vulnerability in at least one dimension, while a third of consumers show signs of vulnerability in multiple dimensions. Less than a fifth of the consumers interviewed show no signs of vulnerability.*[130]

This highlights the point made in Chapter 3, Section 3.3[131] above that vulnerability is a state that affects a multitude of persons, rather than a small, easily defined and ring-fenced (or "*boxed-in*")[132] group of people. Consequently, the vulnerable consumer, who currently is not adequately protected by the law, must be considered and revisited in UK legislation. As suggested by Ruck-Keene,[133]

> *more sophisticated understandings of vulnerability – and in particular of situational vulnerability – will assist in the development of consumer protection law and practice that can do more of the 'heavy lifting' as regards alleviating the concern as to avoiding harm and exploitation that motivated many of the restrictions placed around contract law*.

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[129] ibid.

[130] ibid.

[131] e.g. by Fineman, Diduck, Herring, etc.

[132] Brown, S. (2019) 'Un-Boxing Vulnerability In Protection Of The Credit Consumer' *Journal of Business Law* 7: 511-533.

[133] Ruck-Keene, A. (2016) *Re configuring contract law for purposes of the CRPD*, available at http://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2016/11/Reconfiguring-contract-law-for-purposes-of-the-CRPD-Paper-Discussion-Paper-for-ERC-Voices-Workshop-November-2016.pdf, last accessed on 14 February 2021.

The UCPD do not specifically cover the issues this thesis is reviewing, as by its name and nature it is intended to look at ‘unfair practices’. Instead, this thesis looks at issues that arise for consumers living with dementia, where no unfair practices, no fraud or coercion was applied, but where the outcome is still ‘unwise’ or unfavourable to the consumer living with dementia. However, the UCPD remains relevant in how it approaches the issue of the ‘vulnerable’ consumer.

Indeed, the notion of consumer vulnerability and the consequent need of additional protection should also be applied where the business acts reasonably and fairly. By taking into account the (actual or potential) vulnerability of the consumer, and the risks that consumers will encounter due to age, gender, education, cognitive impairment, or situational factors, enhanced consumer protection must be reconsidered. For the person living with dementia, current consumer legislation in the UK is not always ‘fit for purpose’.

Vulnerability in soft law

In this thesis, the term ‘soft law’ is used to describe general norms or principles but not legally binding rules.[134] In corporate and consumer matters, soft law can have an important part to play in guiding and directing companies to act in certain ways, as defined and regulated by their governing bodies.

The concept of vulnerability has specifically and explicitly been identified by businesses in standards drafted by the industry. Indeed, consumer-facing businesses can see that the risk of harm may be increased for certain consumers. They understand the need to recognise and categorise certain consumers as vulnerable to reduce their risk though specific guidelines.

Consequently, voluntary standards and good practice can be helpful to consumers in vulnerable situations, in that businesses are alerted to the concept of vulnerability when interacting with consumers. The aim of any such self-imposed guidelines is to ensure all interactions with consumers deemed

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[134] Boyle, A.E. (1999) ‘Some Reflections on the Relationship of Treaties and Soft Law’ *International and Comparative Law Quarterly* 48(4): 901-913.

vulnerable are carefully considered, leading to a satisfactory outcome for both business and consumer. Examples of these are the Financial Conduct Authority Occasional Paper[135] and the British Standard 18477 for identifying and responding to consumer vulnerability.[136]

The Financial Conduct Authority, which has examined the issue of vulnerability in much detail,[137] identified that if left unchecked, businesses could cause harm to vulnerable consumers in a multitude of ways.

> *Detriment could take many forms including emotional aspects such as stress and anxiety; financial detriment arising from sub-optimal or reduced choices, a debt spiral, or inappropriate purchases; and, wasted time spent in resolving issues. A negative and unfair experience with a financial service can have a disproportionate effect on people in vulnerable situations, often making a difficult situation worse.* [138]

As a result, the Financial Conduct Authority Occasional Paper recommends treating the customer fairly, putting them at the heart of the business, and doing the right thing for the consumer.[139]

Similarly, Hunter describes how British Standard 18477 on consumer vulnerability

> *details how organizations can treat all customers fairly, identify those who may be vulnerable and provide a flexible response that is tailored to meet the needs of the individual. It covers aspects such as*

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[135] Financial Conduct Authority (2015) *Occasional Paper No.8 Consumer Vulnerability in Financial Services*, available at https://www.fca.org.uk/publication/occasional-papers/occasional-paper-8.pdf, last accessed on 14 February 2021.

[136] British Standards 18477 (2010) *Fair, flexible services for all*, available at <https://www.bsigroup.com/LocalFiles/en-GB/consumer-guides/resources/BSI-Consumer-Brochure-Inclusive-Services-UK-EN.pdf>, last accessed on 14 February 2021.

[137] See Chapter 3.

[138] Financial Conduct Authority (2015). *Occasional Paper No.8 Consumer Vulnerability in Financial Services*, at 29.

[139] ibid., at 31.

> *organizational culture and policies, flexibility at the frontline, staff training, fair marketing and sales, accessible systems, specialised support teams, and the importance of providing a choice of contact methods and information formats.*[140]

These recommendations, guidelines and standards however rely on business staff understanding and recognising vulnerability. This is often very difficult to achieve during a short conversation with a consumer. Some staff may be very good at it, others will be less successful. For the consumer with a vulnerability, much will therefore depend on the luck of the draw as to whether the business representative they are communicating with is able to make this judgment as to vulnerability correctly.

The unifying characteristic of standards, charters, guidelines, recommendations or other self-regulations is that all of these are voluntary. Whilst they are a helpful step towards awareness raising, and whilst many positive outcomes have been reported, they remain dependent on the various industry sectors, individual businesses within each sector, specific training programmes (as well as the frequency and method of training) within the businesses, and individual staff.

In fact, the choice of soft law over legally binding rules imposed on businesses is often intentional. As highlighted by Nolan,

> *Reliance on soft law, whether in this field or others, has not emerged simply because there is a lack of anything better (although there is no denying that can be - and indeed has been in this field - a significant factor in the development of soft law). The use of soft law can be a deliberate choice and often more attractive to the relevant stakeholders (in this case particularly to business and governments alike) because it may contain aspirational goals that aim for the best possible scenario with few constraints if such goals are not met. Thus, it is easier to*

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[140] Hunter, J. (2020) 'The role of voluntary standards in improving outcomes for consumers in vulnerable situations' in Riefa, C. and Saintier, S. (eds) *Vulnerable consumers and the law*. Routledge, at 144.

> *achieve consensus in drafting a document that outlines these types of 'commitments'.*[141]

6.5 Concluding remarks

This chapter has explored which branches of the law are relevant in situations pertaining to the consumer living with dementia. Contract law, capacity law, consumer law and non-discrimination law are all required to map the legal framework for the consumer living with dementia. However, these aspects of the law all consider a different aspect of the 'person' who needs to be protected under legal rules.

Whilst each law individually will look at the situation of the consumer living with dementia and their decision-making ability from different points of view, the various laws need to be interconnected and interdependent. Their common ground must be founded on the need to protect those at risk of harm.

Through the exploration of the status of the person in relation to different branches of the law, this chapter has highlighted the need to view the consumer living with dementia as a whole person, relational to their internal and external environment.

To do so, this chapter has demonstrated that the law generally seeks to ring-fence groups of persons. This categorisation may be based on external factors, i.e. circumstances outside of the person to be protected. For the consumer with dementia, external aspects to be taken into account will relate to their status as consumer, i.e. as a person in a weaker contractual position, and usually weaker economic position, compared to the business. This uneven footing in entering the contract is sufficient to put them potentially at risk of (economic) harm. Whilst this external element is recognised, it does not take into account the compounded risk for the consumer living with dementia.

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[141] Nolan, J. (2013). 'The Corporate Responsibility to Respect Rights: Soft Law or Not Law?' in Deva, S. and Bilchitz, D. (eds) *Human Rights Obligations of Business: Beyond the Corporate Responsibility to Respect?* Cambridge University Press, at 142.

Classification can also relate to internal factors, i.e. attributes personal to an individual, such as a mental or physical disability. For the consumer living with dementia the internal attributes relate to the consequences of the cognitive impairment (for example memory loss or confusion) that they will experience as the illness progresses. The consequence may be an inability for the consumer living with dementia to make decisions and to freely consent to entering into a contract. However, these internal factors are less clearly recognisable. Capacity, as discussed in this chapter, is less easily identified and is to some extent dependent on when, why and by whom the assessment for capacity is carried out. This complicates how the person is categorised and what legal remedies are available to them.

What the exploration of the status of the person shows is that, either explicitly or implicitly, vulnerability is a driving force in the legislation available to the consumer living with dementia. This chapter demonstrates that in legislation, vulnerability is understood in the narrow sense of the concept, recognising an exceptional situation of a small group of persons in need to protection. Consequently the principle of the autonomous person as the norm still primes in law.

In the next chapter, this law review is completed by considering the legal remedies that might be applied to the consumer living with dementia. Taken individually, contract law, consumer law, capacity law and non-discrimination law have clear provisions in relation to a contract between a consumer living with dementia and a business. These individual laws however do not take into account the consumer living with dementia as a whole multifaceted person, nor their relationships to others. It is only when these rules are all considered concurrently that the full picture emerges of what protections are available to those at risk of harm.

Chapter 7 A lack of legal remedies available in law

7.1 Introduction

The previous chapter examined the legal framework in relation to the consumer living with dementia by looking at the ways in which such persons are categorised in law. In doing so, these classifications led to the exploration in detail of the status of the consumer living with dementia.

Chapter 6 presented the many ways in which the law will consider not just the contract and its terms, but the persons entering into the contract, their status and standing, their economic and social position, and the balance of power between the parties. Chapter 6 concluded that a common element of the reviewed laws is the protection of those at risk; those that might be deemed vulnerable in the narrow sense of the word by categorising them as a contained group of persons in need to protection.

In this chapter, this knowledge of the categories will be used to ascertain whether the consumer living with dementia is adequately protected in law. To do so, this chapter questions what legal remedies, if any, specifically cater for the situation of this complex and diverse category of persons. This chapter continues to look at the personal and relational circumstances of the person in law, in addition to the contract itself. Focus will be, first, on legal remedies available to protect those specifically identified in law as vulnerable. Next, this chapter will review 'outlier' remedies, i.e. suggestions, attempts and discussions to extend that protection for those at risk of harm.

In **Section 7.2** the legal remedies that apply when a person is lacking capacity, where they are in a weaker contractual position, when acting as a consumer, and where the person has a disability, will be analysed. These remedies all have in common the legislator's desire to protect the categories that make up the (implicitly or explicitly) vulnerable parties in law. However, none of these legal remedies fully protect the consumer living with dementia.

Next, in **Section 7.3**, 'outlier' remedies as recognised by the courts in specific situations or as argued in doctrine will be looked at in detail. These include a re-interpretation of the capacity law remedies, the exploration of concepts in contract law such as unconscionability or good faith, the examination of the industry-suggested standards and the guidance by the CRPD. All of these remedies look to extend the protection of the categories of persons deemed vulnerable and at risk of harm. Finally, **Section 7.4** draws the chapter together with concluding remarks.

7.2. General legal remedies

Remedies in contract law

The consumer living with dementia may enter into consumer contracts which are later considered unwanted, not needed or that the consumer can ill-afford. They will therefore seek to remedy this situation, usually by attempting to cancel or void the contract entered into. The remedies available to them must therefore be explored. However the legal position with regards to remedies is rigid, and those available to the consumer living with dementia will depend, first, on whether a contract exists.

A contract will be void if it does not fulfil the four conditions of validity,[1] if it is based on a common[2] or mutual[3] mistake, or if its subject matter is illegal.[4] The consequence in such cases is that the contract is treated as if it never existed and the contracting entities must be put back into the position they were in prior to any contract being considered. Where the parties have exchanged goods for money, and the goods are still available in their original unused form, this may be relatively easy to achieve. Where the goods, services or digital content have been consumed or used, this may prove more difficult.

Even where the contract was validly entered into, it may still be voidable by one of the contracting parties. This is the case for example, as was discussed in the previous chapter[5], where a minor enters into certain contracts, such as

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[1] See Chapter 6, Section 6.2.

[2] Couturier v Hastie (1856) 5 HL Cas 673 (res extincta); Cooper v Phibbs (1867) LR 2 HL 149 (res sua).

[3] Raffles v Wichelhous (1864) 2 Hurl & C 906.

[4] Allen v Rescous (1676) 2 Lev 174 (contract to commit a crime).

[5] See Chapter 6, Section 6.3.

contracts relating to the purchase of land, shares, partnership or marriage settlements. These contracts remain voidable by the minor either before reaching their majority or within a reasonable amount of time afterwards.[6]

Where there is no specific legal provision to void the contract, the parties may nevertheless have the possibility to end the contract at a later date, either by agreement or by breach. Termination for breach will usually result in damages being payable by the party in breach, the alternative of specific performance being only rarely applied.[7]

All the above remedies centre on the contract itself. In addition to this classical position, the law will provide remedies depending on the categorisation of the person. Indeed, in addition to the principles set out above on remedies available, the *person* entering into the contract can be significant.

For the consumer living with dementia and their family members, they will often be unaware of a contract having been entered into. The consumer with dementia may not recall agreeing to the deal, and may not be in a position to inform their family of the transaction. When the contract becomes apparent (because goods are delivered, services are rendered, or because money is debited from a bank account), the person living with dementia and their family will often query the validity of the contract. Their reasoning may be that the person with dementia may not have intended to enter into the contract or did not have capacity to do so, or may not have understood the terms and was therefore not able to accept them. Alternatively, they may feel that their disability was not taken into account and that provisions to ensure fair and equal treatment were not complied with. They may argue that they are a vulnerable consumer and that therefore additional thought and attention should have been given to their situation. The legal remedies available are however limited in these circumstances.

Capacity and contract law

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[6] Edwards v Carter [1893] AC 360.
[7] Cohen v Roche [1929] 1 KB 169.

Where a person is "*mentally incapacitated*" under common law, or deemed to "*lack capacity*" under the Mental Capacity Act 2005, this does not necessarily mean that their contracts are automatically void or voidable. Whilst capacity is listed as one of the conditions of validity of contracts, the situation is more nuanced.

First, a contract will be binding on the person lacking capacity if the agreement is a contract for necessities or an employment contract.[8] In line with the situation for minors,[9] the contract is valid, although only a reasonable price[10] is payable by the person lacking capacity.

It might seem logical to infer that if necessities and employment contracts *explicitly* remain binding despite a lack of capacity, then all other types of contract will, in contrast, *not* remain binding, when a lack of capacity has been established. However, this is not the case. The courts have made it clear that in contrast to the situation of the minor, for the person lacking capacity, in addition to having to demonstrate a lack of capacity, further proof is needed that the other party to the contract "*knew or ought to have known*"[11] that the (now contesting) party to the contract in fact lacked capacity at the time of the contract formation.[12] The burden of proof of both these elements lies with the person claiming the lack of capacity and contesting the validity of the contract. The aim of this approach to contract law is to protect the principle of certainty of contract and to not treat the innocent (business) counterpart harshly, if they were unaware of the underlying cognitive impairment.

For the person living with dementia, this double burden of proof ((1) proof of the lack of mental capacity and (2) proof of the other party's knowledge of this lack of capacity) is difficult to establish and makes it challenging to rely on the argument of lack of mental capacity when trying to void a contract with a

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[8] Re Rhodes (1889) 44 Ch D 94.

[9] See Chapter 6.

[10] Sale of Goods Act 1979, c.54, s. 3(2).

[11] Imperial Loan Co v Stone [1892] 1 QB 599.

[12] ibid.

business counterpart. The challenges can be illustrated by returning to *Hart v O'Connor*[13] and *Ayres v Hazelgrove*.[14]

Focus on the person

In *Hart v O'Connor*,[15] the Privy Council had to determine if Mr O'Connor had been able to validly consent to the sale, given his dementia diagnosis and lack of capacity. In this instance, the Privy Council confirmed that to void a contract for lack of mental capacity, in addition to proving his lack of mental capacity, Mr O'Connor would need to show that Mr Hart had knowledge of his cognitive impairment. In this case the Privy Council found that the concept of fairness (in terms of whether the correct market price was agreed) was not relevant[16], and that the outcome would be determined by the knowledge of the parties.

The facts indicated that whilst Mr O'Connor had lacked capacity at the moment the contract was formed, a professional surveyor had completed the valuation of his land. The contract had been drafted and submitted to Mr Hart by Mr O'Connor's lawyers. Mr Hart had agreed to the deal presented to him, and had not had knowledge of any capacity issue relating to Mr O'Connor, with whom he had had no direct contact. Consequently Mr Hart could not have known of the lack of capacity. The contract was validly entered into.

In *Ayres v Hazelgrove*[17] the issue was similarly whether Lady Ayres had been able to validly consent to the sale, given her dementia diagnosis and lack of capacity. The court decided that in order to void a contract for lack of mental capacity, in addition to demonstrating such lack of mental capacity, it would need to be shown that the other party (Mr Hazelgrove) had had knowledge of the cognitive impairment at the time of the contract formation. Again, the concept of fairness of whether the correct market price was agreed was not relevant, only the knowledge of the parties was significant.

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[13] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.
[14] Ayres v Hazelgrove (QB, 9 February 1984, unreported).
[15] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.
[16] Further discussion of this point below.
[17] Ayres v Hazelgrove (QB, 9 February 1984, unreported).

In this instance the court held that the purchaser would (or should) have known that Lady Ayres lacked capacity. The court found that this was made clear by Mr Hazelgrove's own evidence that confirmed that he had chatted to Lady Ayres for forty minutes. This time together (rather than the deal struck between the parties) would have made it clear that Lady Ayres was lacking in mental capacity.

In both Hart v O'Connor[18] and Ayres v Hazelgrove[19] it was not the difference in value between market value and agreed contract price that was of concern to the courts. Indeed, in neither case was the party's knowledge of lack of capacity inferred because of a bad bargain struck. Indeed, as was referred to above,[20] it is a fundamental principle of English contract law that the parties can decide on a price that falls well below market value.[21] The determining factor in relation to value of the deal is simply that there was some consideration, which need not be adequate (market-value) consideration.[22] It is instead the parties' knowledge that will have a greater effect on the contract validity.[23]

Vitiating factors

To vitiate means "*to destroy the force or legal effect of, for example, a deed*".[24] A vitiating factor in contract law is one that will render a contract imperfect and will affect its validity. Here the focus must be on the parties to the contract, rather than on the contract alone, since it is the consent of the parties that is determining in identifying a vitiating event.

In Hart v O'Connor, the Privy Court specifically referred to vitiating factors, making it clear that unfairness (in price) and undue influence/duress were

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[18] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.

[19] Ayres v Hazelgrove (QB, 9 February 1984, unreported).

[20] See Chapter 6.

[21] Thomas v Thomas (1842) 2 QB 851.

[22] Chappell v Nestle [1960] AC 87.

[23] Whilst in Hart v O'Connor the issue of fairness was ignored, there is case law that considered fairness in certain situations. Hence, the concepts of unfairness and unconscionability will be further explored below in this chapter in Section 7.3.

[24] Collins Dictionary of Law, 6th ed.

different concepts.[25] In doing so, the court was making the point that a mentally incapacitated person would still be able to rely on the concepts of vitiating factors to void a contract, even if a bad bargain alone could not do the same.

This was further highlighted in the more recent case of *Re L (Vulnerable Adults with Court's Jurisdiction) (No 2) [2012]*[26] where the court recognised that following the Mental Capacity Act 2005 coming into force, it was possible for persons with cognitive impairments to be deemed to have capacity in light of the requirements set out in the Mental Capacity Act 2005 whilst not being fully able in practice to understand complex contractual arrangements. The court stated that the persons with such impairment would still have "*the inherent jurisdiction of the court if there were vitiating factors*" and that the jurisdiction would "*continue to act as the 'great safety net'…*"[27]

In other words, the court accepted that the Mental Capacity Act precluded them from protecting those that were capable under the definition of the Mental Capacity Act[28] but might have difficulties in reaching decisions in their daily lives. To counter this powerlessness, the court however confirmed that they would still be a 'great safety net' if a vitiating factor could be established.

Whilst this is no different to the protection for vitiating factors afforded to every other person with capacity, it may be possible to argue that the contractual counterpart persuaded, encouraged or influenced the person living with dementia more easily because of the cognitive impairment. This is likely to be of particular relevance to those living with dementia, and it is important to examine this possibility of vitiating events in relation to the consumer living with dementia further, by reviewing the notions of duress and undue influence in more detail.

Duress

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[25] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1

[26] Re L (Vulnerable Adults with Court's Jurisdiction) (No 2) [2012] EWCA Civ 253.

[27] McFarlane LJ in Re L (Vulnerable Adults with Court's Jurisdiction) (No 2) [2012] EWCA Civ 253, at 61.

[28] Mental Capacity Act 2005, s. 3(1).

Duress renders a contract voidable because of the pressure applied (by one of the parties or a third party) beyond reasonable means to ensure the other party enters into the agreement.[29] Over the course of time, the conception of what kinds of pressure will vitiate a contract has evolved, from an initial focus on the threat of physical harm to the concept of economic harm.[30] All forms of duress will make the contract voidable at the request of the party affected by it.

The risk of abuse and fraud for people living with dementia when making financial decisions has been explored extensively in recent literature.[31] However, the focus of the current research is the situation where a person living with dementia enters into a contract with a business counterpart *without* fraud, abuse or threat, and the examination of duress offers no solution in such cases.

Undue influence

Undue influence, which is a more subtle manipulation of the party's decision-making process, and in many cases is identified without any malice or intention to wrong by the parties, deserves further consideration.

In many day-to-day situations, including in consumer matters, the person living with dementia may be willing to trust and rely on those who are present at the time. The person living with dementia, in an attempt to manage situations that seem confusing or difficult, may turn to those in physical proximity for advice.[32] This is the case, for example, in the context of wills or *inter vivos* gifts. The benefiting parties who advise and guide the person living

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[29] Barton v Armstrong [1976] AC 104.

[30] Atlas Express v Kafco (Importers and Distributors) Ltd [1989] 1All ER 641.

[31] See Chapter 5, Section 5.4 on the risk of abuse and fraud for people living with dementia when making financial decisions.

[32] Peisah, C., Finkel, S., Shulman, K., Melding, P., Luxenberg, J., Heinik, J., Jacoby, R., Reisberg, B., Stoppe, G., Barker, A., Firmino, H. and Bennett, H. (2009) 'The wills of older people: risk factors for undue influence' *International Psychogeriatrics* 21: 7-15.

with dementia are those close by, whether carers, visitors, neighbours or other family members.[33]

Where that person close to hand is the business counterpart, it may be questioned if they are a party benefitting from the transaction (more than the consumer) and if the consumer living with dementia was relying on the business extensively, putting their trust and faith into the business counterpart. It is in this context that undue influence must be examined.

As the name indicates, undue influence is not associated with the brute force of threats, but instead relies on the more subtle application of behaviour and words that influence and persuade. Key is that this behaviour goes beyond that which is legitimate in contractual matters.

In broad strokes, undue influence arises, first, where there is *actual* undue influence, with one party intentionally wanting to manipulate the decision-making process of the other to their advantage.[34] In such a case of actual undue influence, there is a "*wrongdoer*" who prevented "*the wronged party from bringing free will and properly informed mind to bear on the proposed transaction*".[35]

However, undue influence can also occur without any intention to do so, simply because of the recognised special relationship between the parties.[36] The presumption exists for relationships that are fiduciary in nature and where the transaction is one which cannot readily be explained by the relationship of the parties.[37] Examples of this may be trustee and beneficiary,[38] solicitor and client,[39] or doctor and patient.[40] Undue influence will be presumed in these cases if the transaction is not to the benefit of the vulnerable party, instead conferring an advantage to the party in a fiduciary position. The equitable

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[33] Quinn, M.J. (2000) 'Undoing Undue Influence' *Journal of Elder Abuse & Neglect* 12(2): 9-17.

[34] BCCI v Aboody [1990] 1 QB 923; [1992] 4 All ER 955.

[35] CIBC Mortgages plc v Pitt [1993] 4 All ER 433.

[36] Goldworthy v Brickell [1987] 1 All ER 853.

[37] *Royal Bank of Scotland v Etridge* [2001] 3 WLR 1021.

[38] Ellis v Barker (1871) 7 Ch App 104.

[39] Wright v Carter [1903] 1 Ch 27.

[40] Radcliffe v Price (1902) 18 TLR 466.

concept in such a situation is that the relationship between the parties, and the "*relative status of the parties*"[41] is such that influence must be *presumed*.

Where there is no fiduciary relationship, there is no automatic presumption arising as a matter of law. Instead, it must be demonstrated that there was a relationship where one party placed their trust and confidence in the other to safeguard their interest.[42]

Whilst actual undue influence in relation to persons living with dementia and others is well established, and presumed undue influence in relation to those with dementia and others in a fiduciary relationship to them have also been explored in court, a presumption of undue influence based on the special relationship of trust between business and consumer living with dementia or a cognitive impairment has not been tested in court and so remains uncertain.

In the interviews conducted as part of this project, the reliance and trust placed on the business counterpart in consumer transactions was expressed in numerous cases.[43] This research suggests that this presumption of undue influence based on trust could be applied in this situation, given the experiences of consumers with dementia.

As shown above, common law on contracts does not provide solutions for the consumer living with dementia. Next the consumer legislation must be explored to seek possible assistance.

Remedies for consumers

As discussed in the previous chapter, a consumer is deemed vulnerable due to their weaker transactional position when entering into the contract. The only vulnerability taken into consideration in either the Consumer Rights Act or the Consumer Contracts (Information, Cancellation and Additional Charges) Regulations is the transactional vulnerability, not the vulnerability of the consumer as a person. Indeed, if not linked to the transaction, then any

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[41] Goldworthy v Brickell [1987] 1 All ER 853, p. 865.

[42] *Credit Lyonnaise Bank Nederland v Burch* [1997] 1 All ER 144 (employer employee relationship).

[43] See Section 11.2 on further thoughts on undue influence.

vulnerability is deemed irrelevant in relation to the contract creation. The Consumer Rights Act sets out how a consumer is to be guarded against businesses selling or lending goods,[44] digital content[45] and services.[46] It aims to protect the consumer by ensuring fairness in all actions of the business, including by ensuring that goods or digital content are of "*satisfactory quality*",[47] "*fit for purpose*"[48] and "*as described*",[49] and that services are carried out "*using reasonable care and skill*",[50] "*at a reasonable price*",[51] within a "*reasonable time frame*".[52] In addition, communications must be clear and "*transparent*", i.e. using "*plain and intelligible language*" that is "*legible*".[53] In addition, it must provide full disclosure of financial matters and important, onerous or unusual terms of the contract.[54]

All of these are essential elements for the consumer to ensure they have a complete picture of the deal they are about to enter into. The consumer, if they are able to fully understand the terms and ensuing rights and obligations, financial and other, is protected. The protections are helpful to the "*average consumer*", defined it the Consumer Rights Act as "*a consumer who is reasonably well-informed, observant and circumspect*".[55] However, for the consumer living with dementia or another form of cognitive impairment, mental health issue or learning difficulties, who might not fully comprehend the complexities of the transaction or may have difficulties retaining the information after the signing of the contract, these provisions are of less value.

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[44] Consumer Rights Act 2015, Part 1, Chapter 2.

[45] Consumer Rights Act 2015, Part 1, Chapter 3.

[46] Consumer Rights Act 2015, Part 1, Chapter 5.

[47] Consumer Rights Act 2015, s. 9 and s. 34, for goods and digital content respectively.

[48] Consumer Rights Act 2015, s. 10 and s. 35, for goods and digital content respectively.

[49] Consumer Rights Act 2015, s. 11 and s. 36, for goods and digital content respectively.

[50] Consumer Rights Act 2015, s. 49.

[51] Consumer Rights Act 2015, s. 51.

[52] Consumer Rights Act 2015, s. 52.

[53] Consumer Rights Act 2015, s. 68.

[54] Consumer Rights Act 2015, s. 62 and 63.

[55] Consumer Rights Act 2015, s. 64(5).

The Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013 outlines the rights of consumers with regards to cancellations for most distance and off-premise contracts,[56] and the information that needs to be provided to the consumer[57] in relation to that right to cancel. Indeed, consumers "*may cancel a distance or off-premises contract at any time in the cancellation period without giving any reason, and without incurring any liability*",[58] subject to some exceptions.

This provision to cancel a contract is greatly valued by consumers, because it is a right to change one's mind. That right to cancel the contract during the 'cooling-off' period relates to contracts that were entered into in all spheres, other than on-premise, i.e. in the shop of the business.[59] Effectively, the cooling-off period relates to two types of situations. On the one hand, it is applied when goods and services are bought via the Internet, where the actual goods or services have not been seen in person. On the other hand, the cooling-off period will apply were the buyer might have been 'pushed' or persuaded into the transaction by a convincing sales pitch, usually at the initiative of the business, be that on the consumer's doorstep, by telephone or postal communication. This is a useful protection for many consumers who after the initial rush into a consumer contract realise subsequently that this is in fact a contract they do not want, need or cannot afford. The ability in these circumstances to simply return the goods and rescind the contract without having to explain, justify or pay a penalty[60] is welcome to many consumers.

In providing this protection in the Consumer Contracts (Information, Cancellation and Additional Charges) Regulations, the legislator removes the burden of proof from the consumer. They do not have to show that the

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[56] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013, s. 29.

[57] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013, s. 19.

[58] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013, s. 29.

[59] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013.

[60] Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2013, s. 29.

received goods or services were of lesser quality, unfit for its intended purpose or not as described. They do not have to demonstrate that in the course of selling there was a misunderstanding, misrepresentation or mistake. Instead, the burden of proof is lifted and allows them to simply cancel the contract and change their mind without explanation.

However, cancellation within a pre-defined window of 14 days may not be helpful to the consumer living with dementia who has, due to memory loss, forgotten that a contract was entered into. Lack of understanding of the terms of the deal may result in the consumer living with dementia not knowing about the cooling-off period or how to cancel the contract, even when they remember that a transaction was concluded with the business.

Where consumer legislation is not able to protect the consumer living with dementia, next non-discrimination provisions may help where the person with dementia is classified as having a disability. In the UK, the relevant legislation is the Equality Act 2010, which is examined next.

Remedies under the Equality Act

Under the Equality Act,[61] vulnerability is implicitly recognised for certain groups of persons, through the provision of rules to counter the risk of harm in the form of unlawful discrimination, harassment and victimisation in the spheres of employment, education, the exercise of public functions, or the provision of services. Among the persons at risk of such harm are those with a disability.[62]

As mentioned above, this thesis excludes the review of situations where the actions by businesses are fraudulent or intentionally harmful (for example coercion, misrepresentation or unfair practices). Consequently, whilst prohibited conduct includes harassment and victimisation, for the purposes of this thesis, the focus will be on discrimination arising from the disability. The consumer living with dementia may be able to rely on provisions relating to direct or indirect discrimination.

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[61] Equality Act 2010, c.15.

[62] Equality Act 2010, s. 6(1).

Direct discrimination

Section 13 considers direct discrimination, where a person will discriminate because of a protected characteristic.

> *(1) A person (A) discriminates against another (B) if, because of a protected characteristic, A treats B less favourably than A treats or would treat others.*[63]

An example for the purposes of this research would be where a business refuses to enter into a contract with a person living with dementia because of their disability. It must be questioned if this is applicable also in cases where the disability manifests itself through confusion, memory gaps or an apparent lack of understanding that makes the business representative question the consumer's capacity. Where the business believes the person does not have capacity, it might refuse to enter into a contract with that consumer. In some cases, it might recommend that they discuss matters with other family members, and that they will only enter into the contract if a family member is there to assist.

However, if the consumer in fact still has capacity under the Mental Capacity Act, the company's refusal might be considered direct discrimination. This example demonstrates the complexity of the situation of the consumer living with dementia. Businesses may be torn because contract law suggests that they should either know, or ought to have known of a lack of capacity. However, the test for capacity is not well known and difficult to apply in a short consumer-business interaction. At the same time, non-discrimination law requires them to not treat a person with a disability differently to others.

Section 13(3)[64] clarifies that, rather than less favourable treatment, where more favourable treatment is provided, there is no discrimination. Consequently the law explicitly allows for favourable treatment of persons with key characteristics. This would mean that whilst businesses cannot discriminate by refusing to conclude contracts with persons living with

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[63] Equality Act 2010, s. 13(1).

[64] Equality Act 2010, s. 13(3).

disabilities such as dementia, they could add specific favourable terms to such contracts, such as advantageous termination provisions. In Chapter 11, ways in which such provisions might be incorporated are considered.

Indirect discrimination

The consumer living with dementia may be able to rely on the provisions relating to indirect discrimination. Section 15 considers discrimination that arises as a *consequence* of the disability.

> *(1) A person (A) discriminates against a disabled person (B) if—*
>
> > *(a) A treats B unfavourably because of something arising in consequence of B's disability, and*
> >
> > *(b) A cannot show that the treatment is a proportionate means of achieving a legitimate aim.*
>
> *(2) Subsection (1) does not apply if A shows that A did not know, and could not reasonably have been expected to know, that B had the disability.*[65]

In the explanatory notes on Section 15[66], the examples given relate to a dismissal from employment or refusal to serve in a pub. Looking at it from a consumer-business point of view, it might be questioned whether there is indirect discrimination where the business refuses to enter into a contract as a consequence of the disease (presenting as confusion and a lack of understanding). However, this treatment might be seen to be proportionate in achieving the legitimate aim of not wanting to contract with someone who may not have capacity.

From the new data collected in interviews it appears that usually the concern is not the refusal to enter into a contract, but rather the refusal to void the contract entered into by a person living with dementia where this contract is

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[65] Equality Act 2010, s.15.

[66] available at http://www.legislation.gov.uk/ukpga/2010/15/section/15/notes?view=plain, last accessed on 14 February 2021.

subsequently not wanted. It may be difficult to argue indirect discrimination, as this refusal to void a contract is not only applied to persons with a disability, but to all consumers.

Section 15(2) highlights that for this section to be applicable, the person indirectly discriminating must have actually known or ought to have known of the disability. This links the legislation to contract law on capacity matters. Again, the burden of proof will rest with the person with the disability to demonstrate the knowledge of the counterpart. As a result, it appears that protection under Section 15 may not be available to consumers living with dementia, if it is not possible and reasonable for the contracting counterpart, the business representative, to identify that the person is living with dementia and may therefore have a disability. The difficulty for the person living with dementia may be the invisibility of the illness at first glance.

An uncoordinated response for the consumer living with dementia

In Chapter 6, the need for complementarity between the different laws was advocated in order to provide sufficient legal remedies for the consumer living with dementia. This ideal is however not met. Instead the laws do not find common ground. Some of the laws are compatible with each other but not to the required extent. For example, consumer law and contract law are closely connected, with legal remedies in consumer law relying on special provisions applicable to the contractual terms between the parties. Contract law is also closely associated with capacity law, as capacity aspects are in principle one of the four fundamental building blocks in forming a contract. However, neither consumer law, nor contract law are complementary with equality law, and consumer law and capacity law are also not directly entwined.

The relevant areas of the law are applied in silos, without concern of each other. This in turn leads to some persons being excluded from (or boxed out of) adequate protection. Instead of the segregation of legal remedies, a holistic view of the law is essential to protect consumers living with dementia.

Further legal remedies must be explored which may have the potential of greater protection of the consumer living with dementia.

7.3 ‘Outlier’ legal remedies

This section is titled ‘outlier’ remedies, because it relates to solutions that are “*situated away from or classed differently from a main or related body… [and thus are] … atypical within a particular group, class, or category*”.[67] The protections discussed in this section are not regularly applied to consumers living with dementia, but the aim is to consider the viability of such an extension of proposed remedies. This section therefore will examine the concepts of unconscionability and good faith, as well as explore the applicability of the CRPD[68] in this context.

As discussed above,[69] one of the fundamental concepts of the classical position of contract law is the sanctity of the (supposed) autonomy of each party to the contract, and by extension, the freedom to contract on whatever terms the parties freely choose. The aim of this stance is to protect contractual freedom and ensure commercial certainty.[70]

The desire for certainty of contract and contractual freedom also means that the parties are not precluded from making bad deals.[71] In Union Eagle Ltd v Golden Achievement Ltd, Lord Hoffmann explained this need for certainty because of “*practical considerations of business*” and further reasoned that if the terms of the contract can be later amended by court order because of unfairness or a bad deal between the parties, contracts and business transactions would no longer have any certainty, enabling “*litigation to be employed as a negotiating tactic*” .[72]

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[67] Merriam-Webster dictionary definition, available at https://www.merriam-webster.com/dictionary/outlier, last accessed on accessed on 14 February 2021.

[68] Equality and Human Rights Commission (2017) *The United Nations Convention on the Rights of Persons with Disabilities: What does it mean for you?*, available at https://www.equalityhumanrights.com/en/publication-download/united-nations-convention-rights-persons-disabilities-what-does-it-mean-you, last accessed on 14 February 2021.

[69] See Chapter 6, Section 6.2.

[70] Atiyah, P.S. (2003) *The Rise and Fall of Freedom of Contract*, Oxford University Press, at 25.

[71] See Section 6.2.

[72] *Union Eagle Ltd v Golden Achievement Ltd* [1997] AC 514 at 519

This principle of certainty has however been tempered by legislation,[73] and the courts have also in certain circumstances looked to ensure that fairness is taken into account when considering contractual matters.[74] One of the champions promoting the need for fairness in contracts was Lord Denning[75] and, whilst his views have been criticised,[76] his words are well worth repeating given the recognition of the impact of his work on contract law doctrine.[77]

> *I put aside contracts or transactions which are voidable for fraud or misrepresentation or mistake. All those are governed by settled principles. I go only to those where there has been* ***inequality of bargaining power****, such as to merit the intervention of the court.* [emphasis added]

Lord Denning identified inequality of bargaining power as something that merited the intervention of the court outside existing legal categories. Just as Lord Denning explained that he did not dwell on those contracts "*voidable for fraud or misrepresentation or mistake*", as they are already "*governed by settled principles*", this research specifically focuses on situations where the business has not acted in a fraudulent manner. For cases of fraud, coercion and unfair practices against persons living with dementia, much has been written on the subject already.[78] Lord Denning's statement highlights the need to examine the positions of the parties, and in particular the vulnerability of the weaker party.[79] This is a crucial point; it is not enough to examine the contract terms alone. This focus on the parties to the contract is important. This thesis

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[73] For example, for employees, consumers, tenants.

[74] For example, Commission for the New Towns v Cooper (GB) Ltd [1995] 2 All ER 929.

[75] Lloyds Bank Ltd v Bundy [1974] 3 All ER 757, at 765.

[76] National Westminster Bank plc v Morgan [1985] 1 All ER 821, at 830.

[77] for example, see Phang, A. (1999) 'The Natural Law Foundations of Lord Denning's thought and Work' *Denning Law Journal* 14: 159-177.

[78] See Chapter 5, Section 5.4 on the risk of abuse and fraud for people living with dementia when making financial decisions.

[79] Koffman, E. and Atkins, R. (eds) (2018) *Koffman and Macdonald's Law of Contract*. Oxford University Press, 16.25 at 403.

argues that the weaker party must be considered when seeking to determine if a contract is voidable for unconscionability or unfairness.

In response to Lord Denning's stance on unfairness, the House of Lords[80] thought that the principle of certainty of contract was not compatible with the flexibility required by the concept of unfairness in contracts. Instead, the opinion of the justices at that time was that any unwanted unfairness should be resolved through legislation.[81] However, more recent case law questions this position, as will be described below when looking at the concepts of unconscionability and good faith. These concepts, which are explored below, represent a somewhat controversial area of common law.

Unconscionability

Unconscionability relates to a lack of good conscience of one of the parties to the contract, and is linked to the notion of unfairness. As such, it explores the idea that contracts between parties of unequal bargaining power should be reviewed to ensure that the contracts entered into are fair to both parties.

In the recent case The Libyan Investment Authority v Goldman Sachs International,[82] questions of undue influence and unconscionability were put to the court. An investor (a sovereign investment fund) had been persuaded by their bank to invest in various products. Significant premiums (approximately USD 1.2 billion) were paid to the bank for these transactions. Unfortunately, the investments resulted in huge losses following the financial crisis of 2007-2008. The investor therefore sought to void the transactions and recoup the premiums paid on the basis of undue influence and unconscionable bargain. Rose J, after considering and dismissing the claim of undue influence on the facts, explored the notion of unconscionability. She did so by referring to the case of Portman Building Society v Dusangh,[83] where

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[80] as it was called in 1985 at the time of National Westminster Bank plc v Morgan [1985] 1 All ER 821.

[81] National Westminster Bank plc v Morgan [1985] 1 All ER 821.

[82] The Libyan Investment Authority v Goldman Sachs International [2016] EWHC 2530 (Ch).

[83] Portman Building Society v Dusangh [2000] 1 All ER (Comm) 221.

the court had summarised previous jurisprudence on unconscionability to present the elements deemed essential in identifying unconscionable conduct.

Consequently, Rose J reiterated the position that for there to be unconscionable conduct, four criteria would need to be met: (1) that the complaining party must have been "*at a **serious** disadvantage*" to the stronger party, (2) the stronger party must have "*acted in a morally reprehensible manner*". (3) The result of the transaction must be "*overreaching and oppressive*", resulting in (4) "*the conscience of the court [being] shocked*".[84]

The words used in defining unconscionability are determining and their forcefulness makes it apparent that the test for unconscionability requires behaviour that is not simply lacking. Indeed, the terms "*morally* reprehensible", "*shocking* the conscience", "*overreaching* and *oppressive"* all speak to the *seriousness* of the actions of one party towards the other.

Ward LJ reiterated these points in the same judgment, highlighting that where there was "*a sale at an undervalue, the undervalue has almost always been substantial, so that it calls for an explanation, and is in itself indicative of the presence of some fraud, undue influence, or other such feature*". One of the cases Ward LJ quoted to emphasise his points is Hart v O'Connor.[85]

As discussed in Chapter 6, in this case, Mr O'Connor, who at the time of sale had dementia, sold his farm to Mr Hart. The sale was at an undervalue of 10%, and some other terms were beneficial to the buyer, such as a staggered payment schedule over a number of years. In Hart v O'Connor, the court had to decide if the sale at an undervalue was an unconscionable bargain. In order to establish unfairness that would allow the contract to be put aside, the Privy Council declared that one of two types of unfairness would have to be demonstrated.

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[84] Portman Building Society v Dusangh [2000] 1 All ER (Comm) 221, Browne LJ.

[85] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.

The first type of unfairness considered by the justices was ‘procedural unfairness’, which related to the manner, i.e. the procedure in which the bargain had been obtained. In other words, the court was concerned with any undue influence or other coercing method applied in getting the other party to enter into a contract. No such procedural unfairness was established in the transaction between buyer and seller, as the parties had had no contact directly and had relied on professional and independent advice throughout.

The second type of unfairness explored by the Privy Council relates to substantive unfairness, i.e. unfairness resulting from the terms of the contract itself or the position of the parties to the contract. However, the Privy Council held that for substantive unconscionability to be considered, the profiting party would have to be aware of the disadvantage of the other party. Indeed, the court held that

> *a suit at law [would fail] on the ground of ‘unfairness’ unless the* ***conscience*** *of the plaintiff was in some way affected. An unconscionable bargain in this context would be a bargain of an improvident character made by a poor or ignorant person acting without independent advise which cannot be shown to be a fair and reasonable transaction.*[86]

In Hart v O’Connor, it was held that no such awareness of any disadvantage of Mr O’Connor existed in the mind of Mr Hart and that, as the contract had been drafted by the seller’s solicitors and the price determined by the seller’s expert surveyor, the buyer could not have used the disadvantage of the seller’s disease to their benefit.

Case law suggests that the scope of unconscionability as a protective mechanism for a person living with dementia when entering into a contract is significantly constrained, because it requires the benefitting party not only to *knowingly* be taking advantage, but also to *seriously* take advantage and to do so “*in a morally reprehensible manner, that is to say in a way which affects*

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[86] Hart v O’Connor [1985] AC 1000 [1024] Lord Brightman.

his conscience".[87] When a business sells goods or services to the consumer living with dementia, it is likely to be difficult to show this level of impropriety and morally culpable behaviour.[88] Other than in very limited situations where a business may expressly target persons living with dementia because of their illness and impose terms that put these consumers in a highly disadvantaged position resulting in a transaction that can then be described as oppressive, unconscionability will be difficult to apply in most consumer-business relationships considered in this research.

Good faith

The concept of good faith was originally a feature in civil law jurisdictions.[89] It has since been applied to some extent in the United States of America, Canada,[90] and the United Kingdom, [91] and might be said to share some similarity with the notion of unconscionability in that it looks at the notion of substantive fairness. However, for the parties to a contract to act in 'good faith', there is need for the transaction to be "*in essence a principle of fair and open dealing*".[92] In other words, it asks the parties to put "*one's cards face upwards on the table*"[93] and clearly set out the terms of the transaction, pointing out the pros and cons of the deal to allow the other party to make an informed decision. This does not require the parties to a contract to act in an altruistic manner. As Keily points out, "*Good faith does not require the*

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[87] Boustany v Pigott (1995) 69 P.&C.R. 298, 303, Lord Templeman.

[88] Other than, in the context of the Directive 2005/29/EC on Unfair Commercial Practices, in situations where vulnerable consumers, such as consumers with dementia, are specifically targeted and the practices deployed fall within the Directive's definition of unfair commercial practices.

[89] for example, French Civil Code (*Art. 1104: Contracts must be negotiated, formed and performed in good faith. This provision is a matter of public policy*.) and German Civil Code (Paragraph 242: *Performance in good faith: An obligor has a duty to perform according to the requirements of good faith, taking customary practice into consideration*.).

[90] for example recently in Bhasin v Hrynew (2014) SCC 71 [93]; C.M. Callow Inc .v. Zollinger (2020) SCC 45.

[91] Mason, A.F. (2000) 'Contract, Good Faith and Equitable Standards in Fair Dealings' *Law Quarterly Review* 116: 66.

[92] *Interfoto Picture Library Ltd v Stiletto Visual Programmes Ltd* [1989] QB 433, Bingham LJ.

[93] *Interfoto Picture Library Ltd v Stiletto Visual Programmes Ltd* [1989] QB 433, Bingham LJ.

abandoning of self-interest as the governing motive in contractual relations";[94] instead it encourages honesty in dealings. [95]

In the United Kingdom, the notion of good faith has been and continues to be a divisive doctrine.[96] It was first proposed in the 1950s by Powell,[97] and revisited by Brownsword[98] in the 1990s.

In this thesis focus will be on contractual duties of good faith. Where good faith is not expressly mentioned in the contract, there is reluctance to accept it as an implied term. Certainty in contract law requires there to be no duty other than the terms agreed upon. For example in MSC Mediterranean Shipping v Cottonex, [99] Moore-Bick LJ described his resistance to the concept of a general duty of good faith in contracts, because of "*a real danger that if a general principle of good faith were established it would be invoked as often to undermine as to support the terms in which the parties have reached agreement*".[100]

Another argument against the application of good faith in contract law is that the notion of good faith is too vague or ambiguous. For example, in Globe Motors v TRW Lucas,[101] Beatson LJ thought that instead of a duty of good faith, a "*duty to co-operate*" would have been more likely to be accepted by the court on the grounds that it was more clearly defined.

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[94] Keily, T. (1999) 'Good faith & the Vienna Convention on Contracts for the International Sale of Goods' *Vindabona Journal Of International Commercial Law And Arbitration* 3(1): 15-40, at 16.

[95] Yam Seng [2013] EWHC 111 (QB); [2013] 1 All E.R. (Comm) 1321.

[96] Indeed, some cases have shown contempt for the (implied) notion of good faith (such as UTB LLC v Sheffield United Ltd & Ors [2019] EWHC (Ch) (no implied duty of good faith), or Russel v Cartwright & Others [2020] EWHC 41 (no overarching duty of good faith), while others have embraced the concept of good faith (Al Nehayan v Kent [2018] EWHC 333 (Comm) (Lord Leggatt again), and Bates & Others v Post Office Ltd [2019] EWHC 606 (QB) more recently.

[97] Powell, R. (1956) 'Good faith in contracts' *Current Legal Problems* 9: 16-38.

[98] Brownsword, R. (1996) 'Good Faith in Contracts revisited' *Current Legal Problems* 49(1): 111–157.

[99] MSC Mediterranean Shipping v Cottonex [2016] EWCA Civ 789.

[100] MSC Mediterranean Shipping v Cottonex [2016] EWCA Civ 789.

[101] Globe Motors v TRW Lucas [2016] EWCA Civ 396.

Despite various opposing views to the principle of good faith in the courts,[102] there has, concurrently, been a recent and steady acceptance of the notion of good faith in some aspects of English law. The argument for good faith in contract law is that in this globalised world the refusal to include the general principle of good faith will lead to legal isolation and is not viable in the long term.[103] In Yam Seng[104] the court felt that if it did not recognise "*any such general obligation of good faith, this jurisdiction would appear to be swimming against the tide*". [105] Consequently, whilst the doctrine of good faith was not specifically adopted, Leggatt LJ likened it to an implied "*duty of honesty*", [106] which can be seen in common law in the implied term of fitness for purpose.

In Al Nehayan v Kent, [107] Leggatt LJ states that "*the implication of a duty of good faith in the contract is essential to give effect to the parties' reasonable expectations*". [108] Here, the parties' expectations are considered significant in understanding the parties' duties.

Good faith may be seen to mean looking beyond the terms of the contracts at the parties to the contract and their expectations that the contract will be performed in a certain way. More recently, it has been linked to relational contracts [109] where the relationship between business partners is taken into

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[102] Ilkerler Otomotiv Sanayai ve Ticaret Anonim v Perkins Engines Co Ltd [2017] EWCA Civ 183; [2017] W.L.R.(D) 204*;* MSC Mediterranean Shipping Co SA v Cottonex Anstalt [2016] EWCA Civ 789; [2016] 2 Lloyd's Rep. 494*;* Compass Group UK and Ireland Ltd v Mid Essex Hospital Services [2013] EWCA Civ 200; [2013] B.L.R. 265*.*

[103] De Boeck, A. and Van Hoecke, M. (2008) 'The Interpretation of Standard Clauses in European Contract Law' in Collins, H. (ed) *Standard Contract Terms in Europe: A Basis for and a Challenge to European Contract Law*, Wolters Kluwer, at 222; Keily, T. (1999) 'Good faith & the Vienna Convention on Contracts for the International Sale of Goods' *Vindabona Journal Of International Commercial Law And Arbitration* 3(1): 15-40.

[104] Yam Seng [2013] EWHC 111 (QB); [2013] 1 All E.R. (Comm) 1321.

[105] Ibid, at 124.

[106] Ibid, 126, 172.

[107] Al Nehayan v Kent [2018] EWHC 333 (Comm).

[108] Al Nehayan v Kent [2018] EWHC 333 (Comm), at 174.

[109] Building on Yam Seng, Leggatt LJ considers relational contracts and good faith in Al Nehayan v Kent [2018] EWHC 333 (Comm), stating at 167 that "*'relational' contracts involve trust and confidence... It is trust that the other party will act with integrity and in a spirit of cooperation. The legitimate*

account. However, the concept of the relational contract could be expanded beyond certain business-to-business relationships to other forms of contract,[110] including consumer contracts.[111] In consumer matters the persons entering into the contracts, and their positions in relational terms, must be considered more closely. This was also argued by Dodsworth, stating that "*there is no reason why this [relational aspect in contracts] could not be extended to consumer contracts to imply a term which requires one of the parties to have regard of the others' interests or in our context, expectations*."[112]

The notion of expectations is important. In the consumer context, Herring points out that

> *When most people sign the contract for electricity provision or click on the 'I agree' button for a download, the consumer is accepting the standard terms, which they do not read, but assume to be reasonable or fair. Ensuring that the terms are reasonable and fair is ensuring the contract meets the expectations of the parties.*[113]

As Gounari points out, in relation to a contract, expectations of honesty and reciprocity already exist in the classical contract law position.

> *Indeed, the expectation of honesty is manifestly operationalised in the doctrines of misrepresentation and, indirectly, mistake, while the*

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expectations which the law should protect in relationships of this kind are embodied in the normative standard of good faith".

[110] See for example Thompson, S. (2018) 'Feminist Relational Contract Theory: A new model for family property agreements' *Journal of Law and Society* 45(4): 617-645, at 617.

[111] Leib, E.J. (2013) 'What is the relational theory of consumer form contract?' in Braucher, J., Kidwell, J. and Whitford, W.C. (eds.) *Revisiting the contracts scholarship of Stewart Macaulay: On the empirical and the Lyrical* Hart, 259-288 at 267.

[112] Dodsworth, T. (2020) 'Vulnerability in the UK Energy Market' in Riefa C, Saintier S (Eds.) *Vulnerable Consumers and the Law – Consumer Protection and Access to Justice*, Routledge, 102-119, at 117.

[113] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 257, referring to Thomas, C. (2010) "What Role Should Substantive Fairness Have in the English Law of Contract? An Overview of the Law' *Cambridge Student Law Review*, at 177.

> *concept of reciprocity has been effectively institutionalised as the doctrine of consideration, which is the very cornerstone of contract law*.[114]

Turning to the definition of good faith in another common law jurisdiction, the United States, good faith requires the concept of expectations to be considered. For example, the US Restatement (Second) of Contracts[115] defines 'good faith' not just in relation to unfair terms or practices. Instead it explores the notion of good faith in a more holistic manner.

> *Good faith performance or enforcement of a contract emphasizes faithfulness to an agreed common purpose and consistency with the justified expectations of the other party; it excludes a variety of types of conduct characterized as involving 'bad faith' because they violate community standards of decency, fairness or reasonableness.*[116]

Keys words are the notions of **common purpose**, consistency with the justified **expectations of the other party** as well as the need to adhere to community standards of **decency, fairness or reasonableness.**[117] Here, the notion of good faith is closely linked to the concept of justified expectations that the parties may have in relation to the contract. It is therefore important to understand what these expectations would be for the consumer.

To some extent, in the consumer context, expectations of the business when dealing with a consumer are already established. Such legitimate expectations would include for example the expectations that the goods are of satisfactory quality, [118] fit for purpose, [119] and as described. [120] The concept of

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[114] Gounari, Z. (2021) 'Developing a relational law of contracts: Striking a balance between abstraction and contextualism'. *Legal Studies* 41(2): 177-193, at 182/3.

[115] US Restatement (Second) of Contracts, 1979, American Law Institute.

[116] ibid., paragraph 205.

[117] These ideals are also highlighted in recent case law, such as Al Nehayan v Kent [2018] EWHC 333 (Comm), at 173, where the notion of common purpose is mentioned in relation to the relationality of the contract.

[118] Consumer Rights Act 2015, s. 9

[119] Consumer Rights Act 2015, s. 10

[120] Consumer Rights Act 2015, s. 11

legitimate expectation is not linked to their status as a person of potential personal vulnerability.[121] Instead these are expectations based on the transactional weakness of the consumer, i.e. expectations that any person acting as a consumer would hold in the situation. These expectations are built on the premise that consumers are, by their very nature, information-poor,[122] "*with neither the time, nor the inclination, nor the funds to enter into an unequal contest with the big battalions of commerce and industry*",[123] and therefore in need to protection in that regard.

The above-mentioned expectations demonstrate that good faith has, to some extent, been integrated in English law through recent legislation, such as consumer law.[124] The concept of fairness and good faith can therefore be said to have been explicitly introduced in relation to the terms of a contract, first in the Unfair Terms in Consumer Contracts Regulations[125] that were made to give effect in the United Kingdom to the Council Directive on Unfair Terms in Consumer Contracts,[126] the later in the Consumer Rights Act.[127]

In The Director General Of Fair Trading V First National Bank Plc,[128] the issue relating to good faith in relation to the unfair terms of an agreement were first introduced in the House of Lords. Lord Bingham explained that a term was unfair if,

> *… it causes a significant imbalance in the parties' rights and obligations under the contract to the detriment of the consumer in a manner or to an extent which is contrary to the requirement of good faith. The*

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[121] See Chapter 3 on vulnerability.

[122] Freedman, S. (2016) 'A short history of the consumer EU policy' in Leczykiewicz, D., Weatherill, S.(eds), *The Images of the Consumer in EU Law: Legislation, Free Movement and Competition Law*. Hart Publishing, 447–462, at 448.

[123] Ibid., at 461.

[124] McKendrick, E. (1999) 'Good Faith: A Matter of Principle?' in Forte, A.D.M. (ed) *Good Faith in Contract and Property* Oxford: Hart Publishing 39-62.

[125] Unfair Terms in Consumer Contracts Regulations 1994 (SI 1994/3159)

[126] Council Directive 93/13/EEC (OJ 1993, L95, p 29) on unfair terms in consumer contracts.

[127] Consumer Rights Act 2015, c.15.

[128] The Director General Of Fair Trading V First National Bank Plc [2001] UKHL 52.

> *requirement of significant imbalance is met if a term is so weighted in favour of the supplier as to tilt the parties' rights and obligations under the contract significantly in his favour. … But the imbalance must be to the detriment of the consumer; a significant imbalance to the detriment of the supplier, assumed to be the stronger party, is not a mischief which the regulations seek to address.*[129]

Further, Lord Bingham considered the notion of good faith, explaining that it requires,

> *… fair and open dealing. Openness requires that the terms should be expressed fully, clearly and legibly, containing no concealed pitfalls or traps. Appropriate prominence should be given to terms which might operate disadvantageously to the customer. Fair dealing requires that a supplier should not, whether deliberately or unconsciously, take advantage of the consumer's necessity, indigence, lack of experience, unfamiliarity with the subject matter of the contract, weak bargaining position or any other factor …*[130]

These points are echoed in the Consumer Rights Act. For example, in section 62, the legislation refers to the business' need to ensure the terms of their agreement with the consumer are fair. The legislation then explains that "*a term is unfair if, **contrary to the requirement of good faith**, it causes a significant imbalance in the parties' rights and obligations under the contract to the detriment of the consumer.*" Fairness instead is achieved by taking into account "*all the circumstances existing when the term was agreed and to all of the other terms of the contract or of any other contract on which it depends.*" [131]

As a result, the Consumer Right Act looks at unfair terms and seeks to strike those out because they do not comply with the requirement of good faith.

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[129] The Director General Of Fair Trading V First National Bank Plc [2001] UKHL 52, at [17], per LJ Bingham.

[130] ibid.

[131] Consumer Rights Act 2015, s. 62(5)(b).

In some cases, the requirement of honesty is extended even further in certain types of consumer contracts, such as in insurance contracts or certain other financial transactions, where the parties are subject to a duty of utmost good faith.[132] This notion of utmost good faith, or *uberrimae fidei*, means that the parties are under the obligation to reveal all information that could influence their decision to enter into a contract with one another, and not to mislead or withhold critical information from one another. This obligation exists both at the outset, when entering into a contract, and also throughout the life of the contract, if new circumstances arise that might subsequently alter the parties' situation.[133] The legitimate expectations of the parties here are of honesty and disclosure of all relevant information. Whilst both parties are required to act in the utmost good faith, in practice, it is "*usually the assured who bears the obligation of disclosure*",[134] because

> *Insurance is a contract of speculation. The special facts upon which the contingent chance is to be computed lie most commonly in the knowledge of the assured only; the underwriter trusts to his representation and proceeds upon confidence that he does not keep back any circumstance in his knowledge to mislead the underwriter into a belief that the circumstances do not exist*. [135]

For the consumer with dementia however, this requirement of utmost good faith is potentially doubly unhelpful. On the one hand the duty of utmost good faith does not require the insurer to do anything but disclose the terms of the contract clearly and fully (which, as seen above, is not always of use to the consumer with dementia). On the other hand, this duty is often detrimental to the consumer with dementia due to their memory issues. They may forget that such an insurance contract exists between them, or that a duty to update and inform of any change of circumstance exists. This is crucial, since it can

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[132] Marine Insurance Act 1906, s. 17, the effect of which was expanded to all forms of insurance and re-insurance contracts in Pan Atlantic Co. Ltd. v. Pine Top Insurance Co. Ltd., [1995] 1 A.C. 501, [1994] 2 Lloyd's Rep 427.

[133] Woloniecki, J. (2002) 'The Duty of Utmost Good Faith in Insurance Law: Where Is It in the 21st Century?' *Defense Counsel Journal* 69(1): 63-70.

[134] ibid., at 70.

[135] Carter v Boehm (1766) 3 Burr 1905.

negate the policy. Alternatively they may no longer know how to contact the insurer to make such statement. Consequently they may not communicate in a timely and adequate manner with the insurer, rendering future claims invalid, whilst still making regular payments (often by direct debit) to the business.

Good faith, rather than the specific concept of the utmost good faith in insurance contracts, may assist the consumer living with dementia where their legitimate expectations are not met. However, this must be tempered in two ways.

First, whilst the Consumer Right Act looks, for example, at unfair terms and seeks to strike those out because they do not comply with the requirement of good faith, for the person living with dementia, regulation of unfair terms *per se* may not be the issue. As mentioned above, these are expectations based on the transactional weakness of the consumer, rather that on the personal vulnerability that the consumer living with dementia may experience. Such a person may enter into a contract that does not contain any unfair terms and yet is still a contract that will be detrimental to their financial situation. This could occur for example when a consumer with dementia enters into multiple contracts for mobile phones, associated loans and related connectivity services. In such a case it is likely that each individual contract will not contain any terms deemed unfair. The legitimate expectation of a contract that is entered into in good faith is met. Nevertheless, for the consumer living with dementia, funding multiple monthly mobile phone contracts would be highly onerous, potentially leading to financial distress and a loss of financial independence.

A difficulty arises even when reasonable expectations to consider the context and circumstances of the consumer are taken into account. This is because this is only possible where the business is aware of the situation of the consumer. As will be examined in Chapter 9, [136] in many chases, consumers living with dementia will hide their illness and potential vulnerability from the business counterpart. Businesses will resist any demand that they be

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[136] See Section 9.3 on knowledge of the parties and Section 9.4 on stigma.

expected to take into account circumstances they are not aware of. Good faith in such circumstances may not provide the protection for such persons living with dementia.

Disability concerns: CRPD

Principles of equality and non-discrimination are at the heart of the concept of human rights. These human rights were first recorded in the aftermath of World War 2 in the Universal Declaration of Human Rights in 1948,[137] followed shortly afterwards in 1953 by the European Convention of Human Rights.[138] Nationally in the UK, the Human Rights Act 1998 has legislated on human rights.

However, despite these various laws, there remain barriers for people with disabilities. Here, the CRPD - the aim of which is to harmonise equality principles by assisting domestic courts, where there is a lack of clarity, in the interpretation of national laws on equality, fairness and non-discrimination – is examined to understand whether it can assist the consumer living with dementia.

Under Article 3 of the CRPD,[139] a number of key principles are presented which are fundamental to the application of the CRPD regulations. These principles include the principle of dignity and respect, and relate to the autonomy or freedom to make decisions.

It can be said that this principle is adhered to in the Mental Capacity Act in their clear statement of presumption of capacity.

Another principle is that of non-discrimination, requiring all persons to be treated equally. As has been demonstrated above, whilst this is covered in the

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[137] Universal Declaration of Human Rights (1948) UN General Assembly 217 A (III).

[138] European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14 (1950) Council of Europe ETS 5.

[139] Convention on the Rights of Persons with Disabilities (2006) United Nations 2515 UNTS 3 (CRPD).

Equality Act, it might not be very helpful to persons living with dementia who may not show any signs of disability.

A further important principle is that of participation and inclusion. Under this principle, it is required that *positive steps* are taken to remove any barriers and provide access to information, among other things. This is significant because it might be understood to mean that businesses must take positive action to assist persons living with dementia to ensure they are fully included and able to enter into contracts with sufficient understanding.

For businesses in certain industries that are aware of a person's disability, this is already strived for to some extent. For example, the Financial Conduct Authority provides guidelines which require businesses and organisations regulated by the Financial Conduct Authority to assist 'vulnerable' consumers in their interactions with them, by providing more time, assisted decision-making and even reviewing the recommendations given in terms of risk, reward and accessibility of funds.[140]

The Financial Conduct Authority, which has examined the issue of vulnerability in much detail,[141] identified that if left unchecked, businesses could cause harm to vulnerable consumers in a multitude of ways,[142] such as "*stress and anxiety; financial detriment…, a debt spiral, or inappropriate purchases; and, wasted time spent in resolving issues.* [143]

To counter these issues, businesses have sought to put in place guidance, guideline and standards that are self-drafted and self-regulated.[144] These voluntary standards and good practice can be helpful to consumers in vulnerable situations, when businesses are alerted to the actual vulnerability

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[140] Financial Conduct Authority (2015) *Occasional Paper No.8 Consumer Vulnerability in Financial Services*, available at https://www.fca.org.uk/publication/occasional-papers/occasional-paper-8.pdf, last accessed on 14 February 2021.

[141] See also Chapter 3.

[142] See Also Section 6.4 on the efforts made by businesses and related organisations through 'soft law'.

[143] Financial Conduct Authority (2015) *Occasional Paper No.8 Consumer Vulnerability in Financial Services*, at 29.

[144] See limitations of self-regulations in Section 6.4.

of a consumer in their interactions. The aim of any such industry-proposed guidelines is to ensure all transactions with consumers deemed vulnerable are carefully considered, leading to a satisfactory outcome for both business and consumer. Examples of these are the Financial Conduct Authority Occasional Paper[145] and the British Standard 18477 for identifying and responding to consumer vulnerability.[146] Whilst these guidelines and recommendations may be helpful, they are not law.

In addition, an *invisible* disability is not clearly protected under these standards or guidelines. This is an issue, as many disabilities including dementia may be imperceptible to businesses and other organisations transacting with consumers.

As a result, it is suggested that in order to consider the position of the person living with dementia, the question of capacity in the context of disability must be explored in more detail. Where the person has capacity under the Mental Capacity Act, they might nevertheless find it harder to exercise their decision-making capacity because of their disability.[147]

For the purposes of this research, focus will be on Article 12 (*Equal recognition before the law*) of the CRPD, which relates to recognition of a person's right to make decisions. Article 12 links back to the concept of autonomy, which in this context, encompassed both "*on the one hand, freedom from discrimination in the recognition of legal capacity and, on the other hand, autonomy and respect of the human dignity of the person*".[148] Hall[149] points out that any "*differential legal treatment on the basis of mental*

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[145] ibid.

[146] British Standards 18477 (2010) *Fair, flexible services for all*, available at <https://www.bsigroup.com/LocalFiles/en-GB/consumer-guides/resources/BSI-Consumer-Brochure-Inclusive-Services-UK-EN.pdf>, last accessed on 14 February 2021.

[147] i.e. the area where a person has mental capacity but might not in practice have the capacity to understand the complex contract.

[148] Arduin, S (2019) 'Art.3 General Principles' in Bantekas, I., Stein, M.A. and Anastasiou, D. (eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* Oxford University Press, 84-105, at 93.

[149] Hall, M. (2019) 'Relational autonomy, vulnerability theory, older adults and the law: making it real' *Elder Law Review* 12(1): i-xxii, at vi.

disability (including impaired decision-making ability) [is characterised by Article 12 of the CRPD] as a form of discrimination contra to fundamental human rights principles".

Under the CRPD, capacity is not defined. Instead, rather than making the distinction between those that have and those that do not have capacity, the CRPD states in its Article 12 that everyone is entitled to *legal* capacity.[150] By providing that "*persons with disabilities have the right to recognition everywhere as persons before the law*",[151] the CRPD confirms each person's legal standing.[152] As seen in Chapter 3, the ability to make choices is sometimes diminished in practice for people with cognitive impairment.

Devi et al. point out that "*In relation to the interpretation of Article 12, most jurisdictions have incorporated substitute decision-making (e.g., guardianship) rather than supported decision-making in their legislation. The best interpretation of Article 12 requires a supported decision-making model.*" [153] It is indeed the supported decision-making model as set out in Article 12 that this thesis wishes to highlight.

Any reduction of their ability to make decisions (which includes decisions made with the support of others) would be contrary to their right under the CRPD to be recognised equally in all aspects before the law. The standing and status of the person before the law must remain equal, no matter what impairments affect the person.[154]

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[150] Series, L. and Nillson, A. (2018) 'Article 12: Equal Recognition Before The Law' in Bantekas, I., Stein, M.A. and Anastasiou, D. (eds) *The UN Convention On The Rights Of Persons With Disabilities: A Commentary.* Oxford University Press.

[151] CRPD Article 12.1.

[152] Naffine, N. (2003) 'Who are Law's Persons? From Cheshire Cats to Responsible Subjects' *The Modern Law Review* 66: 346-367.

[153] Devi, N. Bickenbach, J. and Stucki, G. (2011) 'Moving towards substituted or supported decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities' *Alter* 5(4): 249-264, at 249.

[154] Minkowitz, T. (2017) 'CRPD and transformative equality' *International Journal of Law in Context* 13(1): 77-86.

In addition, Article 12 states that "*persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life*".[155] Here, it is important to note that Article 12 refers to 'legal capacity' of each person. Legal capacity can be defined as the capacity to both hold rights and to act/exercise those rights.[156] Denying legal capacity equates to "*negation of both the right to personhood and the capacity to act*".[157] Denial of legal capacity questions at its core the status of the person so denied. As Harding points out, the "*aim embedded within Article 12*" is that "*shift towards recognising relationality in law*".[158] Article 12 seeks to ensure that all persons are able to live freely and with dignity. This includes having the freedom and (relational) autonomy to make one's own decisions.

Legal capacity also incorporates the right to act, i.e. to have the choice to make, change or terminate legal relationships, agreements and contracts, that is particularly relevant to this research and related analysis. The UN committee considered the assessment of mental capacity to determine legal capacity, and in their General Comment No. 1[159] made it clear that it was not possible to "*accurately assess the inner-workings of the human mind"* and that consequently *"mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon*", but rather *"is contingent on social and political contexts".*

Arstein-Kerslake and Flynn summarise the distinction between these concepts.

> *Legal capacity is a legal recognition. That recognition is not dependent upon the individual's 'mental capacity' – or decision-making ability. …*

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[155] CRPD Article 12.2.

[156] Cifuentes, S. et al. (2008) *Legal Opinion on Article 12 of the CRPD*, available at https://disability-studies.leeds.ac.uk/library/author/legalopiniononarticleofthecrpd/, last accessed on 14 February 2021.

[157] ibid.

[158] Harding, R. (2017) *Duties to Care: Dementia, Relationaliy and the Law*. Cambridge University Press, page 37

[159] CRPD Committee, 'General comment No 1 (2014) Article 12: Equal recognition before the law' in *UN Doc CRPD/C/GC/1* (19 May 2014), paragraph 15.

> *[Legal capacity] simply recognises that regardless of perceived or actual decision-making ability, every individual has a right to be respected as a full person before the law with rights, responsibilities and agency – this is the right to legal capacity on an equal basis.*
>
> *It is the conflation of these concepts that has led to the widespread denials of legal capacity to individuals with disabilities around the globe. Individuals are judged as lacking mental capacity and therefore their legal agency and legal personhood is removed through the denial of legal capacity.* [160]

This short summary explains why the UN's guidance states that mental capacity assessments should not impact on legal capacity. Mental capacity must be assessed in the context of the laws of the relevant state (laws which will be shaped by social and political contexts). In the UK, the Mental Capacity Act discusses not legal capacity but mental capacity.[161] In other words, restriction of any legal capacity in UK law can only incur on the basis of whether the person is legally able to make a decision, not on whether they have the mental capacity to do so.

Article 12.3 provides that in order to allow a person to exercise legal capacity, where necessary, support should be provided to achieve this goal. [162]Article 12.4 refers to decisions made on the basis of will and preference, which

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[160] Arstein-Kerslake, A and Flynn, E (2016). 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law' *The International Journal of Human Rights* 20(4): 471-490, at p. 475

[161] As a side note, in it interesting to note that whilst the Act is named *Mental* Capacity Act, throughout the text of the legislation itself, reference is simply to 'capacity', rather than 'mental capacity'. In doing so, it seems that legal capacity is implied, and that consequently, the only question is whether a person is able to practice their rights, duties and obligations under the law, taking into account their *mental* ability or inability by considering some "*impairment of, or a disturbance in the functioning of, the mind or brain*" (Mental Capacity Act 2005, s. 2(1)**).**

[162] The Committee on the Rights of Persons with Disabilities, in its General Comment No. 1 – Article 12: Equal Recognition Before the Law, paragraph s17 and 18, highlights that such support can be either formal or informal, allowing for family members to step in to support the person living with disability.

allows the person to autonomously, with the support of others, make decisions. This reflects the concept of relational autonomy discussed in Chapter 3, allowing a person to exercise their right to choice and self-determination. [163] It is this relational approach that can demonstrate "*how the universal right to legal capacity in Article 12 might be framed in domestic legislation, through a 'support model' of legal capacity*". [164]

Examining the Mental Capacity Act in detail, it appears that concepts of support have been translated into UK law. The Mental Capacity Act does provide a presumption of capacity, outline a test for lack of capacity in situations where there may be a doubt, and give detailed information about how assisted or supported decision-making should work. However, as stated by Harding and Tascioglu,

> *whilst the MCA is a helpful legal framework for supporting everyday preferences, it has not yet been able to catalyse a shift to supported decision-making in relation to wider life choices or complex decisions* [165]

In relation to the more complex matters, UK legislation may be seen to be at odds with the CRPD in that is certain cases it allows for substitution of decision-making, when it is felt that the person with disability can no longer make a decision due to lack of capacity.[166] Harding and Tascioglu suggest that it is

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[163] See Section 3.4.

[164] Arstein-Kerslake, A and Flynn, E (2016). 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law' *The International Journal of Human Rights* 20(4): 471-490, at 472.

[165] Harding, R and Tascioglu, E (2018) 'Supported Decision-Making from Theory to Practice: Implementing the right to enjoy legal capacity' *Societies* 8(2) 25: 1-17, at 11.

[166] Series, L (2015) 'Relationships, autonomy and legal capacity: Mental capacity and support paradigms' *International Journal of Law and Psychiatry* 40: 80-91.

> *the MCA's decision-specific approach, underpinned by the functional assessment of capacity allows and indeed facilitates the drive towards substitute decision-making for more complex matters*. [167]

Distinction between substituted and supported decision making is significant, especially for the person living with a disability themselves. [168] In the discussions leading to the CRPD, the International Disability Caucus (a group representing the various disability organisations involved in the drafting of the CRPD) explained it as follows:

> *The difference between supported and substitute decision-making is that, in a supported situation, the person with a disability is at the center of the discourse. The premise of supported decision-making is that it ranges from zero to 100 per cent and is a dynamic concept*.[169]

The UN Committee, in their General Comment No. 1 made it clear that supported decision making would also include 'proxy' decision making, i.e. decision making by a party in place of the party, as long as they did so, making all decisions for the person based on the 'best interpretation of will and preferences' rather than a 'best interests' standard.

Series describes 'supporters' as those who "*helping them to obtain and understand information relevant to the decision, talking through the pros and cons of different available options, or helping a person to communicate with*

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[167] Harding, R and Tascioglu, E (2018) 'Supported Decision-Making from Theory to Practice: Implementing the right to enjoy legal capacity' *Societies* 8(2) 25: 1-17, at 14.

[168] ibid.

[169] As described by Series, L. and Nillson, A. (2018) 'Article 12: Equal Recognition Before The Law' in Bantekas, I., Stein, M.A. and Anastasiou, D. (eds) *The UN Convention On The Rights Of Persons With Disabilities: A Commentary.* Oxford University Press, referring to UN Convention on the Human Rights of People with Disabilities, Ad Hoc Committee - Daily Summaries, Daily summary of discussion at the seventh session 18 January 2006, 8(3), available at https://www.un.org/esa/socdev/enable/rights/ahc7sum18jan.htm, last accessed 11 September 2021.

others”.[170] She suggests that this support model is different under the CRPD and the Mental Capacity Act, in that the CRPD considers support “*in a much more holistic way*” allowing for the provision of assistance in “*any areas of decision making where a person wants support*”. [171]

The Mental Capacity Act uses the ‘best interests’ model. This is an important distinction. Where the decisions are based on the will and preferences of the person lacking capacity, the decision can still be one that might not be in their best interests, seen from certain angles. For example, in terms of end-of-life treatment options, decision options might be at opposite ends of the spectrum, with a person’s will and preference opting to forgo further treatment, whist such treatment may, medically, be in the best interests of the person.

The courts have however made it clear that ‘best interests’ must include the views of the person lacking capacity.[172] Harding provides as an example of a relevant case Aintree v James in which Lade Hale stated that “*The purpose of the best interests test is to consider matters from the patient’s point of view*”.[173]

In consumer matters as well, this form of support, where the person living with dementia makes the final decision, must also be implemented. For the consumer living with dementia, support would allow them to further weigh up aspects that they had not been able to consider, or simplify choices and options. It does not preclude a person making a decision that the supporter, looking at best interests, would not have made. Participants of this research

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[170] Series, L. (2015) ‘Relationships, autonomy and legal capacity: Mental capacity and support paradigms’ *International Journal of Law and Psychiatry* 40: 80-91, at 85.

[171] ibid., at 85.

[172] Harding, R. (2017) *Duties to Care: Dementia, Relationality and the Law.* Page 28 Cambridge University Press

[173] Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 at [45].

highlighted this in practice, when assisting their family members living with dementia.[174]

For consumers living with dementia, concerns in relation to consumer transactions will not usually be about substitute decision-making (i.e. someone else making a consumer purchase in their place), or about supported decision-making. In fact, where the consumer with dementia is supported, there is less danger of a contract being entered into unwisely due to a lack of understanding.[175] Instead, for consumers living with dementia, it will often be the case that no supporter is available at the moment of entering into a contract. This was highlighted by this current research. Participants often talked of their ignorance of consumer contracts entered into by their family members living with dementia. The person living with dementia had in most cases acted alone, without any support or help. It was only much later, when sums were debited from bank accounts or unwanted goods appeared, that the issues became apparent. [176]

Often in academic literature,[177] as well as the legislative texts themselves,[178] capacity to make decisions is considered in terms of care or treatment. However, Article 12 and the equal recognition before the law principle highlights that the state must ensure that all persons, including disabled persons, can manage their finances independently, be that in terms of

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[174] In Section 8.3 Nicole's describes how she and her brother wanted to check their mother's will and preference, rather than making a decision in her best interests for her, in relation to a recurring subscription to a lesser-known cancer charity. They would not have chosen to make those payments, it was not necessarily in their mother's best interests, but they simply explored and then respected her final decision on the matter.

[175] An example of this is illustrated in the description of Kate and her husband, who was living with dementia. In Section 8.2 Kate talks of her supporting intervention at the moment of contract creation leading to a better outcome for them as a couple.

[176] For example, in Section 8.2 Mary's account of her mother's subscription to a book club demonstrates how easily the person living with dementia may be persuaded to enter into a contract unbeknown to those that seek to assist and support them in such tasks.

[177] for a recent overview of literature on capacity in treatment matters, see Lee M. and Wang K. (2020) 'Assessment of Capability and Capacity' in Chun A. (ed) *Geriatric Practice*. Springer.

[178] e.g. Mental Capacity Act 2005, s. 5.

property owned, sales and purchases, as well as access to financial products and services, such as loans, mortgages or investments.[179]

This is significant, because as discussed in Chapter 2, well-being and quality of life will to some extent also be dependent on one's ability to live independently, including financially independently. The more financial restrictions a person faces, the more other aspects of their lives will also be reduced or restricted (including choices of where and how to live, what treatments to have, what consumer choices to make). This is why the right to own property is a fundamental human right.[180]

As seen in Chapter 5, there is much academic research on the difficulties encountered by some persons with cognitive impairments, such as some persons living with dementia, to understand financial concepts.[181] Consequently, a person living with dementia might have a harder time, comparatively to the 'average person', to understand and make financial choices. This is important and highlights that current consumer legislation, which protects the average person, is inadequate for vulnerable consumers, such as consumers living with dementia. These discrepancies will vary considerably depending on internal and external factors affecting the person with impairment.

As a result, it is important to consider these issues carefully to ensure avoidance of financial harm to a person with disability. The difficult but important question is then if any protective measures should be general or specifically target certain groups of people. So far, in the UK, the provisions to deal with this are limited to general provisions for consumers, by increasing their rights and prohibiting certain sales methods or forms of marketing. Furthermore, termination provisions have been strengthened.[182] However, again these general provisions for consumers relate purely to the average consumer. This monolithic view of the consumer is however neither realistic

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[179] CRPD Article 12.5.

[180] Universal Declaration of Human Rights 1948, article 17.

[181] See Section 5.3.

[182] e.g. Directive Concerning Unfair Business-To-Consumer Commercial Practices In The Internal Market (2005) 2005/29/EC, Articles 5-9.

nor helpful. It follows that under current law, the basis for intervention is the transaction rather than the consumer. This is not sufficient and further protection is required for consumers that do not fit the mould of the average consumer.

Article 12.5 focuses on more targeted positive duties for persons with disabilities.

> *Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.*[183]

Such *appropriate and effective* measures would ensure not only that people living with disability can make these decisions, but that they are given additional (legislative or practical) support to ensure they have access (subjectively) equally to the same financial services and products and can enter into contracts, including consumer contracts, as would any other consumer.

One concern with such a targeted approach would be that again how this is categorised and which parties might fall outside of any definition or be unaware that they can be identified as being part of a specific (protected) group because they are not diagnosed. Consequently, general provisions that work for all, including persons with disabilities, may be more effective.

7.4 Concluding remarks

This chapter has critically considered the adequacy of the various remedies that are available currently as well as those that might be available to the consumer living with dementia.

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[183] CRPD, Article 12.5.

In relation to remedies that were clearly available, these could be classified as rules that implicitly recognised vulnerability in law. However, even in such situations, this chapter has demonstrated that the remedies are often not far reaching enough to fully protect and assist the consumer living with dementia. Be it capacity law, contract law, consumer law or equality law, none of these fully appreciate the position that the person living with dementia may face when acting as a consumer.

In relation to many of these remedies, the stumbling block for the person living with dementia will be practical, in that they will have to shoulder the burden of proof. This might be in contract law the need to show that, in order for a contract entered into to their detriment to be void or voidable, the other contracting party must have known (or ought to have known) of that lack of capacity.

In relation to vitiating factors, the act of undue influence will usually either involve a degree of malice by one of the contracting parties (with one party intentionally wanting to manipulate the decision-making process of the other to their advantage), or relate to a contract entered into between parties where one had a fiduciary duty towards the other. Where neither of these elements is present, the person living with dementia will be required to demonstrate their state of mind, i.e. their trust and confidence placed in the sales person, which may be difficult to prove after the event.

Where it is not the burden of proof that makes the remedy less accessible to the person living with dementia, their cognitive impairment, the very essence of the disease, may hinder protection as foreseen by the legislation. Consumer law is designed to protect the consumer in their transactions with businesses; however, the consumer targeted by the legislation is the ‘average consumer’ [184] rather than the vulnerable consumer. This chapter has demonstrated that these protections designed around the notion of full disclosure are of lesser value for the consumer living with dementia where comprehension and understanding was reduced due to cognitive impairment. Similarly, rules on permitted cancellation within a pre-defined window of time

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[184] Consumer Rights Act 2015, s. 64(5).

might also not be helpful to the consumer if, due to memory loss, the person has forgotten that a contract was entered into, or that they have 14 days to rescind the contract.

Finally, even if the person living with dementia can be defined as having a disability, the provisions of the Equality Act, may not assist fully if the consumer living with dementia has entered into a contract that subsequently is considered unwise, i.e. to their detriment. In fact, the provisions on direct discrimination in relation to the person with dementia, may lead to situations where a business will specifically seek to enter into a contract despite concerns about capacity, in order to not be seen as being directly discriminatory.

As discussed above, capacity is difficult to recognise by medical professionals, let alone by untrained sales operatives within businesses. Consequently situations can arise where a business might want refuse to enter into a contract with a person living with dementia because they believe they do not have capacity to do so, if for example they are displaying signs of confusion, memory gaps or an apparent lack of understanding. However, if the consumer does still have capacity under the Mental Capacity Act, the company's refusal might be considered discriminatory. This example demonstrates the complexity of the situation of the consumer living with dementia.

Furthermore, in relation to 'outlier' remedies, the concepts of unconscionability and good faith remain controversial areas of common law which have not been finally resolved. Unconscionability requires behaviour beyond 'simply lacking'. In most cases were there is no abuse, the required seriousness of the actions of the business party will not be present for such qualification.

Where good faith is a duty of honesty, rather than "*abandoning of self-interest*",[185] businesses in any event must comply with the full disclosure

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[185] Keily, T. (1999) 'Good faith & the Vienna Convention on Contracts for the International Sale of Goods' *Vindabona Journal Of International Commercial Law And Arbitration* 3(1): 15-40, at 16.

requirements of the Consumer Rights Act. The good faith doctrine may not be as fruitful as at first hoped for consumers living with dementia.

In the next chapters, the law is considered in light of daily life. The next three empirical chapters will explore the experiences of persons living with dementia and their families when entering into transactions with businesses.

Chapter 8 Experiences of confusion in relation to capacity

8.1 Introduction

The next three chapters analyse the findings from the interviews conducted with persons living with dementia, their family members and carers, and charity representatives, in order to understand the lived experience of a consumer living with dementia. In doing so, the data highlights the inadequacies of the law today. The chapters broadly follow the lifecycle of a contract, starting with the point of entry, i.e. the initial meeting between two contracting parties, then considering the obligations of the respective parties throughout the life of the contract, before exploring the issues arising at the end of the contract term.

One aspect of paramount importance at the start of the contract is the need to establish that the parties to a contract are indeed able and willing to enter into that contract. Capacity is therefore one of the key components to be considered at the moment when two parties are looking to contract with one another.

As discussed in Chapters 6 and 7, capacity law is set out in legislation and at common law. A fundamental principle set out in the Mental Capacity Act[1] is the presumption of capacity.[2] Where there is doubt as to a person's capacity to make decisions, a four-tiered test to establish capacity, and by inference lack of capacity,[3] is provided in the legislation. This test is then to be applied for each decision to be taken.

However, in relation to everyday decisions and consumer matters, capacity law is often not applied to the person living with dementia as intended. The data from the interviews shows that in many cases family members do not consider capacity as set out in the Mental Capacity Act when caring for a person living with dementia. Instead, issues of safety and protection of both the person and their financial assets mean that the question of capacity is

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[1] Mental Capacity Act 2005, c.9.
[2] Mental Capacity Act 2005, s. 1(2).
[3] Mental Capacity Act 2005, s. 3.

often ignored. These findings therefore show a discrepancy between the law in theory and experiences in practice, and the need for change.

The interview data also demonstrates that the notion of capacity is raised more frequently when family members are seeking to support the person living with dementia formally by ensuring that relevant legal documentation is in place. In these circumstances, where the family seek to record a transfer of powers to the family members (for example by lasting power of attorney), the question of capacity becomes highly relevant. However, a lack of clarity of how to assess capacity and by whom leaves many persons living with dementia and their family members uncertain as to how best to proceed.

Section 8.2 first looks at capacity in practice by considering the position of the person living with dementia. In doing so, the project explores the transitions experienced by the person living with dementia. Beyond any medical (physical and mental) changes, the person living with dementia will experience an evolution from being considered ‘normal’, i.e. without problems or challenges beyond the usual matters affecting most people (i.e. the norm), to being labelled as someone ‘with dementia’.

This transition of the person living with dementia automatically brings about a further change, namely that of the family member. **Section 8.3** explores through the interview data how considerations of capacity also mean that family members experience an evolving role themselves in relation to their loved ones living with dementia. This in turn has a direct effect on how capacity in practice is considered.

In **Section 8.4**, capacity in law is reviewed in light of the interview data by exploring how, when and by whom the law is applied in day-to-day life. Using lasting powers of attorney[4] as an example of when people will seek assessment of capacity, this project then analyses *why* assessment is sought

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[4] These lasting powers of attorney are described in the Mental Capacity Act 2005, ss. 9-14, and relate to documents that transfer powers to named third parties make decisions for the signatory of the document, in relation to health or financial matters in specified circumstances (i.e. either immediately once signed, with further consent, or once capacity is lost). See also Chapters 6 and 9 herein.

in such specific cases. The experiences of those who have requested assessment of capacity highlight the concerns, the variety of choices and the challenges encountered.

Finally, the practical question of *who*, be it family members or professionals such as doctors or lawyers, is best placed to assess capacity is considered in **Section 8.5.** The empirical data shows a wide range of practices in relation to who is most suited to perform such assessment. These experiences show the confusion and the difficulties experienced in relation to capacity matters. **Section 8.6** finally provides concluding remarks on the issues raised.

8.2. Experiencing the transition "from normal to symptomatic"

Changes due to dementia are often so gradual that it is very difficult, even for close family members, to identify when the illness first took hold. As Chick and Meleis point out, *"adjustment to slowly occurring change may be so gradual as to be almost imperceptible"*.[5] While external events, such as a diagnosis of dementia, are clearly identifiable,[6] the transition undertaken by the person with the illness is an internal process, effectively "*a passage from one life phase, condition or status to another*".[7]

In the interviews conducted for this research, many reported that they were not sure when the first events occurred that could be identified as being due to cognitive impairment. Instead, many family members at first thought the behaviour of their parent or spouse could be explained by age, character traits, eccentricities, or external circumstances.

Irvin's mother, who lived with dementia,[8] had become a widow and had to deal with the finances for the first time in her life. With hindsight, Irvin believed

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[5] Chick, N. and Meleis, A.I. (1986) 'Transitions: a nursing concern' in Chinn, P.L. (ed) *Nursing concern methodology*, Boulder CO Aspen, 245.

[6] Meleis, A.I. (2015) 'Transition theory' in Smith, M.C. and Parker, M.E. (eds) *Nursing theories and nursing practice*, 4th edition. FA Davis Co.

[7] Merriam-Webster dictionary definition of the word 'transition', available at https://www.merriam-webster.com/dictionary/transition, last accessed on 14 February 2021.

[8] The family members participating in this project spoke warmly about their loved ones with dementia, both where the person with dementia was still

this might have also been a time when first symptoms of dementia became visible, although he did not realise this at the time.

> *Irvin: I think she was of the generation that the husband/father was in control of the finances. … And to cut a long story short, [when my father died he left her all his assets.] Now that sort of money completely freaked my mother out… I think she felt very vulnerable at that time … she had no confidence when it came to money.*

In the same interview Irvin reflects on when the dementia may have started.

> *Irvin: To go forward a stage, …we sat down with her and some psychiatrist, … and they were trying to investigate when the dementia first started and when her unhappiness kicked in and her depression, which is all related, and it was very much when my father died, her whole world just disappeared.*

The small changes to cognitive function in this case were masked in part by external circumstances, the change of situation of Irvin's mother due to her husband's death.

Mary, whose mother lived with dementia, also expressed how her mother's behaviour changed so subtly, that it was difficult to recognise the symptoms of early cognitive decline.

> *Mary: Yes, my mother had dementia. The process started a long time before we knew. At first we thought that her odd behaviour was part of her eccentricity but then we noticed that she was often confused. And then we noticed that when the post arrived, she would cover it up with tea towels. It was very clear that she didn't know how to cope with things and so she was coping by doing that, by hiding… For example, she had joined a book club and was receiving books by post. And yes,*

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alive, or where they had died prior to the start of the project. To reflect this, the thesis will refer to participants as "[name], whose parent/spouse *lives* with dementia" or "[name], whose parent/spouse *lived* with dementia", to accurately reflect the conversation with the participant.

> *the books started piling up and she was hiding them under the tea towels.*

Mary's account above demonstrates how difficult any identification of the onset of the illness is. The transition is slow and gradual, and goes from the person living with dementia simply being 'Mum', to acting oddly (but still explainable because of perceived character traits), to being confused, to finally not being able to cope. In other words, in the description of her mother's transition, Mary's mother's behaviour goes from being usual (and within the perceived notion of 'normal'), to being symptomatic of something more concerning. The transition was complete when Mary identified her mother as no longer being able to cope – she was deemed, in the eyes of her daughter, to no longer be capable of making decisions independently.

Similar descriptions of the transition of the person living with dementia in the eyes of family members occurred in nearly all of the interviews with family members of people living with dementia. The perceived transition was often delayed because of specific quirks, characteristics, eccentricities or oddities that were associated with their loved ones. Participants said that at first they tried to explain the behaviour as being inherently part of the person, rather than face the possibility of cognitive impairment. For example, for Ursula, whose mother lives with dementia, a diagnosis of dementia was not considered for a long time.

> *Ursula: Well, without going into great detail, my mother has always been quite a difficult person, she has fallen out with various people, relationships within the family have been strained for a long, long time, and so I suppose it is hard to know [when we first noticed signs of dementia]. It was not that we were not in contact with her, but rather, her behaviour is quite erratic anyway. I was thinking, "Gosh, you really can't remember this anymore", but all the other strange, repetitive kind of story-telling, not being able to see a point of view, not being able to relate, was sort of part of her make-up, of who she was.*

Again, Ursula's recollection of her mother shows how difficult it is, even for close family members, to pinpoint the moment where a person may be acting in a way that is influenced by dementia, rather than by character traits.

In these early stages therefore, capacity is not doubted and whilst a person may have a lapse of judgment or make an unwise decision due to the nascent cognitive impairment, their full status, both as person and consumer is unquestioned.

As a *person* with full standing, the person in the initial stages of dementia is able to live independently; their every-day decisions are not queried or reviewed. Their choices are respected, even when family members do not understand these. As a *consumer*, it is their economic rights that remain intact. Their actions as consumers have financial consequences. However, family members at this stage would not suggest that their rights to enter into contracts should be questioned or curtailed in any way. Linking back to Chapter 3, the above experiences highlight how the person living with dementia is seen as able to make their own choices, free to contract and able to do so 'autonomously'. The lack of awareness of any contractual, financial or other risk at the early stages of dementia means that family members will not intervene or offer support in the decision-making process.

It is only after a certain period of time, when actions are taken or omissions identified that seem more significantly out of line to what otherwise would be considered 'normal', that family members start to question if the behaviour of their loved one is now symptomatic of an illness or an impairment that needs to be addressed.

> *Rose, whose husband lived with dementia: He went on making decisions, but they became erratic and illogical. I mean, there are lots of times when I said to him, "But that is not very logical. Why on earth would you want to do that?" And he would get quite annoyed with me.*

During this period of transition,[9] most persons will continue to be living independently, and at least for a while will be undiagnosed. Given that the transition from ‘normal’ to ‘symptomatic’ is gradual, subjective and difficult to identify accurately and precisely, it is instead the relationship between the person living with (undiagnosed) dementia and the family members that will determine the identification of any issues.

Family members who live in close proximity to the person with (undiagnosed) dementia, and therefore see them and their actions regularly, may question certain behaviours and seek medical help earlier, to determine what has brought on some of the recognised changes in attitude, ability and character, whilst more irregularly visiting family members will accept the relationship as unchanged for much longer.

Jane and other family members were in regular contact with Jane’s mother, who lived with dementia. This meant that they sought a diagnosis relatively early on:

> *Jane: No, what happened was that, actually she had, before she had the medical condition, before she went to hospital, her memory wasn’t so good, but we just put that down to old age because she was in her early 80s, actually late 70s, and because she wasn’t coping at home very much, the family had to help a lot with housework… We were aware that her memory wasn’t so good, so we got her down to the doctors’ and the doctor said, “Right, I think it might be best if we do a dementia test”, and so they got somebody from the mental health team to come out.*

In contrast, Garry was living far away and was only able to visit once or twice a year. He would speak to his mother, who is living with dementia, from time to time on the telephone. He was only made aware of his mother’s illness when her doctor made contact with him.

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[9] A detailed description of the stages of dementia is set out in Appendix 7.

> *Garry: OK, well I will start with my mother, she is 77 years old and she, until a few years ago, she was living alone in [name of location redacted; over 300 miles away from Garry] where she was getting care through carers as well as her doctor. Then a couple of years back the doctor decided that either she needed to go to a care home or move closer to her family, so because we felt that she did not yet want to go to a care home, we moved her closer to us.*

The subjective way in which family members view the transition from 'normal' to 'symptomatic' will have a direct effect on capacity questions in practice, both as a person and as a consumer. This determination of capacity in practice will for example have an impact on fundamental liberties, such as restrictions on where to live, how to live, and what treatment to undergo.[10] However, it will also extend beyond these questions to financial and consumer considerations, such as what money may be made available, what transactions are deemed acceptable, and how money is to be spent by the person living with dementia. It is at this stage that their ability to make decisions alone will be questioned. As was discussed in Chapter 3, the person living with dementia will want to continue to make their own choices. Family members however will feel that it is important to support the person living with dementia. As a result, the relationship between the parties is significant and will impact on the choices made. Here, autonomy can be seen to be relational, subject to the interconnected family links.

Part of the context will be the determination of a person's capacity in practice. Family members will consider whether their relatives living with dementia are able to make decisions (including decisions in relation to consumer and other financial matters) themselves, or whether they consider their status to be reduced. The interviews show that family members were able to assert their views of perceived capacity on the person living with dementia and could even impose their perception of the person's standing on third parties,

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[10] See Section 2.3 for an explanation of what is included in the term 'fundamental liberties'.

including other family members or businesses that might be interacting with the person living with dementia.

For example, Kate, whose husband lived with dementia, described how she felt her husband was no longer able to make decisions independently, forcing her to take over day-to-day and financial affairs. This also meant she would discourage businesses from communicating with her husband.

> *Kate: …with the wine club, again, he spoke to them on the phone, but then I also spoke to them… in fact, once I told them that my husband had Alzheimer's, they stopped immediately. That worked. They were very good about it.*

This demonstrates that capacity in practice is not assessed in any formal or professional way, but rather is determined by family members in an attempt to allay any perceived risk or unwise behaviour. In the eyes of family members, the worry about their loved ones being taken in by fraudsters or making unwise decisions is justification for overriding their express wishes. Family members will at this stage consider the person living with dementia in context, taking into account internal and external circumstances. Whilst the person living with dementia remains able to make decisions, family members will support them in doing so. This highlights the relational aspect between these parties. In some cases however, family members may seek to remove the freedom of choice. Whilst these restrictions are done with their best intentions at heart, this highlights the fine line between supported decision-making and substituted decision-making, as discussed in Chapter 7.[11] For complex decisions, the data suggests that family members might substitute their decisions for those of the person living with dementia, in an attempt to protect them either physically or financially.

This limitation of freedom of choice of the person living with dementia is the result of the revised view of who they have become (i.e. transitioned into) in the eyes of their family members. This demonstrates the challenges faced by family members and persons living with dementia in identifying when a person

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[11] See Chapter 7, Section 7.3.

living with dementia is in need of legal or practical assistance and support. It is this lack of clarity, brought on by the development of the illness itself, which means that current legal safeguards are difficult to apply early on.

During that same time period, a second parallel evolution takes place; family members will assign revised roles to themselves. As with the person living with dementia and their (perceived) transition from ‘normal’ to ‘symptomatic’, the family members will find themselves evolving at a similar pace, be it in the opposite direction.

8.3 Experiencing the relinquishing of control

Positions within families shift and new roles emerge, not only for the person living with dementia but also for their loved ones. As pointed out by Turner, *“Roles are continuously constructed and reconstructed as individuals engage in role-making in the course of interaction with incumbents of alter roles…”*.[12] These perceived transitions are brought on by the changing environment. In other words, the transition is the result of a series of specific events, as well as experiences and influences that the family member is subject to.[13]

Meleis explains the differences between events, experiences and influences. *Events* may be punctual, visible, external signs of the illness, such a medical diagnosis, a visit to a hospital, or a discussion with a neurologist. Conversely, *experiences* relate to the interactions with the person living with dementia, and subsequent recognition of memory losses, uncharacteristic behaviour, or a loss of skills or abilities. Finally, *influences* may be societal, cultural or organisational, such as the perceived pressure to act in a protective, caring and dutiful way towards a parent, spouse or other family member in this situation. The interviews conducted as part of this thesis cast new light on these transitions in a legal context.

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[12] Turner R.H. (2001). *Role Theory*. In: Turner J.H. (eds) *Handbook of Sociological Theory. Handbooks of Sociology and Social Research*. Springer, Boston, MA.

[13] Meleis, A.I. (2015) *Transition theory*. in Smith, M.C. and Parker, M.E. (eds.) *Nursing theories and nursing practice*, 4th edition. FA Davis Co.

Consequently, in parallel to participants' views on the evolving nature of the person living with dementia, they recognised their own transition from having a certain role as a specific family member (such as daughter, son, spouse) to taking on a different role (such as carer, assistant, attorney) and even feeling a complete reversal of roles within the family relationship.

For example, a grown-up child might look at their parent with dementia and over time see themselves taking on different roles: First, they might be acting as daughter or son, simply observing the parent's decision-making behaviour. In this phase the roles are still firmly as they always were. The daughter or son might raise an eyebrow or make a comment when they think their parent is acting in a somewhat unusual way, but leave decision-making with the parent.

> *Vaughn, whose father lived with dementia: He carried on the same, his personality didn't really change. He was always quite tight, that did not change. What happened was he became quite paranoid about bills coming in.*

Vaughn's description of his father living with dementia indicates that at first, whilst aware of some changes in behaviour (here, a certain paranoia), their relationship as father and son did not change because of the diagnosis. The father '*carried on the same*', with the son simply observing his parent's decision-making.

Oscar also did not realise at first why his parents' attitude was changing:

> *Oscar, whose parents both lived with dementia: They thought, they thought people were after their money. Looking back now, because we didn't get the diagnosis until my mum was living with us, we now know what the warning signs are. I think if we had been better equipped, more experienced some years earlier, we would have stepped in much more and put more help in place. Looking back, there were times when it was funny, and times when it was quite heart-breaking. And I got quite angry with myself, because I got quite angry with them. You know, a bit of self-beating over the head, [saying to myself,] "You could*

> *be more patient, you could be more tolerant." Not knowing, I just thought they were being bloody-minded.*

Again, Oscar's description of his relationship with his parents in the earlier stages of the illness shows that he felt that the roles of parents and son were firmly entrenched. As their son, he did not think to put help in place for his parents, but accepted their behaviour as it was, putting it down to stubbornness. In these instances, the decision-making of the person with dementia is not at all questioned. Their status and standing remains clearly that of the independent parent, able to make decisions, even if over time these appear more unusual or unexpected. Capacity in practice is not hampered in any way at this stage.

Next, the (grown-up) child as active carer, stepping in to support or assist with decision-making, will try to oversee spending and other decisions:

> *Nicole, whose mother lives with dementia: Yes, she was accepting [of my brother's and my help]. We had the power of attorney sorted out soon after her diagnosis. We were doing quite a lot for her anyway, with her consent. For example, the shopping, I would do the shopping and then put things right. You see, I have a little notebook and will keep careful accounts.*

Nicole further described how she and her brother wanted to make sure her mother was protected, but that her wishes were taken into account at all times.

> *Nicole: The other thing that we were a bit concerned about was, as I said, my brother dealt with her finances, and he noticed that there was a direct debit which was started up, that was going to a charity. I don't really know, but we are pretty sure that that came through the telephone. Because at that stage I don't think Mum would have been able to fill in a form and put it in the post. So we were pretty sure that that had happened. Someone had phoned her. So my brother discussed this with her, because it was not one of the more well-known cancer charities, but he did discuss it to ascertain really whether she*

> *wanted to go ahead with that, you know, because you know, if she wanted to, then that was fine. It was just, again, we wanted to be sure this was what she wanted.*

This is a good example of someone taking on this new role as assistant or supporter to the principal decision-maker. Beyond simply being a grown-up child observing their parent's behaviour, they transition into a son or daughter as carer, who takes on a more active role to support with decision-making and verify that previous decision-making was done with full understanding. In this case, Nicole's mother retained her freedom to make her own choices, supported by family members.

Whilst vulnerability is recognised in these instances, it does not result in the grown-up child taking over. Instead, the understanding of their parent's more vulnerable state is translated into the desire to learn about their wishes and take into account the choices made by the person living with dementia. Their freedom to make decisions is not questioned or diminished in any way. Instead, because the son or daughter in a supporting role recognise the full standing and status of the person living with dementia, they take positive actions to ensure that all wishes, opinions, choices and values are taken into consideration.

In the final stage, in many cases, the vulnerability of the parent living with dementia, as perceived by their grown-up children, is likened to the vulnerable state of an under-age child. This infantilisation of the person living with dementia leads in practice to a removal of their full personhood and therefore the removal of the presumption of their capacity. Consequently, the roles appear to be reversed, with the grown-up child acting as a parent to the person living with dementia, and intervening more directly and taking over some (and in some cases eventually all) of the decision-making.

For example, Mary, when talking about the decision by her and her siblings to put their mother into a home against her wishes but for her protection, stated, *My advice to everybody now is, "Just be brave, you're their mother now".* Her mother's capacity to make this decision was not consciously considered.

Instead, by looking at their parent as a person who needed to be ‘mothered’, i.e. cared for, protected and controlled for their own good, capacity in practice was removed.

This thought process was reflected by a number of other participants, such as Lauren, whose mother lived with dementia.

> *Lauren: That [taking over a parent’s decision-making] is very difficult. And it is a changing relationship, you know, you become less like a daughter and become more like the mother as time goes on.*

Lauren recalled a significant event that made her realise that she now needed to take on a more controlling role within the relationship, following an incident with a door-to-door business describing themselves as ambulant gardeners.

> *Lauren: There was an occasion where I happened to arrive at my mum’s house, and she was busying about. There were two men in the back garden and she said, “Oh, I could do with the hedges cut”. So they had been out in the garden for about half an hour, and this huge man came to the back door wanting his money. And I said, “What have you done?” And they said, “Oh, we cut the hedges”. And I said, “Well, where are all the clippings?” “Oh well, we put it in the van.” “Okay, right’”[sarcastic tone], I said. And Mum comes into the room with the cheque book and says, “How much did you say that was?” “Well that, my dear, for what we’ve done this morning, that’s £500. We’ve got two of us and we’ve worked really hard all morning and we are taking it all away”. “Okay”, she said. “Well, if I sign it [the cheque], perhaps you could fill it in”, she said.*
>
> *So I said, “I don’t think so”, I said. “I’d better have the cheque-book”, I said. But she’d already signed a blank cheque. Those fellows kept saying, “Well, this is a contract we entered into with your mother”. And I said, “Well, I cannot see that you’ve done anything and you are certainly not having any money”. He said, “I demand my money”. But I can be quite firm and I said, “You might be demanding your money, but you are not getting it. I don’t care what you want. Just wait a bit, my*

> *husband has power of attorney and I will ask him to come and we can discuss this together".*
>
> *But he and his friend just went like that – whoosh - and went down the road. And I said to Mum, "You can't have people like that come to your house". And that was the day I had to take the cheque book off my mum. And I explained to her, "The reason why is that you never know what someone might do or take. So that is why I took the cheque-book away".*

This demonstrates that in practice, with new responsibilities taken on as they see their parent living with dementia struggle or make (perceived) unwise decisions, family members feel compelled to intervene to some extent on behalf of the person living with dementia. Ascertaining where the right level of intervention should lie is left to the family member. In this situation, freedom of choice may still be achieved for other types of decision that the person living with dementia will face in her daily life. It is only in relation to financial decision-making that the supporter will feel that they need to step in with greater support to protect the person, given the context and circumstances surrounding the person living with dementia.

On the level of intervention and timing, a charity worker at Age UK summarised the situation as follows.

> *Charity worker: Yes, what I find is that some families have almost, have disempowered their older generation by, too soon, taking control of those things. But for others, they have held back longer than would have been helpful if the person had agreed to help. So it is very difficult for families to know, even if they have the capacity to help. It is hard for them to know when to step in, and obviously there must be an acceptance by the other person who may in fact, especially with dementia, get more and more resistant to help.*

A consequence of this change of role is an increase of responsibility taken on by the grown-up child for their parent. This demonstrates how family members or carers understand the effects of the illness and perceived lack of legal remedies available to the person living with dementia.

In addition, this change results in a revision of the grown-up child's understanding of the status and standing of the person living with dementia. By reducing the position of the parent living with dementia to the equivalent position of a minor, some of their rights to act and decide are removed in practice. This leads to a loss of freedom to make their own choices, accepted by the caring family members as a necessary step to protect them and their finances, but to the detriment of the person living with dementia, who may not want to see their standing reduced or not understand why their choices have been lessened in this way.

In some of the interviews, family members talked openly about their struggles to come to terms with denying their parents' capacity. When observing others take over, they felt powerless to intervene. For example, Irvin describes the relationship between his older brother and his mother, who was living with dementia:

> *Irvin: He [my older brother] felt he was in charge of the family and I would say he bossed Mum about… I can see why he was doing it, he thought he was being kind and helpful, but he wasn't really. It was the wrong thing.*

In contrast, in some circumstances a presumption of capacity may lead to difficult situations for the person living with dementia, if they are left to make their own decisions. These decisions may be in relation to their well-being (their choices of home, treatment, care), but also in relation to their consumer choices.

Indeed, the House of Lords Select Committee,[14] reviewing the Mental Capacity Act, considered the issue of presumption of capacity and highlighted

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[14] House of Lords Select Committee on the Mental Capacity Act 2005. (2014) *Mental Capacity Act 2005: Post-Legislative Scrutiny*. HL Paper 139, para 110, available at

this difficult balance to strike. The Select Committee concluded that *"The presumption of capacity… is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm."*[15]

This was the worry of several of the family members participating in this research. For example, Jane talked about the conflict of position in relation to capacity between social services and herself as daughter of a person living with dementia. Whilst the social worker felt her mother still had capacity to make decisions about where to live, Jane was most concerned about the risks of living at home alone.

> *Jane, whose mother lived with dementia: [When my mum was in hospital following a stroke] we had the social worker involved who said, "Oh, I don't think you are well enough to go home" and my mother said, "I want to go home, I want to go home, like now." And the social worker said, "Right, we will let you go home, but under the premise that you have carers come in." … But she couldn't see the fact that this was not a safe place for her to be.*

After moving back into her own home, Jane's mother had another series of falls and strokes before it was decided that, against her mother's wishes but for her protection, she would no longer be able to live at home alone. This was a relief to Jane who all along had worried about her mother's safety.

This demonstrates that questions regarding capacity will sometimes be ignored. As was seen above, in many situations, family members are not consciously considering whether the person living with dementia has the capacity to make decisions. The Mental Capacity Act[16] was introduced to encourage and enable the decision-making of those who find themselves in a vulnerable state, either independently, with the help of others, or by others in

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https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf, last accessed on 14 February 2021.

[15] ibid., at para 105.

[16] Mental Capacity Act 2005, c.9.

their best interests.[17] However, on a day-to-day basis, it can be difficult to ensure compliance with the legislation.

8.4 Experiencing challenges around capacity requirements

In 2014 the House of Lords Select Committee, reviewing the Mental Capacity Act, recommended that *"the Government consider urgently the need for assessing usage of the core principles across the range of decisions affecting people lacking capacity, including in sectors such as banking and policing."*[18]

The Mental Capacity Act[19] specifically provides as a fundamental principle that capacity in all adults is presumed.[20] In other words, capacity is the 'default position' for all adults.[21] However, the four-tiered test as set out in the Mental Capacity Act[22] is not well known outside professional (medical and legal) circles. The interview data demonstrates that family members do not apply the test in day-to-day situations. Instead, how the person living with dementia and the family member interact will depend on the family members and their attitude to money, spending and decision-making, as well as their relationship with the person living with dementia.

Among those interviewed, it was only for decisions perceived to be more formal that an assessment was undertaken in line with the Mental Capacity Act 2005. The reasoning was that assessment of a person's capacity, or lack thereof, was needed in situations requiring more rigorous action to ensure that the decision would not be subsequently questioned, whether by other family members, the public at large, or civil servants and social workers. This was most often the case when persons living with dementia intended to enter into lasting powers of attorney or write/re-write their wills. Indeed, many of the

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[17] Mental Capacity Act 2005, s. 4.

[18] House of Lords Select Committee on the Mental Capacity Act 2005. (2014) *Mental Capacity Act 2005: Post-Legislative Scrutiny*. HL Paper 139, para 110, available at https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf, last accessed on 14 February 2021.

[19] See Chapter 7, Section 7.2.

[20] Mental Capacity Act 2005, s. 1(2).

[21] Mental Capacity Act 2005, s. 1(2).

[22] Mental Capacity Act 2005, s. 3.

participants reported that upon diagnosis, medical professionals would recommend that valid lasting powers of attorney and up-to-date wills were in place.

Taking as an example a lasting power of attorney, [23] a complex process must be followed to set it up. [24] The written consent of the person nominating their attorneys and giving them certain powers at certain times (known as the 'donor') is required. This is achieved through the completion of a formal document, signed by the donor and witnessed by a third party. That third party (known as the 'certificate provider'), in addition, "*confirms you're making the LPA [lasting power of attorney] by choice and you understand what you're doing*",[25] i.e. they must attest to the fact that the donor had at the moment of signing the lasting power of attorney the capacity to make the decision to sign the document.

Whilst lasting powers of attorney can, in theory, be completed without external help, many participants felt that a professional was required to assess capacity, to witness signatures and/or to assist with completing the form. Especially in relation to the older generation, many did not think they could complete the form as it is usually done online, requiring a certain level of computer literacy and Internet knowhow. However, opting to enrol professional help was seen as costly for a number of participants.

Catherine, whose husband lives with dementia, described her frustration well:

> *Catherine: Yes, I have been nagged [by my daughters to get a lasting power of attorney for my husband] and I went to see a solicitor. But it costs £450 and I cannot do myself it on the computer. Well, I could do it, but it wouldn't be legal! It is just something that needs to be done.*

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[23] See Section 10.5 on lasting powers of attorney.

[24] Government guidance (2020) *Make, Register Or End A Lasting Power Of Attorney*, available at https://www.gov.uk/power-of-attorney/make-lasting-power, last accessed on 14 February 2021.

[25] ibid.

In addition, the Office of Public Guardian[26] require the dates accompanying the signatures of all involved in the completion of the lasting power of attorney to follow a strict order, which means that many lasting powers of attorney are returned to the applicants as incorrectly dated and therefore unregistered due to procedural errors in completing the form.

An Age UK representative described the frustration felt by an applicant trying to register her lasting power of attorney:

> *Charity worker: We had, I had, a call this morning from somebody who was trying to do it [a lasting power of attorney] themselves. Her application was sent back to her twice. She knows what she has done wrong but she just cannot face going through this again on her own. She is coming to see me.*

The juxtaposition of a relatively relaxed way of considering capacity in day-to-day matters and the highly stressful, costly and time-consuming manner of ensuring capacity is assessed for other occasions is telling. It reflects a hierarchy that family members (rather than the law) attribute to different decisions to be made by people living with dementia.

This hierarchy is not built on the basis of any legal requirement, nor is this hierarchy necessarily constructed on the grounds of what is most important for the person living with dementia. For example, a decision by a family member to withhold a chequebook and bankcard, effectively no longer allowing the person to make any decisions alone about how to spend their money, may be seen as being as just as significant (if not more so) to the person living with dementia as their decision on who within their circle of family members should act as their attorney.

Several of the persons living with dementia who lived with their spouses talked of restrictions imposed on them as to what financial decisions they were allowed to make. They were grateful to their spouses for their care and attention, and in their quips about the situation, demonstrated that they were

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[26] ibid.

not embarrassed or upset that their spouses supported them in financial decision-making. This was illustrated by David’s comments:

> *David’s wife: We are careful about what we buy and my husband doesn't buy anything online. If he wants something he will tell me.*
>
> *David, who lives with dementia: That is when I go into begging mode… [all laugh]*

And later in the conversation:

> *Interviewer: Maybe the last question for David. Do you sometimes wish people would ask you as to whether you feel you can answer a question, or are you quite happy for people to address your wife and offer to deal with matters through her?*
>
> *David: You see, my wife does all that for me and an awful lot more. So she runs the family, she runs the household, you know she runs everything, you know. On a Thursday I have to get on my knees to get my pocket money! [all laugh]*

In relation to the assessment of capacity, family members differentiate between two types of control of the person living with dementia; in some circumstances control requires formal assessment of capacity and for other decisions, control is deemed acceptable (irrespective of capacity concerns) because it is done to keep the person living with dementia (financially or physically) safe.

Looking at the empirical data gathered through interviews in this thesis and the types of decision which were made after a formal assessment of capacity was carried out, this research suggests that the hierarchy of importance attributed to control is determined by the *effects it will have on the family members* that are putting in place a framework to protect (the financial positions of) the person living with dementia.

Where the family member cannot be seen to personally and directly benefit, for example with regards to decisions about where the person living with dementia might live, or how much cash they should carry on their person, it is easier for them to rely on their (common) sense of what is right to ensure the safety of their loved ones. However, where there is the potential for their (the family member's) integrity to be questioned, because they put themselves into a position where they could benefit (for example as attorney, by having access to bank accounts), there is a strong desire to counter, or at least reduce, any such risk by ensuring all is done by the letter of the law, with a relevant assessment of the person's capacity to make such decisions.

Vaughn described how the family pleaded with their dad to sign the lasting power of attorney, so that they could help without perceived difficulties:

> *Vaughn: Basically, we are four brothers, and we just said, "Dad, you've got to do this [sign the lasting power of attorney], because it will be a nightmare if you don't. You've got so many shares, all these things, all over the place, there is the house and everything", but we had to say this without him thinking we were after it. My brother took him to the solicitor, and my dad said to him, "Why am I doing this, this is my stuff?", and my brother said, "Yes, this is your stuff, but you…", he said to him, "please dad, you have to do this, for the grandchildren, please just do, it will make life so much easier for everyone". And eventually he did it.*

This demonstrates the strong pressure felt by family members to get the right paperwork in place, under the watchful eye of the third party acting as assessor of the person's capacity, to assist with or take over decision-making, especially in relation to financial decisions, such as selling or renting out the person's house (if they have to go into a care home), and dealing with shares or bank accounts.

Oscar's account is very similar, describing the urgency and importance he felt in getting the lasting power of attorney signed by his parents:

> *Oscar: The lasting power of attorney was useful in some ways. The biggest problem was getting it activated… And when the solicitors went around, you know, my daughter [who is a doctor] had to be there. And*

> *they [my parents] were saying, "Oh, we're not too sure, this gives anybody the chance to take our money". And I have to admit, this is one of the times I lost it, and I said, "This has been going on for months, we have been talking about this for months. And this is to protect you. It is to stop anyone taking your money. Nobody can take your money but me. And if you don't trust me then we can all go home". ...*

This last quote again highlights the pressure felt by family members to put the right paperwork in place to ensure they can help their family members with financial decision-making. Harding, refers to these difficulties in getting a person to sign the power of attorney.

> *Many of these participants reported some of the tensions and difficulties in getting their loved ones to grant PoA and in using PoA. We might even in some cases understand their stories as bordering on the coercive, especially if we understand PoA as an individualistic power that one individual holds over another. Yet if we view PoA through the lens of relationality, it makes significantly more sense: it is a way of recognising and respecting the relationships between people. It is a mechanism that allows people to continue to live and make decisions within the relative privacy of known, trusted and interpersonal relationships.* [27]

This demonstrates again the relational aspect which allows persons living with dementia in conjunction with their loved ones supporting them in their decision-making to achieve relational autonomy. The lasting power of attorney can be seen as a decision-supporting tool.

For the family members arranging the lasting power of attorney, in addition to the need to ensure written documentation is properly processed, the question also arose as to who should assess capacity when such decisions are made.

8.5 Experiencing a lack of assessors of capacity

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[27] Harding, R (2017) *Duties to Care: Dementia, Relationality and the Law*. Cambridge University Press, at 104.

Another issue identified by the House of Lords Select Committee upon review of the Mental Capacity Act was in relation to assessment, stating that "*Many of the criticisms raised about the way in which capacity is assessed appear to result from assessments being carried out by professionals who are not closely involved with the care of the person affected …"*[28]

This highlights a further issue that family members must contend with when considering capacity under the Mental Capacity Act, namely the need to determine *who* should assess the capacity (or lack thereof) of the person living with dementia. The Mental Capacity Act is silent on the issue and questions about the assessor remain largely unresolved in practice.

Taking the lasting power of attorney again as an example, many family members and future attorneys of the applicants worry that the lasting power of attorney may be queried in the future, if the applicant's capacity at the time of the signing of the power of attorney is not verified by a professional. Whilst this is not expressly required under the Mental Capacity Act or the lasting power of attorney guidelines,[29] it is recommended by many of the professionals assisting with the form filling, be they charities (such as Age UK) or law firms. The following interview extract records the frustration felt in having capacity assessed:

> *Age UK representative: Where someone has or hasn't got a diagnosis of dementia, but is obviously struggling in their decision-making capacity…. To me, I'm saying in order to avoid any kind of contention, it might be best to get a professional witness as certificate provider. So the issue with the certificate provider is that [locally] one of the major providers has withdrawn from that service arbitrarily.*
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> *Interviewer: This was a doctors' practice?*

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[28] House of Lords Select Committee on the Mental Capacity Act 2005. (2014) *Mental Capacity Act 2005: Post-Legislative Scrutiny*. HL Paper 139, para 110, available at https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf, last accessed on 14 February 2021.

[29] Office of Public Guardian (2017) *LP12 Make and register your lasting power of attorney: a guide*, at 38.

> *Age UK representative: Yes, this was a doctors' practice, one of the larger practices.… I asked the other practices, would they consider, because they are doing it for their patients, would they consider doing it for other practice patients? You know, perhaps for even more money, but they wouldn't entertain it either.*

The recommendation on assessment given to a charity worker by the Office of Public Guardian is also telling in that it struggles to remain in line with the Mental Capacity Act provisions:

> *Charity worker: … I rang the Office of Public Guardian… Their answer to me was, "Of course the person doesn't need a professional certificate provider", and the actual answer to me was, "if the GP won't do it and the family are confident enough that the person does understand what they are agreeing to, that the way to belts-and-braces that is to have a another person who has known that person act as certificate provider and around the same time the client who will be the donor is seen by the doctor. "Doctor, do you feel I've got capacity?" Or wife says, "Would my husband have capacity to make a lasting power of attorney arrangement?" and ask for it to be recorded in the notes so that if it was contentious in the future, the Office of Public Guardian could request such kind of notes from the doctor." But they… it's kind of tricky for the GP practices to come to the same conclusion. And it's only a bit of a guide, because it's decision specific.*

As the charity worker rightly points out, a general statement by a doctor about whether at the time of the visit to the surgery the doctor found the person to have or lack capacity may not be determining as to whether they had capacity or not at the time of signing the lasting power to attorney itself.

In theory, the legislation, as stated by the Office of Public Guardian, simply requires the assessment, without prescription as to who the assessor should be. A person who knows the person living with dementia or has time to talk to them about the decision they are about to make is sufficient for the purposes of the Mental Capacity Act.

One of the participants asked a long-term friend to act as assessor:

> *Rose: So I took him round to a friend of mine who he has known for years... And we chatted for ages, we had tea and cake and he and his wife talked to [name of husband] for ages and said about what lasting powers of attorney were, how did he feel about it, was it a good idea, did he think that he would give these powers to his wife and two daughters in the event of something happening, maybe he might step under a bus, or anything could happen. And he thought about it, and it seemed like a logical thing to do. And so he said, "Yes, I'm ok with that". So we filled in all the forms. And I set it all going, did it all online, and it all came back, registered and everything.*

In some cases, participants explained that they simply went ahead and got their family member with dementia to sign the lasting power of attorney, to allow them to step in and help with financial matters, despite questions about their ability to fully understand the consequences of the document.

> *Mary: Yes, power-of-attorney. So she [Mary's mother] signed it without us questioning her legal capacity. Although she was losing it and you're not really supposed to do it at that point, are you? But anyway, everything was very easy because we had access to her funds [to pay for her care home].*

However, many of the participants were anxious to ensure capacity was assessed in some way and asked for signature to take place in the presence of a solicitor or doctor.

> *Jane: Of course we had never come across it before so it was all new to us to find out what the power of attorney was. And I spoke to my brother who I am closest to and I explained to him what it was and I had to explain to my mother what it was because of course she had to sign the paper work. And of course the solicitor had to come round to the residential home to talk to my mother to see if my mother had the understanding, the capacity.*

This demonstrates that many family members were concerned to get the right documentation in place to be able to assist with financial and other decisions.[30] How they assessed capacity was not consistently done, with some family members self-assessing, others getting a friend or professional to confirm capacity.

Harding and Peel's socio-legal research on the lasting power of attorney[31] describes the cautiousness and difficulties experienced by family members when seeking to obtain a lasting power of attorney for persons they were caring for. For example, Harding and Peel highlight this in their analysis of a discussion by 'lay' persons issues around capacity determination.

> *For instance, Morris (lines 10–12) contrasts the importance of timely advice about power of attorney with his wife's reticence to agree, but rather than stopping at characterizing his wife's state as 'really on her last legs' (which suggests close to death, and likely not capacitous), he adds 'of signing'. He then completes his turn by alluding to 'buying' ('private doctor', line 17) the ability to have the LPA certified.*[32]

This demonstrates that the legal requirements on capacity assessment are not always clear to the public at large. Family members of persons living with dementia might be uncertain as to how to effectively and legally fulfil the requirements relating to assessment, relying in turn or doctors, lawyers, or friends. Others will opt to avoid the question altogether by eschewing assessment altogether.

Oscar spoke openly about the ways in which the doctor assessing capacity of his parents, who both lived with dementia, was not genuine in his assessment. In his eyes this was acceptable because if was done for subjectively right reasons to protect them and keep them safe.

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[30] See Section 7.2 on capacity rules and requirements to protect the person no longer considered capable.

[31] Harding, R. and Peel, E. (2019). 'Polyphonic Legality: Power of Attorney Through Dialogic Interaction' *Social & Legal Studies* 28(5): 675-697.

[32] Ibid., at p. 684.

> *Oscar: The GP, our local GP, he is actually a good guy, we've known him for 30 years, he's sort of a friend. I lose in golf to him! He had to sign that they [my parents] were 'compos mentis', to sign the paperwork… They [my parents] were really on the borderline of being capable, but he [the GP] said, "I know you and I know the family, so I took a broader view that this needed to be done".*

As this and other quotes above demonstrate, the aim in all of these situations was less to consider the capacity of the person living with dementia, and more to ensure that a valid document had been created that could be applied when needed to assist, or take over for, their loved ones.

The diversity in understanding and applying the lasting power of attorney was highlighted by Harding and Peel. They concluded that "*in all areas of law, legal rules are used and interpreted by different actors, to shape, shift and create the totality of the regulatory framework.*" [33]

8.6 Concluding remarks

Capacity is one of the key components to be considered at the moment when two parties are looking to enter into a contract. As described in Chapter 3, capacity might be "*used by law as a key marker between the vulnerable and the non-vulnerable*",[34] with capacity being seen as a pre-requisite to the right to autonomy.[35] Consequently, the law tends to consider those that have capacity as being autonomous and able to contract, whilst those who lack capacity are deemed vulnerable and in need to legal protection. This chapter aims to demonstrate that this distinction between the capable and the vulnerable however does not work, as it does not take into account the fluctuating nature of capacity, nor the difficulties encountered in recognising whether a person has capacity issues. In addition, some persons might be

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[33] Harding, R. and Peel, E. (2019). 'Polyphonic Legality: Power of Attorney Through Dialogic Interaction' *Social & Legal Studies* 28(5): 675-697, at 693.

[34] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 45.

[35] Ibid.

considered “*capable but vulnerable*”. [36] This chapter aims to therefore highlight the limitations of the current system. Instead, it is suggested that vulnerability must be viewed beyond the limited group of those that lack capacity. In other words, the laws need to take into account that all may be vulnerable now or at some time in the future.

The current legal system relies on recognition of capacity, or a lack thereof, as a key component of contract law. However, the experiences of persons living with dementia and their family members relayed in this chapter demonstrate that a lack of capacity is difficult to ascertain in practice. Capacity law is often not applied as intended by the legislation in relation to everyday decisions. The data shows that in many cases in practice, capacity concerns are not considered by family members when caring for a person living with dementia. Instead, for many family members and carers, their concerns in relation to the risk of harm (both physical and financial) will trump any regard for the need of the person living with dementia to remain able to make their decisions independently for as long as possible.

This disregard of the presumption of capacity was explored and understood through the perceived changes within the roles of all parties involved. The data collected from interviews demonstrated that many family members saw the transition of their loved ones living with dementia move from ‘normal’ to ‘symptomatic’ as justification in their eyes for their increased interference.

The data further highlights the perceived changes of the role of family members. Parallel to the progression of the cognitive impairment experienced by the person living with dementia, family members experienced an evolution of their roles. This culminated in some cases in a complete role reversal of the positions of parent and child. Whilst in all cases the actions of family members were done out of love and concern for the safety of their loved ones with dementia, this infantilisation of the person living with dementia led to the removal of the presumption of their capacity.

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[36] Hall, MI (2009). ‘Capacity, Vulnerability, Risk, and Consent’ in O’Connor D and Purves B (eds.) *Decision-Making, Personhood and Dementia, Exploring the Interface,* Jessica Kingsley Publishers, at 119.

In contrast to the above-described disregard for capacity questions in day-to-day decisions (including consumer decisions), the new data showed that capacity was at the forefront of family members' minds where a written document was required that might subsequently be questioned or contested. Typical examples include people's wills or their lasting power of attorney. In such situations, the test to verify capacity or lack thereof was used to ensure the validity of the document, rather than, as was initially intended, to listen to the person whose capacity was questioned. In other words, whilst family members in all cases encountered in the interviews acted out of kindness and concern, capacity questions were usually only raised in order to ensure that subsequent actions taken by family members or third parties named as attorney on behalf of the person living with dementia were protected.

These outcomes demonstrate that the legislation[37] as currently drafted is not consistently applied to all situations where capacity matters arise.

The next chapter focuses on the question of knowledge, and will consider the knowledge that the two contracting parties have when entering into a contract. This includes knowledge of each other, i.e. knowledge of any challenges or vulnerabilities of either of the parties. In relation to this, the chapter will also explore the concept of stigma as it applies to dementia.

Chapter 9 also includes a review of the knowledge by the parties of the contract itself, both in relation to the terms and conditions to be adhered to at the outset of the contract, but also all on-going obligations that the parties need to comply with throughout the life of the contract. This is particularly pertinent in relation to consumers living with dementia who may have memory or other cognitive impairments that make it more difficult to observe all such on-going requirements.

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[37] Mental Capacity Act 2005, c.9.

Chapter 9 Experiences of concern about knowledge and understanding

9.1 Introduction

Alongside the capacity considerations explored in the previous chapter, the parties to a contract will also need to be aware of, and agree to, the set of terms and conditions that make up the agreement between them. Communication between the business and the consumer (which may or may not include individual negotiation of the terms)[1] will involve an exchange of information about the terms of the deal. In addition, the parties will weigh up what information should be shared about each other. The parties will need to consider what personal or professional details are necessary or helpful, and conversely what information they believe is not required or may hinder the contract formation. All these decisions on disclosure or non-disclosure of information will carry consequences that will be examined in this chapter.

The term 'knowledge' is used in this thesis to describe the understanding of the parties, both of each other and of the rights and obligations within the contract. Different facets of knowledge of the parties are considered herein. This chapter will explore what the parties understood of the contract (their '*transactional knowledge*') and of each other (their '*relational knowledge*') when they first entered into the consumer contract. It also explores what the parties understood of the rights and obligations attached to an on-going contract and how to comply with these (their '*compliance knowledge*'), on both practical and legal levels.

As discussed in Chapter 6 on the relevant legal framework, under general contract law principles there is no legal obligation to offer unrequested information to the other party in a contractual transaction.[2] A common law principle is that whilst a contracting party cannot actively deceive the other party, silence, i.e. the non-disclosure of information, will not render a general

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[1] CMA (2015) *Unfair contract terms explained*. CMA37(a) National archives, available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/450410/Unfair_Terms_Explained.pdf, last accessed on 14 February 2021.

[2] See Section 6.2.

contract void.[3] Instead, it is up to the contracting parties to make all necessary enquiries. As a result, it can be inferred that the validity of the contract is not necessarily subject to the completeness of their *transactional knowledge*. **Section 9.2** explores the issue of *transactional knowledge* by looking at the understanding of the terms of the contract by the person living with dementia when first entering into a consumer contract. It is the knowledge of the contract itself.

However, what the parties knew of each other can be decisive when considering if a contract was validly entered into. As discussed in Chapter 7,[4] a contract will not be deemed voidable for lack of capacity where a party to the contract did not have the relevant *relational knowledge* of the other party. Instead, the rules on voidability of a contract for lack of capacity will only apply in circumstances where the other contracting party "*knew or ought to have known*"[5] about that lack of capacity. This raises the question of what relational information must be disclosed, i.e. what knowledge about each party to the contract is significant in a consumer transaction. **Section 9.3** examines the issue of *relational knowledge*. In particular, this means looking at the knowledge that the parties may have of any challenges (such as cognitive impairment) that might make entering into the contract more difficult, or that might result in a party being unable to comply with the obligations throughout the life of the contract.

Next in **Section 9.4**, the issue of non-disclosure of information and the implications of this for the contractual relationship is addressed. This non-disclosure may be due to ignorance of what is relevant, or due to the fear of stigmatisation. The experiences of participants highlight the worries, challenges and difficulties encountered and the consequential fear, rightly or wrongly, to divulge their status as a person living with dementia in consumer matters. As a result, for many people living with dementia, withholding some information is seen as the preferred route.

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[3] Keates v Cadogan (1851) 10 CB 591.

[4] See Section 7.2.

[5] Hart v O'Connor [1985] 2 All ER 880 [892]; see also Ayres v Hazelgrove (QB, 9 February 1984, unreported).

The concept of knowledge however is not limited to that point of entry into the contract. Throughout the lifecycle of the contract, knowledge and understanding of the contract is essential for the contracting parties. *Compliance knowledge* will be looked at in **Section 9.5**. For example both parties must have knowledge and be aware of the rights and obligations that might arise on an on-going basis. These might include a need to make payments regularly, provide new information (such as a meter reading), or inform the other party of any change of circumstances. A lack of understanding of these obligations may lead to non-compliance of the contractual terms, which in turn may void the contract to the detriment of one of the parties. In addition to knowledge of the contractual terms, on a more practical level, knowledge and understanding of how to comply with these contractual obligations is another key. Finally, **Section 9.6** provides concluding remarks.

9.2 Experiencing a lack of transactional knowledge

This section explores the lack of transactional knowledge, in other words the challenges faced with *understanding the terms of the contract*. To do so, this section will focus on the parties' knowledge and understanding of three key points in relation to the terms of the consumer contract.

First, at a general level, the terms of several available deals need to be understood by the parties to the contract. The consumer is faced with the need to understand a multitude of deals to select the one most suited to them, as well as understand the specific terms of the consumer contract chosen.[6]

Next, more specifically, this section will explore the knowledge and understanding that the consumer living with dementia might have of the payment term.

Finally, knowing the price of goods or services is only useful if the consumer also understands at a basic level the value of money. For the person living

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[6] This point also links to the discussion on capacity in Chapter 8 above, as understanding of the choices is the first step in the four-tiered test as set out in the Mental Capacity Act.

with dementia, because of memory loss and cognitive impairment, their knowledge of what a certain amount of money is worth is often distorted. However, knowledge by the party living with dementia of the value of money is important, as that will impact on the ability of that party to understand the consumer contract presented to them and its financial consequences for the consumer and (potentially) their family members.

Understanding the terms of the deal

Both the choice available relating to consumer contracts, as well as the terms of any consumer contract itself, may be immensely complicated, and whilst the Consumer Rights Act[7] requires businesses to be clear and transparent in relation to the terms offered to consumers,[8] the complexity of the deals may nevertheless render such contracts opaque and difficult to understand for the person living with dementia.

A charity worker described such difficulties of understanding, focusing on the various offers available from utility providers. Trawling through the various deals, trying to ascertain the precise terms and conditions, and comparing these between companies is a complex undertaking, made more difficult where there is some cognitive impairment such as memory loss.

> *Advice provider at Age UK: I mean, as we know from our work, one of the complexities of modern life and stress is the potential, the possibilities we are faced with. The government, the media, will be stressing to people that they should be switching [gas and electricity] companies, but… the complexities of actually working out the benefits of switching can be quite difficult. Because you are basing it on previous usage and looking at the coming year, not just looking at the switching website and seeing what they tell you. It is a maths question… Also, you have to have the understanding that if you come out sooner, you might still owe money. You have to accept that you might in the short run be paying more in order to save more in the long*

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[7] Consumer Rights Act 2015, c.15.
[8] Consumer Rights Act 2015, s. 64.

> *run... And so for people with a consumer decision who are perhaps in early cognitive changes, it is quite tricky, which is to the advantage of the companies that disadvantage loyal customers.*

This quote emphasizes the complexity of selecting among the many consumer contracts. This difficulty of making a choice is identified for most consumers. Indeed, in the final report of their energy market investigation,[9] the Competition and Markets Authority highlighted that

> *We calculate that, over the period Quarter 1 (Q1) 2012 to Quarter 2 (Q2) 2015,* ***most customers*** *of the Six Large Energy Firms could have made considerable savings from switching a combination of suppliers, tariffs and payment methods: for some categories of customer, the average gains from switching were equivalent to more than 20% of their bill over the period.*[10]

However, whilst this is a general issue for consumers, for "*customers who are less able to engage to exploit the benefits of competition",*[11] including consumers living with dementia, this is a particular obstacle. Indeed, the report identified that those most likely to be unable to engage with the choice provided by the market included factors such as "*low levels of income; low levels of education; living in social rented housing; and having a disability*."

The issue is not limited to utility companies alone. Many of the other sectors that provide on-going services fall within this category, be it mobile phone companies, banks or insurance providers. In many cases, when consumers are faced with a choice between different companies and varying deals, they require the ability to have personal information ready (such as, in the case of the utility markets, previous and future estimated usage data of gas or electricity in the home), which is sometimes difficult to identify for the client,

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[9] CMA (2016) *Energy Market investigation: final report*. National archives, available at https://assets.publishing.service.gov.uk/media/5773de34e5274a0da3000113/final-report-energy-market-investigation.pdf, last accessed on 14 February 2021.

[10] ibid., at 6.

[11] ibid., at 935.

especially for customers with a cognitive impairment. Furthermore, many consumer contracts will require the consumer to retain information, both of the offer made and of other offers available in the wider ‘marketplace’ in order to compare deals and select the most appropriate one. However, the opacity of the pricing models makes comparisons often difficult. Finally, many consumer contracts will also require mathematical skills to understand if a deal is, in the longer term, beneficial and affordable to the consumer.

The above demonstrates that transactional knowledge is therefore not restricted to the terms of the contract itself, but also to the terms of other contracts in comparison. Effectively, the consumer must be able to retain knowledge to understand the terms of a particular contract, as well as be able to compare and contrast it with others. The Mental Capacity Act does not distinguish between these two types of knowledge and understanding. It refers to the immediate choice a person is faced, which could be a choice about a specific transaction, or require the person to be able to weigh up multiple alternatives. However where the choice relates to the latter, this requires a much higher level of knowledge, understanding and capacity. The practical consequence that can be identified from this data is that many consumers living with dementia will not be able to recognise different deals to make an informed choice.

Understanding the payment term

Once a specific offer is selected, other challenges arise. Money is often handed over without an understanding of what is agreed between the parties in terms of consideration provided. This can be highly problematic, if large sums of money are spent that the person living with dementia and their family members (in particular their spouse) can ill afford. Even when the sums are smaller, it may be the frequency with which money is spent that causes concern.

In the previous chapter,[12] Lauren talked about her mother who was living with dementia writing blank cheques for work to be done around her home, such

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[12] See Section 8.3.

as for *ad hoc* gardening work. To this person living with dementia, the contractual term relating to the payment to be provided was no longer something that she could focus on, leading to her spending large amounts of money. The lack of knowledge of the payment term meant that she no longer understood what was owed.[13]

Similarly, Mary explained that her mother, who is living with dementia, would also relinquish any control over the amounts to be paid to the business.

> *Mary: … she used to write cheques to people, you know, the gardening lady, but there were other people and we will never know. And she would sometimes say, "Well, I will just give them a blank cheque." And you know, we just had to trust people. That was before my brother took over the finances. And so she was very vulnerable, very, very vulnerable.*

These issues concerning a lack of understanding of a key aspect of the contract, namely the ability to understand what cost was stated in their consumer contracts and therefore what money they were required to pay, was reiterated time and again. If it was not a blank cheque, it might be that they would readily hand over their purse or wallet to allow their contractual counterpart to help themselves to the relevant amount.

For example, Helen reported this in relation to the local cafe that her mother, who lives with dementia, would regularly go to.

> *Helen: … she [my mother] did say, "sometimes I just give them the purse", and because she is in a small area – this is not London – it is people who know her and know her partner, they go to the same cafes, so no one is taking the mickey – but they could.*

This quote again shows that there are risks incurred by people who do not have full knowledge and understanding of the key aspects of the consumer

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[13] Whilst it is not the intention herein to challenge the adequacy of consideration, the lack of understanding of the payment term and value is nevertheless something that must be considered.

contract they are entering into. The consequences for the person living with dementia are that they are not always fully aware of the fundamental terms of the contract that they are entering into. As their risk of harm increases, through for example memory loss of heightened cognitive impairment, the exercise of their freedom to make choices will need more significant support.

Understanding the value of money

In many instances reported by participants in this project, it can be difficult for the person living with dementia to retain a clear grasp of the value of money. Lack of transactional knowledge might therefore also relate to the value given to money, goods or services.

Edvardsson and Nordvall[14] identified that due to dementia it was common that a person might not remember "*where they were, how old they were and if they were ill or healthy*." They found that to counter-balance this uncertainty, people with dementia would often find themselves talking about their earlier lives, families and homes, in the belief they were now in that time or place.

Inflation means that the same amount of money will have a different value at different times of their life. For example, whilst £2000 could buy a house in 1960, it could buy some living room furniture in 2020. Where the person living with dementia is unclear of their age and the decade they are presently in, they might lose grasp of the value that money currently has.

Nicole talked about her mother living with dementia, who one Christmas surprised her and her brother with large sacks of compost that she had bought for them from a cold caller.

> *Nicole: To be fair, Mum was really pleased about it, she had bought it independently and it was a surprise, but it rang alarm bells for us because it meant that somebody had come knocking on her door and we do not know how much she spent. It rang alarm bells; it was a bit*

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[14] Edvardsson, D. and Nordvall, K. (2008) 'Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia' *Journal of Clinical Nursing* 17(4): 491-498.

> *scary that someone might have ripped her off. She is quite an innocent person, quite vulnerable, you know, she is in her 90s. She would not have known what a fair price would have been.*

Catherine also felt that her husband with dementia was no longer able to clearly understand the value of money.

> *Catherine: … it was a gradual thing. He [my husband] had always been a good man with money and gradually he couldn't fathom it anymore. He was getting it all wrong. And I am no good with money!*
>
> *Interviewer: But was he forgetting how much money was worth or…?*
>
> *Catherine: Yes, yes, he'd think, like, £20 is a fortune.*

Patricia also had experienced her husband's decline in understanding the value of money. Her husband, who lives with dementia, decided to sell his collection of expensive, well-maintained and branded power tools.

> *Patricia: … he said, "I can handle it". And then I found out afterwards that … [name of husband] had only charged £50 for quite a lot of expensive tools that were probably worth £200-300.*

These responses demonstrate the difficulties in identifying if the consumer living with dementia has full knowledge and understanding of the value of money when entering into a contract. Most of the issues raised in this section by family members will be unnoticed by the business counterpart, unless the discrepancy in value offered by the consumer and the market value is significant. Whilst a bad bargain is not a reason to question the validity of a contract, as was discussed in Chapter 6 above, it may speak to issues of capacity and consent.

9.3 Experiencing a lack of relational knowledge

In addition to understanding the contract itself, the knowledge of the parties to the contract is also significant. This is especially the case if the consumer has a mental health issue, learning disability or cognitive impairment. Any of these challenges may make entering into the contract more difficult, even if that consumer retains their capacity (under the Mental Capacity Act 2005) to do so. Significantly, in order for a contract to be validly entered into, beyond the question of capacity, awareness of capacity will also play a role.

Therefore, in a first instance, awareness of the situation of the consumer will be explored. Consequently, this section looks at the parties' knowledge of the consumer and that consumer's ability to enter into contracts. Next, the consumer's knowledge of the business is reviewed, as this may also have an impact on the parties' actions.

Knowledge of the consumer

As noted in Chapter 7,[15] knowledge of the situation of the consumer (in terms of their capacity) is essential. Indeed, where the business does not know that the consumer did not have capacity, and that business was not negligent or oblivious to obvious signs (i.e. where they '*did not know or ought to have known*'),[16] then the consumer contract entered into between the parties cannot subsequently be voided for lack of capacity.

Capacity issues unbeknown to the business

It will not always be the case that the business knows or, from the behaviour of their contracting counterpart, ought to have known, that they are facing a consumer living with dementia.

Assessing capacity under the Mental Capacity Act is, as has been described above,[17] a four-step process,[18] which at first glance appears relatively easy to administer. However, such an assessment is in practice a demanding task. Even in the health care sector, where the Mental Capacity Act and its test are well known, studies have found that the application of the test is challenging

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[15] See Section 7.2.

[16] Hart v O'Connor [1985] 2 All ER 880 [892]; see also Ayres v Hazelgrove (QB, 9 February 1984, unreported).

[17] See Section 6.2.

[18] Mental Capacity Act 2005, s. 3(1).

and requires further improvement.[19] Marshall and Sprung identified that "*the required knowledge and confidence of nurses to perform accurate assessment of mental capacity*"[20] was often lacking. Williams et al. similarly demonstrated in their study that health care professionals were often reluctant to assess capacity, deferring final decisions to others.[21]

This difficulty is further compounded where the assessor is not within the health care setting, is unfamiliar with the person living with dementia, and unfamiliar with the traits of dementia. Many business representatives will be unfamiliar with the concept of capacity. Only few will have had training that allows them to consider this notion and then make an accurate capacity assessment in line with the Mental Capacity Act prescribed test. As a result, in a short conversation prior to entering into the consumer contract, it will be difficult for most business representatives to identify any reduction in capacity.

Often, it is only when family members have the opportunity to step in before the contract is signed that the business is put on alert of a potentially difficult situation.

Kate described how her husband, who was living with dementia, would still like to go regularly to the corner shop for purchases.

> *Kate: At the local shop, they knew that my husband had dementia, and they were brilliant, I had gone to see them to explain the situation. He used to go to pick up the paper and he would forget his voucher, or pick up the wrong paper, and they were just lovely.*

However, it was up to her to ensure that the shop employees were fully aware of the situation.

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[19] Marshall, H. and Sprung, S. (2018) 'The Mental Capacity Act: 10 years on – the key learning areas for health care professionals' *Nursing: Research and Reviews* 8: 31.

[20] ibid.

[21] Williams V, Boyle G, Jepson M, Swift P, Williamson T, Heslop P. (2014) 'Best interests decisions: professional practices in health and social care' *Health and Social Care in the Community* 22(1): 78-86.

> *Kate: There was a high turn-over and they were not well informed, but I would go down there regularly to explain the situation to any new member of staff.*

In addition, Kate's husband would often enter into consumer contracts on the telephone. One time, Kate was listening in when her husband picked up the telephone and started discussing an offer to join a wine club.[22] It was only when Kate notified the business of her husband's cognitive impairment that the business could take that new information into account and revise their sales strategy accordingly.

> *Kate: Once I told them [the wine club] my husband had Alzheimer's, they stopped immediately. That worked. They were very good about it.*

The above demonstrates that where the person with dementia or their family members do not provide information, it can be very difficult for a business representative to realise that there are any issues of understanding.

Persons living with dementia will often show no signs of any difficulty or lack of understanding during short encounters. Garry explained how his mother would hide symptoms of the disease.

> *Garry: She [my mother with dementia] was very good at pretending nothing was wrong… she would always be nodding and be very interested and not ask too many questions…. So it would then just seem like she was having a normal conversation and liked to listen to people.*

Barbara had a similar account of the behaviour of her husband, who lives with dementia. She explained that identifying any such issue can be very difficult.

> *Barbara: He is very good at hiding it! … he is also very clever, so he will turn the conversation around to something that he wants to talk about.*

Later in the interview, she developed this further.

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[22] This is also discussed in Chapter 8, Section 8.2.

> *Barbara: Yes, and the thing about [name of husband] is, on the surface…. I mean, a lot of people say, "I wouldn't know there is anything wrong with [name of husband]". But then, you know, if you get into a sort of deeper conversation, then you realise that there is a huge lack of comprehension.*

This demonstrates that there will be situations where the business counterpart is not aware of the mental and health situation of the consumer facing them. The legal consequence for the person living with dementia is that the contract will not be void or voidable, even if at a later stage a lack of capacity at the moment of executing the contract can be demonstrated.

In addition to dementia not being easily detectable in short encounters, many participants, both persons living with dementia and their family members, talked of the fluctuating nature of a person's ability to make decisions where there was cognitive impairment. Whilst at times a person living with dementia may struggle visibly and alert the business representative of potential vulnerability, in many cases there were no signs of any issues.

Eduard has dementia and he and his wife expressed the challenges of the fluctuating nature of the illness well.

> *Eduard: Very often.... I mean I can't remember a damn thing sometimes...*
>
> *Eduard's wife: Occasionally you can't even talk, it is all gobbledygook that comes out.*
>
> *Eduard: Yes, yes, I was like that when I first met you [the interviewer] this morning.*
>
> *Interviewer: … a little bit tongue-tied.*
>
> *Eduard: I couldn't put two words together.*
>
> *Interviewer: …and now, completely fluent!*
>
> *Eduard: Yes, it comes back. So that is what my problem is.*

Nicole, whose mother lives with dementia, had a similar experience.

> *Nicole [talking about her mother's decision-making capacity]: And her ability to make decisions will vary, even within the day. For example, at the end of the day she might find it much harder to make a decision. From day to day it will vary.*

From these experiences it is demonstrated that depending on the day, and even depending on the time of day, a person living with dementia will be able to communicate and make decisions to varying extent. Similar observations were made by many of those interviewed. As a result, many family members worried about the offers put before the person living with dementia. They all expressed concern that their loved ones with dementia might sign up to consumer contracts without fully comprehending the complexities of the deals, whilst the business remained oblivious to any lack of understanding.

This highlights the difficulties encountered by family members trying to support their relatives living with dementia after a contract is entered into.

Capacity issues unbeknown to the person living with dementia

In addition, it was apparent from the interviews that in many cases family members felt that their relatives living with dementia could not recognise when they were no longer able to engage with consumer matters. Lauren, talking of her mother who lived with dementia, describes this well:

> *Lauren: … she was absolutely convinced that she was fine and that she had the capacity to deal with anything. So it wouldn't have mattered about going into a shop that was dementia-friendly… [unless] I stood behind her with a sign that said, 'Dementia!', they wouldn't have known.*

This highlights how difficult it is for business representatives to know if the consumer they are dealing with has capacity of not, or, more generally, might benefit from assistance or further advice before entering into a contract.

To counter this difficulty, the Financial Conduct Authority suggests that it would be helpful for businesses to be told if their customers are vulnerable.[23] To that effect they suggest that consumers actively inform businesses or banks of their situation. However, such disclosure is not always possible.

Disclosure of dementia

Lauren recounted how she witnessed a person at the bank openly talk to both her and the bank employee about her dementia in order to get assistance from the bank.

> *Lauren: …just the other day, at my bank, I was standing in one of those endless queues, and there was a little old lady before me… and we were chatting and she said, "I've got dementia, you know", and I said, "How very unfortunate". And then when she spoke to the cashier, she was asked about her bank details and she said she could not remember…*

This demonstrates that some persons living with dementia will feel comfortable to directly inform the relevant business of their situation. On a wider scale, there are registration services for vulnerable persons that purport to flag up the issue of vulnerability to all companies on their register, avoiding the consumer having to remember to do so each time.[24] However this blanket approach may not be attractive to its target audience.

For example, Alice, who is living with dementia, explained in her interview that she would be willing to disclose her diagnosis of dementia to a business, if this meant that she would then enjoy additional rights in relation to the contract, should the contract at a later stage be deemed unwise. As a solution to readily disclose her illness, Alice talked about a 'check-box', which would allow a person voluntarily to identify as living with dementia. In doing so, she

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[23] Financial Conduct Authority (2015) *Occasional Paper No.8 on Consumer Vulnerability*, available at https://www.fca.org.uk/publication/occasional-papers/occasional-paper-8-exec-summary.pdf, last accessed on 14 February 2021.

[24] Such as https://www.vulnerabilityregistrationservice.co.uk, last accessed on 14 February 2021.

would expect the business to take this information into account when contemplating what goods or services to offer, how to assess risk, what advantageous termination provisions to include and what further questions to ask before a consumer contract was entered into. However, in other instances, where no advantages were visible from the disclosure, Alice was much more cautious about providing that information.[25] Alice's reluctance shows the difficulty people face when contemplating divulging this highly private and significant piece of information, which can be used both to their benefit or their detriment.

Non-disclosure of dementia

Indeed, whilst disclosure is an option considered by some people, it might not always be possible or desirable for the person with a cognitive impairment to disclose this fact to a business.

There are many reasons why such disclosure of dementia by the person living with the illness may not be appropriate or possible.

Reason 1: undiagnosed

It may be that the person living with dementia has not been diagnosed and therefore neither they nor their family members know that they have dementia. As a result, this unknown fact cannot be disclosed to a business. As was discussed above,[26] between 50% and 80% of all people living with dementia in high-income countries are not diagnosed.[27]

Reason 2: diagnosed but unaware or unaccepting of diagnosis

Alternatively, for those that have a diagnosis, non-acknowledgement of the illness may be because they do not accept the diagnosis, or have forgotten that such a diagnosis was ever made.

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[25] See a more detailed account of Alice's quandary in Section 9.4.

[26] See Section 2.2 on further details of a lack of diagnosis worldwide.

[27] Alzheimer's Disease International (2015) *World Alzheimer Report 2015*. Alzheimer's Disease International London.

Kate explained that her husband with dementia would never have talked about his dementia diagnosis to a business he was contracting with.

> *Kate: Not because he would have wanted to hide it, but because he would have forgotten to do so. In fact in the last two years of his life, he did not ever acknowledge that he had dementia.*

This was echoed time and again by many of the participants in the research.

> *Lauren: She [her mother living with dementia] would never have acknowledged that something was wrong with her. "There is nothing wrong with me". [she would say to Lauren].*

Lauren later in her interview summarised her thoughts on this topic well.

> *Lauren: If people won't accept that they have dementia, they will not accept help, and that is the stumbling block for those with dementia. And that is where shops and businesses that rely on contracts will not be able to know about those with dementia. If they have some policies [on how to assist a person living with dementia] these only work if they know who the people with dementia are.*

Helen's experience is similar. Her mother lives with dementia and both her mother and her mother's partner are refusing to acknowledge the diagnosis.

> *Helen: She is not acknowledging the dementia, because she also has Parkinson's disease and she is talking about Parkinson's disease all the time… her partner has said, "Don't mention the dementia", to one of my sisters who then told us… So we are now all pretending she hasn't got it… So we are in this funny position where nobody is telling the truth about anything…*

These quotes demonstrate that in many cases the person living with dementia will actively work to ensure that their illness remains hidden from the contractual counterpart. Consequently, the business is able to state that they did not know, and could not have known, about the illness. In Chapter 11 [28] this thesis will explore whether this is reason enough to remove all responsibility from the business in such situations.

Reason 3: aware of diagnosis but wanting to keep information private

Whilst some persons might remember that they have a diagnosis of dementia, they may simply not want to divulge their health status.

For example, when Ellen and her husband, who is living with dementia, were planning a holiday, Ellen's husband was in charge of booking the trip and buying travel insurance.

> *Ellen: Yes, we had travel insurance, but the only things we mentioned were the things that affected you physically rather than…*
>
> *Interviewer: Ok, so the dementia was not mentioned at all?*
>
> *[Ellen shakes her head.]*

In other cases, participants did not think that it was anyone else's business to know about their health status. The question here is whether it is right that people living with dementia should be made to divulge this highly personal information when entering into a consumer contract.

David, who lives with dementia, expressed this very clearly and forcefully in his interview.

> *David: My family knows that I have dementia, but apart from that, we keep it between our walls.*
>
> *Interviewer: Yes, I see. So for example your bank, would they know that you have dementia?*
>
> *David: No.*
>
> *Interviewer: And you feel it is not necessary for them to know it.*

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[28] See Chapter 11, Section 11.2 on vulnerability today being seen as the norm and consequences that can be drawn from this.

> *David: No.*
>
> *Interviewer: Do you think you keep it to yourself because you are worried about how they might react?*
>
> *David: No, I think it is just the simple case that it has got nothing to do with them.*

This shows a dissonance between the right to privacy of the person and the need for the contracting party to be made aware of any potential cognitive impairment, should the person at a later date wish to rely on this fact when contesting a contract. These responses show that this is clearly a private and sensitive issue that many people do not wish to share widely. This may in part be due to the stigma[29] that persists around the notion of dementia.

Knowledge of the business

The issue of knowledge of the parties to a contract is however not confined to knowing about the consumer living with dementia and their possible vulnerability or capacity consideration. The consumer living with dementia might not know who they are dealing with. This can have consequences as to what they agree to. Garry describes this well in relation to his mother, who was living independently with dementia at that point:

> *Garry: I think at this stage she would trust anyone, so if someone told her, "You need to sign this", she would at first maybe be a little bit, "Oh?", but with a simple – any kind of – explanation, she would sign anything.*

This demonstrates the difficulties that people living with dementia may have over time to recognise people, and make good contractual decisions on that basis. Where it is no longer clear to the person living with dementia if the person asking them to sign a contract is an impartial adviser or an interested party, there must be some doubt as to whether this lack of understanding is significant if there are future doubts about the contractual relationship.

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[29] Stigma is discussed in more detail in Section 9.4.

9.4 Experiencing a fear of stigma

This section explores the fear of stigma, which can be equated to a fear of unfair treatment or blame due to their set of particular circumstances. Looking at stigmatisation generally, Goffman defines stigma as "*a sign of disgrace or discredit that is considered to be undesirable by society*".[30] As a result, those who are associated with such stigma are sidelined, avoided or ostracised.[31]

Illnesses will often carry stigma, especially were the symptoms are "*visible and intrusive*".[32] In addition, illnesses that are thought to be due to the behaviour of the person or affect the mind (such as dementia) are subject to stigma.[33]

Mary felt strongly about the stigma associated with dementia.

> *Mary: But the fear of the person with dementia… the word dementia is already such a horrid word. You know, when [you] read Harry Potter, there are the 'dementors'! Things haven't gotten any better.*

While this was one of the most strongly worded responses on why there was a worry of divulging a diagnosis of dementia, there was a general sense that there were various negative stereotypes and ideas associated with dementia and that these negative images could lead to the stigmatisation of people living with dementia.

For the persons living with dementia who were interviewed, their illness is not something they wish to broadcast widely. They worry that identification as a person with dementia means they will be seen as a lesser, weaker person, diminished in some way. This is confirmed by various prior research. For example, looking at the stigmatisation of care in the context of dementia,

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[30] Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Penguin.

[31] Byrne, P. (2001) 'Psychiatric stigma' *British Journal of Psychiatry* 178(3): 281-284.

[32] Scambler, G. (1998) 'Stigma and disease: changing paradigms' *The Lancet* 352(9133):1054-1055.

[33] Albrecht, G., Walker, V., Levy, J. (1982) 'Social distance from the stigmatized: A test of two theories', *Social Science and Medicine* 16: 1319-1327.

Benbow and Jolley highlight the focus on "*personhood and relational aspects of care*".[34] They found that because of prejudices brought on by the connotations of the word 'dementia', carers were more likely to have a perception of reduced standing with regards to people living with dementia. This in turn might translate into reduced interactions in care settings. Benbow and Jolley conclude that a further consequence of the stigma attached to dementia is likely to result under-diagnosis of dementia by physicians.[35]

Fear of stigma by the person with dementia

Persons living with dementia may fear the label of 'living with dementia' due to their concern that there was a tendency for society to dehumanise those that have a form of serious disability .[36] This in turn causes people living with dementia to feel a loss of self-worth and self-esteem.

> *Lauren: She [my mother with dementia] didn't want to seem diminished. I know that inside she felt it, but she would not admit to any of it.*

Rose also voiced a similar experience with her husband with dementia.

> *Rose: Just being ill, not being healthy. I think he thought there was a stigma about that. He wanted to be healthy, he wanted to be fit, he wanted to be the fittest!*

Jane explained the upset that her mother, living with dementia, felt when asked to have her memory tested by an expert from the local health trust. For her, it was the words used that made her feel a loss of self-worth. In her eyes, her memory loss was causing others to see her as less than normal.

> *Jane: We were aware that her [Jane's mother's] memory wasn't so good, so we got her down to the doctors'… and they got someone from the mental health team to come out. At first she wasn't very happy to*

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[34] Benbow, M. and Jolley, D. (2012) 'Dementia: stigma and its effects' *Neurodegenerative Disease management* 2(2): 165-172.

[35] ibid. at 165, 168.

[36] Kitwood, T. (1997) *Dementia reconsidered: the person comes first*. Open University Press, at 12.

> *have someone from the mental health team come out because she said, "I'm not mental!"*

The connotations around some of the language that is used commonly may further lead to a fear of being seen as less able. Words such as 'mental' or 'demented' conjure up images of an older generation referred to pejoratively as 'senile folk', 'mad old bats', 'silly old (wo)men'. Whilst 'mental health' and 'dementia' today have very different meanings and understandings by the wider public, some of the expressions may still lead to stigmatisation. The fear of stigma and diminished standing is a significant reason why persons living with dementia will not disclose their diagnosis of dementia in a consumer context. As a result, often the illness will be considered a private business that is not to be shared outside of the circle of close family and friends. The presentation of self before others becomes a 'performance', which "*will tend to incorporate and exemplify the officially accredited values of the society*".[37]

As discussed in Chapter 3, [38] the concept of autonomy has been revived and strengthened, including in recent case law, with for example Charles J in V v V[39] referring to the "*new respect for individual autonomy*".[40] In this context, wanting to appear fit and healthy, independent and autonomous, is often a sought-after goal, especially when cognitive impairment threatens this self-image. Performing the role of the capable person becomes face-saving in order to appear strong. Divulging a disability may be perceived as shameful.[41] After all, the sales representatives and other persons interacting with the person living with dementia do not usually broadcast the challenges they might face, be these mental or physical health issues.

Diana spoke about why they did not often mention the dementia diagnosis of her husband to businesses:

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[37] Goffman, E. (1959) 'The Presentation of Self in Everyday Life' in Calhoun, C., Gerteis, J., Moody, J., Pfaff, S. and Virk, I. (eds) (2012) *Contemporary Sociological Theory*. John Wiley & Son.

[38] See Section 3.3.

[39] V v V [2011] EWHC 3230 (Fam).

[40] V v V [2011] EWHC 3230 (Fam) at 36.

[41] Scambler, G. (2018) 'Heaping blame on shame: 'Weaponising stigma' for neoliberal times' *The Sociological Review* 66(4): 766-782.

> *Diana: It is a catch 22, isn't it? I can understand the banks' point of view because obviously if they do know, then in theory they wouldn't try and offer certain things that are inappropriate. But when you have dementia, it is... I don't know, I suppose when you start telling friends and other institutions, you can start to lose…. There is a lack of control over it. And that can be frightening.*

In the same interview, Diana also talked about insurance companies and the difficulties she felt exist when considering disclosing a diagnosis of dementia.

> *Diana: Yes, because I think they [travel insurance companies] class people.... they don't understand that there are different levels of dementia, and having an early diagnosis of dementia doesn't mean that you don't know where you put your head, but might mean you don't know where you put your keys!*

It is the fear of misunderstanding or oversimplification of what it means to live with dementia that will drive the desire to suppress relevant information. The fear of reduced status that may arise from an admission of vulnerability, and associated stigma, prevents many people from disclosing a diagnosis of dementia.

For example, Alice explained that at one point she had taken out pet insurance by telephone. She had specific concerns in mind that she voiced, and the sales representative told her in response that these were indeed covered by the policy. When she later needed to make a claim, the claim was initially denied, because the insurance company then asserted that the circumstances were not insurable. Because of her dementia, Alice felt she could not be 100% certain of the initial telephone conversation, even though she was adamant that she would not have entered into the contract unless this point had been clarified as she remembered it.

> *Alice: I was convinced that I said it but I could not look anybody in the eye and say, "I said that"… I couldn't have counted on that. In the past I would've known what it was that I had said, my memory was very*

> *good, but now I can't trust that. I doubt myself all the time. If they did not have the transcript I would've rolled over.*

It was only after the insurer listened to the recording of the initial sales pitch that Alice's claim was successful. Alice was asked about whether she had told the insurer about her dementia diagnosis.

> *Alice: No I didn't, I didn't, I was wondering if I should or not…*

This is a dilemma often faced by people with dementia. The worry is that they will be treated differently (disadvantageously) if the diagnosis becomes known to the business. The risk they perceive is that they will no longer be seen as the person who entered into the contract, but rather a lesser person who, whilst bound by the contract, cannot stand up for themselves when wanting to exercise their rights under the contract. Their freedom to contract and make decisions might be questioned or even denied.

Whilst any such denial of contract on the basis of a protected characteristic, such as age or disability, would contravene the Equality Act 2010, in practice persons living with dementia may find it hard to access justice in such a situation.[42]

Finally, the stigma may be attached to a sense of shame or dread of no longer being able to cope, and of having others take over for them, be it in day-to-day activities and tasks, such as personal and financial decision-making.[43] The stigma relates to the fact that this is considered a mental rather than physical illness, which might imply a loss of independence or personhood.

Rose talked about the upset her husband had felt when he was described as being cognitively impaired.

> *Rose: So he [my husband] wouldn't hear of being, certainly, mentally ill. He wouldn't hear of that because, you know, the thought that I was*

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[42] A more detailed discussion of such potential barrier to justice is presented in Section 11.4.

[43] Riley, R.J. et al. (2014) 'Anxiety and Stigma in Dementia' *Nursing Clinics* 49(2): 213-231.

> *suggesting, or that anyone was suggesting that there was something wrong with his brain, oh, that really got to him. That was far worse than saying he had something wrong with his stomach, his feet, or the like.*

As a result of the fear of stigmatisation, people living with dementia and their family members may feel inclined to keep information of the diagnosis to themselves. This in turn can then lead to them not getting the consideration, advice and assistance that would be most helpful to them in all aspects of their lives, be it care, medical treatment, adequate housing, to name but a few.

To counter stigmatisation, education was mentioned by several of the persons living with dementia participating in the study. To them, this was the key, both for them personally, and to de-stigmatise dementia altogether.

Alice expressed this well.

> *Alice: Well yes, they [my friends with dementia] are talking about it [dementia] all the time. They are trying to raise awareness. I think, once you know you are not on your own, it makes such a difference. You become part of something. You can make a difference and it gives you a purpose and a value to do something. It makes you feel a bit better about the things you can control. And the stuff you can't, you have just got to learn to let it go. But I can still do a lot, so I am grateful for that. So I will keep doing it for as long as I can.*

In order to reduce the stigma, the threat of a lessening in personhood must be removed for consumers with dementia. They must still be able to participate in consumer transactions, without fear of negative or exclusionary consequences. At the same time, they must be provided with additional protections that stem from the relational aspect between the business and the consumer. The business must take the consumer as they find them, and accept that this may therefore lead to differing contractual norms (such as favourable termination provisions in certain circumstances).[44]

Until dementia is better understood and any stigma removed, the effect of stigma and subsequent coping methods, specifically in relation to *consumer* matters involving persons living with dementia and their families, is therefore wide-reaching. In practice, they may chose to refuse to disclose their illness, hide symptoms and/or pretend to understand when this is not the case. This is turn will have the potential to affect their financial situation and their independence and financial security.

Whilst many of the participants thought they would not disclose their illness due to the stigma attached to dementia, others felt differently.

> *Alice: The key is that it is a disease and that it is outside of your control, which makes all the difference. That is a very different to the narrative to 'You are mad, you are a loony'. … In all honesty if I didn't know it was a disease, I would not talk about it the way I talk about it. I would be ashamed that there was something wrong with me that was in my power to do something about, that I could change.*

Fear of stigma by family members

Stigma is not only associated with the person living with dementia themselves. In relation to dementia, this research confirms previous research[45] that indicates that the stigma of dementia affects both the person with dementia, as well as their family members. Kate, whose husband lived with dementia, expressed this well.

> *Kate: Everywhere we went, I was really upfront about it [my husband's dementia]. My husband was happy for people to know about this, he was very laid back about everything… My husband was never embarrassed, but I was embarrassed for him sometimes. I thought it*

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[44] See Chapter 10 for more detail on possible future protection.

[45] for example Ablon, J. (2003) 'The nature of stigma and medical conditions', *Epilepsy & Behaviour* 3(6S2): 2-9.

> *was a private matter, but I thought it was more useful for people to know.*

This statement demonstrates that the stigma does not only lie with the person with dementia. In some cases, the family members fear the stigma surrounding the illness as well.

Goffman[46] describes this stigma experienced by family members as "*tribal stigma*", i.e. stigma by association. This type of stigma relates to an increased risk of experiencing similar consequences to those of the initially stigmatised person, including negative emotions and social isolation.[47] In addition to worrying about how people might react to the knowledge of their loved one's dementia, many of the participants who were family members of people with dementia were also fearful of society's judgement of their own behaviour. They were concerned that there would be a question about the risk of abusing their loved one with dementia either financially or emotionally by taking over various aspects of their lives. Even though they knew they were stepping in to protect them from physical, mental or financial harm, they were often worried that others might interpret their actions differently.

For Jane, who had power of attorney for her mother with dementia and cared for her daily, this situation came to a head after she returned from a short holiday to find that her mother (who was upset because her routine had changed during the holiday) had contacted the bank and accused Jane and her brother.

> *Jane [reporting what her mother had said to the bank]: [She said to the bank,] "They are spending all my money, they are taking charge of my money, and they are not letting me have any of my money…*".

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[46] Goffman, E. (1986) *Stigma: Notes on the Management of Spoilt Identity*. Touchstone, at 11.

[47] for example, Angermeyer, M.C., Schulze, B., and Dietrich, S. (2003) 'Courtesy stigma - a focus group study of relatives of schizophrenia patients' *Social Psychiatry and Psychiatric Epidemiology* 38(10): 593-602; Chang, K.H. and Horrocks, S. (2006) 'Lived experiences of family caregivers of mentally ill relatives' *Journal of Advanced Nursing* 53(4): 435-443.

The bank stopped the bankcard held by Jane and issued a new bankcard to Jane's mother. This was devastating to Jane, who felt let down by the bank. The bank had seen Jane and her mother weekly when they went into the branch to take out cash for Jane's mother.

> *Jane: You see, I got blamed for everything, it was always my fault… [even after all paperwork about the power of attorney was provided] there was never an apology [from the bank].*

Jane's experience highlights the issues of stigma that might be felt by family members who are trying to help, but are at the same time worried about how their roles and actions will be viewed and considered by those around them. With stories of abuse and neglect of people living with dementia by their relatives in the media, family members are often fearful of being grouped into that category of abusers, despite not being at fault in any way.

9.5 Experiencing a lack of compliance knowledge

The issue of knowledge is not limited to the moment in time when the contract is signed. Throughout the duration of the contract, knowledge and understanding of their rights and obligations are essential for the contracting parties. For example, a lack of understanding of on-going obligations may void the contract to the detriment of one of the parties. A typical example is that of an insurance contract, which will contain provisions requiring the consumer throughout the term of the contract to update their information regularly. Non-compliance with these on-going obligations by the consumer (such as if a change of circumstance is not reported in a timely manner) will result in the insurance contract being voided.

In addition, the consumer living with dementia must also know how to comply with their on-going obligations, or how to assert their on-going rights. In many consumer contracts, such as insurance, mobile phone or utility contracts, terms may allow the business to 'roll-over' the contract, i.e. to automatically renew the contract, for example reverting to 'standard terms' after an initial period in which a more favourable 'fixed term deal' was granted. In such renewal cases, contracts can be rolled-over unless the consumer indicates that they do not wish such renewal.[48] This is particularly important to note for the consumer living with dementia, who might not remember that a contract is on-going over a number of years, or may not grasp the consequences of such an automatic renewal clause on less favourable terms.

In certain sectors, such as the telecoms industry, more stringent rules are in place for renewal for another fixed term (in this case express consent is required from the consumer);[49] nevertheless, the consumer living with dementia may not understand the consequences of such an extension of contract and agree to such renewal to their financial detriment. Indeed, "*an automatic renewal by the same term burdens the consumer, who might not have considered such an automatic extension, while at the same time benefitting the service provider, who retains a customer for another fixed term*."[50]

A charity worker described the following in relation to utility providers:

> *Charity worker: The other thing they don't make easy is to tell you when your current contract ends. So, they give that information, but they will give it to you ideally when your current contract has already ended. Or they just sometimes don't give you that information, so your current contract ends, you then go on to the standard tariff which is the most expensive, and it is then up to you whether you then notice it. So that is another bit where they are kind of misleading vulnerable people and where they have obligations to communicate that better.*

This highlights the fact that many contractual terms are drafted to ensure a consumer needs to take a series of actions proactively at a later stage after the contract was initially concluded, in order to avoid adverse changes to their

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[48] Consumer Rights Act 2015, sch. 2(9)

[49] Ofcom. (2015). *Consolidated version of general conditions*, available at https://www.ofcom.org.uk/__data/assets/pdf_file/0026/86273/CONSOLIDATED_VERSION_OF_GENERAL_CONDITIONS_AS_AT_28_MAY_2015-1.pdf, s.9(3)(a)(i), last accessed 14 February 2021.

[50] Dodsworth, T.J. and Bisping, C. (2019) 'Consumer Protection and the Regulation of Mobile Phone Contracts - a Study of Automatically Renewable Long-Term Contracts Across Jurisdictions' *Journal of Consumer Policy* 42: 349-375, at 357.

consumer relationship with the business. With roll-over provisions, despite the possibility of memory issues, consumers living with dementia are required to retain information on when the advantageous contract term will end, and what action would need to be taken at that transition point to ensure similar beneficial terms.

Under the Consumer Rights Act, automatic renewal terms may be considered 'unfair'[51] if such term "*has the object or effect of automatically extending a contract of fixed duration where the consumer does not indicate otherwise, when the deadline fixed for the consumer to express a desire not to extend the contract is unreasonably early*." [52]

Whilst consumer rules have made the use of automatic renewal clauses more visible, in that consumers are now asked to expressly agree to such clauses and are given time to cancel the new contract, nevertheless they are still used regularly in consumer contracts and remain problematic in many cases. Consumers will often not fully understand the implications of agreeing to the renewal provision, and "*some consumers [will] mistakenly forget to cancel the agreement in due time and are subsequently inefficiently bound for a new term*".[53]

To this effect, the Citizens Advice Bureau submitted a super-complaint to the Competition and Markets Authority in 2018, highlighting the issue of automatic renewal and consequential loyalty penalty,[54] especially for vulnerable and low-income consumers. The Citizens Advice Bureau called for a "*principles-based regulation regarding what pricing strategies are permissible, putting the*

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[51] Council Directive 93/13/EEC of 5 April 1993 on Unfair Terms in Consumer Contracts, Article 3(3).

[52] Consumer Rights Act 2025, Annex 2, s. 9; and also Council Directive 93/13/EEC of 5 April 1993 on Unfair Terms in Consumer Contracts, Annex 1(h).

[53] Kovač, M., Vandenberghe, A. (2015) 'Regulation of Automatic Renewal Clauses: A Behavioural Law and Economics Approach' *Journal of Consumer Policy* 38: 287–313.

[54] Citizens' Advice (2018) *Excessive prices for disengaged consumers, A super-complaint to the Competition and Markets Authority*, available at https://www.citizensadvice.org.uk/Global/CitizensAdvice/Consumer%20publications/Supercomplaint%20%20Excessive%20prices%20for%20disengaged%20consumers%20(1)pdf, last accessed on 14 February 2021.

responsibility on companies to judge whether their practices are consistent with treating customers fairly".[55] This suggestion of fairer trading practices is reviewed in more detail in Chapter 11.[56]

Whilst the Competition and Markets Authority responded positively in 2018,[57] and has since published two follow-up papers,[58] acknowledging the difficulties these roll-over practices provided, and identifying that those most at risk of harm were vulnerable and low-income consumers, no binding regulation has since been introduced.

Several of the participants in the interviews discussed such rolling contracts. Participants felt strongly that people with cognitive impairment, such as consumers living with dementia, were particularly disadvantaged, as they needed, in the first instance, to understand what an automatic renewal clause entailed, and then later be able to comprehend that automatic renewal was about to take place, consider if a new contract made sense to them, compare past and new pricing (maybe further compare new prices within the relevant market place), remember to cancel, recall how to contact the business, or make sure to speak to a family member, carer or assistant to ask them to support them in this task.

Several family members talked about finding direct debits set up on the account of their family member living with dementia, which related to something they no longer required, but that had rolled over repeatedly. Top of

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[55] ibid., at 46.

[56] See Chapter 11, Section 11.3 on fairer practices.

[57] CMA (2018) *Tackling the loyalty penalty, response to a super-complaint made by Citizens Advice on 28 September 2018*, available at https://assets.publishing.service.gov.uk/media/5c194665e5274a4685bfbafa/response_to_super_complaint_pdf.pdf, last accessed on 14 February 2021.

[58] CMA (2019) *Loyalty penalty update: getting better and fairer deals, June 2019*, available at https://assets.publishing.service.gov.uk/media/5d08f9daed915d42ea95ddb4/Progress_update_June2019_31916_.pdf, last accessed on 14 February 2021; CMA (2020) *January 2020: Loyalty Penalty Update*, available at https://assets.publishing.service.gov.uk/media/5e25d4b540f0b62c54df7fc1/Loyalty_penalty_update_20_Jan.pdf, last accessed on 14 February 2021.

that list were insurance payments for breakdown cover, when the car had been sold years before.

Walter, whose mother lives with dementia, talked of his frustration with these contracts and the difficulty staying in control.

> *Walter: Yes, I hate those [automatically renewed contracts]… people get rid of their car, and their breakdown insurance goes on. But that goes back to the renewal of insurance which is just - I really gets me going, that - I have to phone them up in advance to say, "Don't take my money.", and when I am saying that, I am in control of it. And sometimes if you forget…*

Later in his interview, Walter gave further thought to the issue of automatic renewal.

> *Walter: So, if you think about it, we have an ageing population, people are living longer, physically older, mentally not doing so well, so it is going to get a lot worse, and the way the money systems work, it is going to work in favour of the businesses because of automatic renewals….*

These quotes show the powerlessness felt by many family members trying to assist their loved ones who are living with dementia.[59] There is a feeling that the odds are stacked against them and protect the business rather than the consumer, especially when the consumer is in any way vulnerable and less likely to proactively take control.

Another issue is that even when a person living with dementia wants to comply with their obligations under an on-going contract, they are often prevented from doing so because the means of contacting the business are beyond their capabilities. As a cost-cutting exercise,[60] many companies

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[59] Powerlessness is further discussed in Chapter 10 below.

[60] Couto, V., Plansky, J. and Caglar, D. (2017) *Fit for Growth: A Guide to Strategic Cost Cutting, Restructuring, and Renewal***.** John Wiley & Sons.

favour communicating with their customers by electronic means, be it via a web page, by email or through a call centre.

Some older people are not as familiar with the Internet as the younger generations. A survey carried out in 2019 by the Office of National Statistics found that Internet usage among adults differed greatly depending on age.

> *Virtually all adults aged 16 to 44 years in the UK were recent Internet users (99%) in 2019, compared with 47% of adults aged 75 years and over*.[61]

Cognitive impairment such as dementia may be a barrier for some people to learn how to use a computer at an older age. As a result, some consumers may be precluded from communicating with businesses via webpages or email. Turning to call centres to comply with their obligations (such as providing updated meter readings or informing the business of a change of circumstance) might also be highly challenging for some consumers living with dementia.

This was described well by Mary, whose mother had dementia.

> *Mary: …. People in the earlier stages of dementia and without a diagnosis may perhaps still be engaging with businesses and getting into a terrible muddle, actually. … we do so much on the Internet now, banking, passwords, but there may be a time when we can't do that. What do you do then? Who is the person at the end of the line who is not just a computer? Who is there to help when people can't navigate online anymore? It is a real-world problem.*

In order to streamline and simplify their business for financial and administrative purposes, many companies are closing high street outlets.

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[61] ONS (2019) *Internet users, UK: 2019. Internet use in the UK annual estimates by age, sex, disability and geographical location*, available at https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2019, last accessed on 14 February 2021.

PWC who undertook research on store closures[62] found that, for example, for banks and other financial institutions, there was a move to digital platforms as consumers "*become increasingly comfortable performing regular tasks and chores online*". In addition, there is an increased reliance on telephone centres, often situated outside the UK. Further economies are made by putting in place automated systems which are the first line of contact when making a telephone call, requiring the consumer to make a series of decisions in order to reach the relevant (human) customer service employee to whom to speak.

For some consumers however, this might mean that it is more difficult to contact, communicate with, or ask questions of, the business. Eduard, who lives with dementia, explained that he volunteered with a group that would visit organisations, such as post offices, GP practices and businesses, and assess their requirements for knowing passwords or pin codes in order for consumers to communicate with them. His wife confirmed that it was very difficult for Eduard on the telephone as well, when passwords were needed or security questions had to be answered.

> *Eduard had the last word on this point: About 8 years ago… I had no problem at all….[I] dealt with all the things you have got to deal with, the bills you have to pay, everything like that. And then gradually it sort of got worse and I used to forget to pay things and stuff like that…*

Consumers with dementia will, as discussed above, have to retain information about the contract's existence, but also about the need to check regularly if the contract has come to an end, if its on-going payment demands have increased, if the contract was automatically renewed beyond the initial contract period. All of these requirements are a challenge for most people. For those with cognitive impairment such as memory loss, the task of keeping track of all of these on-going obligations is an even more difficult task. People with cognitive impairments are therefore more likely to remain loyal to

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[62] PWC (2019) *Store closures and openings - 2019*, available at https://www.pwc.co.uk/industries/retail-consumer/insights/store-openings-and-closures-2019.html, last accessed on 14 February 2021.

businesses, such as insurance providers, utility providers, banks and other organisations providing on-going goods or services, but their inability to switch business relationship easily, and their subsequent loyalty, is often penalised.

9.6 Concluding remarks

The aim of this chapter has been to explore the function of knowledge and information in consumer transactions. Information about an individual's capacity, depending on what is disclosed, when, and indeed whether, will determine how a consumer contract will be viewed and actioned. The validity of the contract will be considered in the light of the information available to the parties; their knowledge is an essential factor. As this chapter has demonstrated, knowledge is multifaceted, and includes relational knowledge (the information made available about the parties to the contract), transactional knowledge (the information the parties have of the contract terms) and compliance knowledge (the knowledge needed in order for the parties to comply with their obligations).

At the opposite end of the spectrum, a lack of knowledge will have an impact, both on whether a contract is entered into, and on whether the parties may be able to disentangle themselves from a contract at a later time. Lack of knowledge of the business counterpart may be due to withholding of information by the consumer living with dementia. There are a number of explanations why information might be withheld in that context. In addition to the illness not being diagnosed, or the diagnosis of dementia being either forgotten or rejected, in many cases the fear of stigma means that information about the consumer's circumstances is omitted. This is because a diagnosis of dementia is often associated with vulnerability.[63] Where vulnerability is considered narrowly, applied only to a small group of persons, it is likely to have negative connotations. In such circumstances, where vulnerability is viewed as something exceptional and problematic, consumers living with dementia may be fearful of this resulting in their diminished standing in

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[63] Harding, R (2018). *Duties to Care, Dementia, Relationality and Law*. Cambridge University Press, at 223, referring to Fineman.

society. This in turn will prevent them from relying on any legal remedies that might allow them to rescind the contract because of their situation.[64]

Beyond the information needed at the start of the contract, clauses in the contract that require actions throughout the life of the contract are also significant when considering the knowledge of the parties. In particular, this chapter has focused on clauses allowing for contracts to roll over and automatically renew, often on less favourable terms. In relation to these practices, this chapter looked at the significance of the relationship between the parties. Given the recent general acceptance of (potential) vulnerability of a majority of consumers, [65] it is suggested herein that there be a shift in the relationship between business and consumer requiring businesses to increase their assistance in relation to all consumers to ensure compliance with their rights and obligations.

As was discussed in relation to contract law, [66] there are expectations of the parties that the terms will be reasonable and fair [67] and that the parties will act with honesty. [68] This needs to be extended further to take into account the circumstances and context of the parties, including of the consumer living with dementia, by placing the person back in the centre of a contractual interaction.[69] That relational approach to contract law would therefore allow

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[64] Hall, M. (2019) ‘Relational autonomy, vulnerability theory, older adults and the law: making it real’ *Elder Law Review* 12, at 8.

[65] FCA (2017) *Understanding the financial lives of UK adults: findings from the FCA’s financial lives survey 2017.*

[66] See Section 7.3.

[67] Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 257, referring to Thomas, C. (2010) “What Role Should Substantive Fairness Have in the English Law of Contract? An Overview of the Law’ *Cambridge Student Law Review*, at 177.

[68] Gounari, Z. (2021) ‘Developing a relational law of contracts: Striking a balance between abstraction and contextualism’. *Legal Studies* 41(2): 177-193, at 182/3.

[69] Thompson, S. (2018) ‘Feminist Relational Contract Theory: A new model for family property agreements’ *Journal of Law and Society* 45(4): 617-645, at 617.

for the contract to be interpreted looking at “*the reality of the parties’ relationship and actual intentions”.* [70]

In the next chapter, findings will be presented and analysed in relation to the participants’ sense of powerlessness to question or cancel concluded consumer contracts. In addition, their solutions, both pragmatic and legal are explored in more detail.

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[70] Gounari, Z. (2021) ‘Developing a relational law of contracts: Striking a balance between abstraction and contextualism’. *Legal Studies.* 41(2): 177-193, at 181.

Chapter 10 Experiences of both powerlessness and protection

10.1 Introduction

The two previous chapters have examined the issues that arise, first, when the contract is entered into and then during its existence. This chapter now turns to the issues that arise at the end point of the contract, i.e. at the moment of termination. It looks first at the powerlessness experienced by families when attempting to assist their loved ones with dementia in contractual matters. In interviews family members expressed the difficulties they encountered when seeking to void or terminate consumer contracts that a person living with dementia had entered into to their financial detriment. This powerlessness came from the realisation that in many cases the consumer contracts entered into were valid and that termination or cancellation of the contract would be complex and onerous.

As discussed in Chapter 6 above, the law does not allow for contracts to be voided simply because one of the parties made a poor deal.[1] Indeed, certainty of contract is a fundamental principle of contract law. Its intention is to protect the parties from the uncertainty that would arise if either party could change their mind or renegotiate the deal whenever it suited them. Whilst this is an important and useful protective mechanism for equal partners to a contract, it is less clear whether it is appropriate for persons in an unequal contractual relationship. Currently, the fact that a person was in a vulnerable situation at the moment of entering into the contract is not automatically taken into account. The Consumer Rights Act specifically expects consumers to be "*reasonably well-informed, observant and circumspect*"[2] when contracting with a business. The Mental Capacity Act specifically states that an "*unwise decision*"[3] is not a reason to suggest that a person lacks capacity. Even when capacity is lacking, the courts have made it clear that knowledge of the parties will also need to be considered before a contract can be voided.[4] As

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[1] See Section 6.2.

[2] Consumer Rights Act 2015, s. 64(5).

[3] Mental Capacity Act 2005, s. 1(4).

[4] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1; Ayres v Hazelgrove (QB, 9 February 1984, unreported).

demonstrated in Chapter 7, only a *known* lack of capacity will void the contract.[5]

As a result, the remedies available to the consumer living with dementia, or their family members acting on their behalf, are limited. They may be able to cancel the contract in line with the contract terms, although these may require a further financial outlay due to either a delay in cancellation as a result of prior-notification requirements or because of provisions demanding administrative or early-termination payments.

For example, cancellation of a consumer contract with a telecom provider may require the prior notification several months in advance of the actual termination of the contract. Only after such notification and the expiry of the additional term can the contract be ended. Of course, during the notification period, the monthly fee will remain payable. Another example could be that of a utilities provider that imposes the payment of penalties to terminate the contract earlier than the intended termination date. These examples illustrate the difficulties encountered when looking to extract a person living with dementia from a consumer contract.

In fact, as highlighted in Chapter 7, the consumer in a vulnerable situation has few rights and remedies, if they want to terminate or void a contract that is to their detriment. This chapter explores how persons living with dementia and their families experience this, as well as the ways in which in practice family members have sought to terminate contracts entered into by persons living with dementia. It also evaluates a number of possible solutions as envisaged both by family members and people living with dementia in light of their experiences.

The chapter is structured in the following manner. **Section 10.2** will focus on the powerlessness of many participants. The main reasons for such feelings of powerlessness were two-fold. First, many participants reported that they were ignorant of most (or all) of the consumer contracts that had been entered into by the person living with dementia. They were therefore unable to react

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[5] See Section 7.2.

until much later. Next, even when these consumer contracts were apparent to them, they encountered legal barriers that prevented the situation from being easily remedied.

Participants talked frequently about the way that contracts had been entered into. From the interviews it became apparent that most contracts that were later deemed unwanted were contracts that the business had initiated. This trend and its consequences are explored in **Section 10.3**.

However, not all experiences were negative and **Section 10.4** will focus on the solutions that participants found worked for them in practice. In addition, many participants had suggestions as to how they would tackle the issues, and these represent valuable ideas to be considered.

The lasting power of attorney was a solution with a solid legal foundation that was put into practice in all cases by the participants of the interviews conducted in order to allow for assisted decision-making. The lasting power of attorney however brought its own challenges, as discussed in **Section 10.5.** Finally, **Section 10.6** provides concluding remarks.

10.2 Experiencing powerlessness in cancelling detrimental contracts

Many of the participants, including a person living with dementia and most of the family members of people living with dementia, expressed their frustration at not being able to do more when a consumer contract was entered into that was subsequently deemed unwanted.

There were two key reasons for the difficulties encountered. First, in many cases, family members did not find out until much later that a consumer contract had been entered into. The other challenge, faced by both people living with dementia and their family members, was that, even when these contracts resulting from ‘unwise decisions’[6] were apparent to them, they were prevented from terminating the consumer contract without incurring penalties. Each of these will be explored in more detail below.

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[6] Mental Capacity Act 2005, s. 1(4).

Powerless when unaware of the existence of detrimental contracts

Very often, it was only when direct debits or large sums of money were removed from the bank account of the person living with dementia that the family members were alerted to the situation.

Mary explained that her mother, who lived with dementia, was overwhelmed with books that were being sent to her monthly by a book selling company. This company advertised itself as an international book club. Mary's mother joined the scheme at some point, unbeknown to her (grown-up) children. Under the terms of the agreement, the book club would select one or several books each month which members were deemed to have accepted, unless they expressly rejected the selection of books. If Mary's mother did not actively engage with the company and state that she did not want that selection, it was shipped to her and money was taken by direct debit from her account. While she was unable to stop these repeat sales herself, she did not mention it to her family for a long time. One weekend, she finally opened up to her daughter.

> *Mary: I am remembering now, I was staying there one weekend and the post came and she said, "Look!", and it was some kind of inertia selling, I can't quite remember how it worked but she belonged to it [the international book club] and unless you checked, unless you sent a letter back to say, "I don't want the next month's selection", it would come. I don't remember how the payment went, I just know that she didn't know how to stop it, she felt she hadn't asked for them and it was really, really difficult. In the end, and I don't know how long after this this was, my brother just phoned up and they put a stop to it. But I think she had already paid for the books because it was one of those automatic coming-out-of-your-bank-account things. And he stopped them from sending any more. I don't know what we did with all the books; I suspect we took them to the charity shop. But it caused a lot of anxiety, and it was only by chance that we learnt about it.*

This demonstrates not only the powerlessness felt by the person living with dementia, where they could not understand the basis of the contract, why goods or services were being delivered or how these might be stopped, but also the powerlessness of family members who can only help if they know about the contract that was signed, if they are aware of the unwanted goods or services received and if the person living with dementia remembers to talk about these challenges they are facing. Even if they remember, it may be an embarrassment to them to admit that they cannot cope, which again might lead to such consumer contracts being hidden from family members.

Powerless to change the situation

In some cases family members felt that the goods or services could not be returned and in these situations, families found themselves powerless to change a difficult situation. The person living with dementia was deemed to be tied into the consumer contract with no way out.

Oscar felt strongly about this. His parents, who both lived with dementia, thought it would be good to install a stair lift. At first Oscar tried to dissuade them, but seeing their insistence, he found a local company that could install a suitable stair lift for £4000. His father however decided to make his own enquiries.

> *Oscar: He [my dad] contacted them [Stena Stairlifts] directly, the day after I told him, “Look, there is a local company, they can fit it.”… So I go round and this bloke is fitting it. And I said, “What the hell is going on?” It was disgraceful, I was absolutely furious. I think it was either £6000 or £8000.*

Oscar was convinced that Stena Stairlifts were not offering more (in terms of services or goods) for the money than the local company. He thought his father was no longer able to ‘shop around’, compare deals and choose the consumer contract most suited to his needs. Instead, Oscar felt his father had been rushed into the deal and had not had a chance to discuss it with anyone. Oscar was frustrated that he did not know how to get out of the agreement on behalf of his parents, now that the stair lift was installed in their home.

> *Oscar: And to do it so quickly, within one day to come and view the job and install it… no time to discuss it with anyone. I have power of attorney so I could have refused to pay, but I was advised that in that case they would sue me…*

This situation very clearly sets out how consumers living with dementia and their families will often feel powerless to question a consumer contract once entered into, especially once the goods or services have been delivered and are may be difficult to return.

10.3 Experiencing concerns about cold calling by businesses

Whilst Oscar's father in the example above proactively contacted Stena Stairlifts, this was not the norm. From the interviews it emerged that most of the contracts that were later deemed problematic and which the person living with dementia or their family members sought to cancel or void related to contracts that had been initiated by the business, rather than contracts in relation to which the person living with dementia had approached a business. This is unsurprising given that contracts initiated by the consumer are more likely to relate to goods or services that they want or need, whereas those initiated by the business will often relate to goods and services they had not actively considered previously. It is nonetheless significant that participants identified that many contracts entered into by persons living with dementia were unwanted or unneeded.

With this in mind, it is important to review the evidence as to how contracts were initiated, to highlight the risk of harm to the person living with dementia [7] and the powerlessness of family members. Cold calling may increase the risk of (financial or other) harm of certain groups (such as for example persons living alone with dementia) who might in such circumstances be considered especially vulnerable. As discussed in Chapter 3, the universalist approach

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[7] MacKenzie, C. (2014) 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in MacKenzie, C., Rogers, W. and Dodds, S. (eds) *Vulnerability. New Essays in Ethics and Feminist Philosophy,* at 33-59. Oxford University Press.

states that all persons are vulnerable,[8] it is the case that some have the potential of compounded vulnerability because of circumstances, either internal or external to the person.[9]

As discussed in Chapter 3, people living with dementia may need to be supported for certain decisions, such as some consumer decisions with financial implications for the person. The issue with cold calling by businesses is that the interaction between business and consumer living with dementia often takes place without available support to the person living with dementia. This may be either because they might be physically alone at home at that moment in time, or because of the immediacy of decision-making, which seldom leaves room for reflection and discussion with any supporter.

Many of the incidents have already been described in previous chapters, but it is worth repeating some of the examples to emphasise the issue and allow the experiences of concern and frustration of the participants to be heard.

On the door step

In a number of cases, the person living with dementia was approached at their home. A door-to-door salesperson or other trader would make contact directly, offering goods or services. In this way, Nicole' mother bought bags of manure,[10] and Lauren's mother had agreed to various gardening jobs.[11] These examples have in common that the trader approached the consumer living with dementia, and that the family member was concerned about the vulnerability of their parent in this situation, especially in relation to the risk of financial harm.

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[8] Fineman, M. (2008) 'The Vulnerable Subject: Anchoring Equality in the Human Condition' *Yale Journal of Law & Feminism* 20(1): Article 2, at 12.

[9] For example, MacKenzie, C. (2014) 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in MacKenzie, C., Rogers, W. and Dodds, S. (eds) *Vulnerability. New Essays in Ethics and Feminist Philosophy,* at 33-59. Oxford University Press; and Herring, J. (2016) *Vulnerable Adults and the Law*. Oxford University Press, at 7.

[10] See Section 9.2.

[11] See Section 8.3.

> *Nicole: It rang warning bells, it was a bit scary that someone might have ripped her off. She is quite an innocent person, quite vulnerable. You know, she is in her 90s, she would not have known what a fair price would have been.*

This demonstrates the family's concern that reduced capacity would make their mother more vulnerable when approached directly at home without support when making financial decisions. Whilst family members wanted their parent to retain freedom of choice, they were aware that they required assistance in certain circumstances.

Similarly, Lauren felt that her mother was at greater risk when approached on her doorstep because of her dementia and reduced capacity. Section 8.3 reported of her concerns when she had gardening work done by door-to-door tradesmen. In the same interview, Lauren recounted how her mother had agreed to her driveway being redone by another trader knocking on her door.

> *Lauren: Well, travellers called at her door, and asked if she wanted her driveway done. And she agreed there and then because it was a very charming young man, an Irish chap full of Irish charm. She agreed. I knew nothing of this until a neighbour called up and said that there was a team of people digging up the front drive.*

This demonstrates the ease with which a tradesperson may be able to persuade a consumer living with dementia to enter into a binding agreement that minutes before they did not want or need.

Lauren was frustrated that her mother, who at that point had reduced capacity, had signed an agreement without fully understanding, especially as it was for a large sum (£15000 in total) that would substantively deplete her savings.

> *Lauren: The travellers had written the contract, and mum had signed it. The first payment was for £2000, and then there was going to be another payment for something else, and mum had signed it, "Oh yes,*

> *that's fine". The policeman asked her "Have you got any written document?" and she said, "Oh yes, yes, yes, I've got this".*

In this case the police was called, but in many cases the contract made with the door-to-door sales representative will stand, leaving family members feeling powerless to remedy the situation without financial loss.

By post

In Section 8.2, Mary told of how her mother had signed up to an International book club, and was receiving books monthly that she felt powerless to stop. Money was being taken from her account monthly and family members were unable to act because they were unaware of the situation. Even when they finally helped put an end to the contract, prior payments were not challenged. That money was lost. The unwanted and unread books were simply handed to a charity shop.

> *Mary: I just know that she didn't know how to stop it, she felt she hadn't asked for them and it was really, really difficult. In the end, and I don't know how long after this this was, my brother just phoned up and they put a stop to it. But I think she had already paid for the books because it was one of those automatic coming-out-of-your-bank-account things. And he stopped them from sending any more. I don't know what we did with all the books; I suspect we took them to the charity shop. But it caused a lot of anxiety, and it was only by chance that we learnt about it.*

This shows again that the contract, when initiated by the business, is more likely to be one that is later found to be unwanted. For a person living with dementia who may not fully understand the terms of the contract, the complexity of an adhesion contract, whereby books are automatically agreed to unless actively rejected, will often be too difficult to deal with alone.

By telephone

In Chapter 8,[12] Kate talked of her husband, who was living with dementia, being invited to join a wine club by telephone. It was only because she overheard the conversation that she was able to stop a contract being formed. However, this was not the only purchase offered to her husband by telephone.

> *Kate: Part of it was his character, if somebody phoned up, he quite liked to keep talking to the cold caller on the phone. He could be quite naughty! But he did buy things. The olive oil is a classic; he stayed on the phone with them for half an hour. And it was only ended because I was there hovering by him, saying "Give the phone to me, give the phone to me!" And he was quite upset by that, because he felt I was interfering and I also felt I was interfering. In the end he did pass me the phone and I explained the situation. If I hadn't been there he might have bought something.*

In her interview, Kate did express the opinion that without her presence, contracts would have been entered into with these businesses, simply because they had initiated contact by telephone. Whilst Kate wanted her husband to remain active and busy, it was important to her that she was available to support his decision-making and step in where his increased vulnerability due to the cognitive impairment might prevent him from fully understanding all implications of a decision.

Similarly, Nicole described how her mother, living with dementia had contracted to pay a lesser-known charity on a monthly basis.

> *Nicole:*[13] *The other thing that we were a bit concerned about was, as I said, my brother dealt with her finances, and he noticed that there was a direct debit, which was started up, that was going to a charity. I don't really know, but we are pretty sure that that came through the telephone. Because at that stage I don't think Mum would have been able to fill in a form and put it in the post. So we were pretty sure that that had happened.*

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[12] See Section 8.2.

[13] See Section 8.3.

Again, the business approached the consumer, leading to a legally binding contract. In the next chapter,[14] a suggestion is set out to counter such business practices, which are generally detrimental to the consumer living with dementia.

10.4 Experiencing power and protection in practice

Not all experiences were negative and participants identified various solutions that in practice worked for them. In addition, many participants had suggestions of how they would tackle the issues, and these represent valuable ideas to be considered further herein.

Successful steps taken in practice

Reminding the business that their reputation may be at stake

In several cases, it was the desire of the business to retain their good reputation which was a key factor in getting the business to agree to terminate a contract that the person living with dementia, or their relatives acting on their behalf, deemed detrimental.

For example, at one point Garry's mother, who is living with dementia, entered into an unsuitable mobile phone contract. It was of no use to her, because it had specific restrictions on it that prevented her making calls abroad. However, part of her family was overseas and she needed to make regular calls to them. The fees were high and included charges for data or texts that she could not use due to her cognitive impairment and consequential inability to learn how to navigate the mobile phone and use text or internet tools.

> *Garry: We were able to cancel the contract by writing to them and explaining the situation, I believe. I am not sure if it was specifically because of the dementia, but because she was an elderly person… I feel we were able to explain that she was an elderly lady who felt a bit more taken advantage of, so for them to not make unnecessary waves, maybe they cancelled the contract.*

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[14] See Chapter 11, Section 11.2 on a mandatory pre-contractual reflection period.

Here, it seems that appealing to the business's better nature, and not wanting to appear uncaring towards an older person allowed the grown-up child to terminate the contract without relying on legal means.

Withholding money owed

In some cases, especially where fees are payable on a regular basis, one tactic used by participants was to withhold money owed.

For example, Walter, whose mother lives with dementia, felt strongly that in order for the business to take notice and seek a mutually successful solution, the best way was to withhold further payment. He explained his method in relation to a mobile phone contract his mother had entered into, that was not being used and that he consequently wanted to terminate.

> *Walter: I would cancel the direct debit straight away. No doubt about it. Because I have a particular thing about finances and accounts, the only time you can make a bank listen is when you don't pay them. So you cancel first, then you go and have a chat. You don't keep paying, that is the way they wake up. If you keep paying, there is no incentive. You have to cancel the direct debit. And of course if you are acting for someone, if you are their attorney, and it is a person who is elderly, the point is you are not sure if they understood the consequences of entering into that contract. That is how I deal with it, "Well, what are you going to do about it?" And then you have an argument, a squabble, and then usually it would go away.*

Whilst this worked for this participant, it can be a difficult option. In refusing to make a payment when due under the terms of the contract, the person living with dementia is placed in a position where they are in breach of contract. Other family members interviewed expressly stated that they would worry if they received legal letters, payment demands, threats of being sued, or if they simply did not comply with what the contract required them to do.

Reversing the roles

In many cases, it was the person living with dementia or their family members that are dreading cold calls or postal adverts. This was because often the person living with dementia would not understand the voluntary nature of signing up to an offer, leading to difficulties later on if they had completed forms and provided name, address, bank details and consent to receive certain goods or services.

However, in one case, the roles were inadvertently reversed. Vaughn reported how his dad, who is living with dementia, had received multiple calls from an alarm installation company, offering to upgrade his old alarm system for £500. In his confusion, Vaughn's father thought *he* owed the alarm company £500. Vaughn called the company to ask that they stop making these calls, explaining the situation.

> *Vaughn: So I rang this guy and said, 'Look, can you stop ringing my dad, he is frightened, he is scared, he has got dementia, he thinks he owes you £500.'*

Despite Vaughn's request to cease all marketing to his father, the cold calls continued. Vaughn was about to speak to the business again, when he got a phone call from the alarm installation company.

> *Vaughn: A few days later, this guy rings me and he says, "Will you stop your dad from ringing me; he is ringing every five minutes? He says he owes us £500 and we tell him he doesn't and he doesn't seem to understand it"… My dad would not remember how often he called, so I will never know just how often he rang.*

Whilst this is not a solution as such, but rather a further manifestation of the problems faced by people living with dementia when approached by businesses, the reversal in roles did stop a persistent company vying for further business.

Possible solutions suggested by participants

Some of the participants, both persons living with dementia and their family members, thought it might help if the businesses were informed of the illness. This, they reasoned, would in turn then lead to the business having to make concessions to the person living with dementia, making it easier for them to terminate the contract if later deemed detrimental to them financially or otherwise. However, all of the participants who made this suggestion were also aware of some of the potential downsides and highlighted the risks that would flow from making a statement about a diagnosis of dementia.

Garry, whose mother lives with dementia, made the following suggestion, demonstrating his internal conflict between wanting to ensure more beneficial terms to assist his mother with dementia, whilst also being aware of her right to privacy in relation to health matters.

> *Garry: It would be useful to have a longer cancellation period, but then companies would need to be informed and have to ask, "Are you classed as having dementia?" And that might involve having to divulge medical information that they might not want to divulge.*

Lauren, whose mother had dementia, thought it would be good to identify both the person living with dementia and the person within the business that had specific dementia-related training. She suggested this could be achieved non-verbally by wearing a small recognisable pin.

> *Lauren: In hospitals, they have dementia friendly wards. There is a little flower up and then you know you will be well treated. That could also be in shops… and banks, just a little sign that gives recognition. [If a person with dementia] was wearing one, it might alert the employee to the fact that she might need extra help.*

Later in the interview she did however point out the risk she saw associated with being able to identify a person with dementia through such a symbol.

> *Lauren: I think I would be a little bit anxious about such symbols going on someone's door. Because it could attract unscrupulous people.*

Again, this shows the difficulty in alerting the business in advance to a vulnerability because of the fear of being exploited.[15] As a result of the fear of such behaviour, many persons living with dementia will choose to remain quiet about a diagnosis of dementia, in which case the business might not be able to help or adapt their sales behaviour/strategy. Subsequently, this non-disclosure might lead, as explored above,[16] to the company insisting that a valid contract was formed.

Alice, who lives with dementia, suggested that consumer contracts could include a tick-box which vulnerable consumers, such as consumers with dementia, might be able to tick at the moment of signing the contract. This would then give them additional benefits, such as prolonged penalty-free termination rights. She did however concede that this tick-box would have to be a voluntary option, and that not ticking the box could not later be used against the consumer to state that, as no disclosure had taken place at the moment of signing, no new information on the consumer’s disability was admissible.

> *Interviewer: … you have mentioned a tick box, which I thought was a great idea. Someone else however mentioned that a person with dementia might have forgotten that they have dementia or might not want to divulge the diagnosis.*
>
> *Alice: I agree with those points as well, but I think it is better to have something there which might get missed, rather than not even having the chance of doing something about it.*

The ability to voluntarily disclose the illness easily and draw benefits from that disclosure would be a valuable tool for the consumer living with dementia.

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[15] As a side note, where a business were to exploit their knowledge of a vulnerability such as dementia, the business would be likely to be in breach of relevant laws (for example, they may be found guilty of fraud, duress or undue influence, see also Section 7.2.). This could result in the contract being rescinded and criminal and civil remedies becoming available to the wronged consumer. However, for the purposes of this thesis, deliberate acts of fraud, duress or coercion are expressly excluded from this analysis.

[16] See Chapter 7, Section 7.2.

Others felt that even if the illness was expressed to the business, it was a lottery if the customer-facing employee was able to take this into account in order to assist the person living with dementia adequately. Where the benefits were not in relation to future advantageous termination provisions, but rather in relation to the advice and assistance given at the time of entering into the contract, then it was down to the awareness and knowledge of the business representative.

Helen showed little confidence in any disclosure of the illness leading to a better outcome. She was therefore suspicious of businesses that displayed signs indicating they were dementia-friendly or dementia-aware.

> *Helen: No idea… I suspect it is just a sign, "Here is awareness that there are lots of older people around", a bit like [when] they put the breastfeeding-friendly signs up, you could easily walk into that café and the guy behind the till does not even know that sticker is on the door… until someone with dementia comes in, and then they go, "Hang on a minute, oh, I don't know" and then they react on the hoof… I don't think there would be any understanding from the 16 year old that has just been employed last week … I can't see it being effective at all.*

Helen makes the point that disclosure of dementia is of no use unless the business counterpart is aware and adequately trained in order to respond appropriately. This need for better education and training is explored in more detail in Chapter 11[17] below.

There has been recently an interest by businesses to respond to the difficulties faced by vulnerable customers. This has been achieved through guidelines and standards, created by and for the various industries.[18] For example, the Financial Conduct Authority published Occasional Paper No.8 on Consumer Vulnerability,[19] businesses and banks, working with Alzheimer's

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[17] See Section 11.3 on educating businesses on vulnerability, including that of persons living with dementia.

[18] See Section 7.3 on 'soft laws'.

[19] Financial Conduct Authority (2015) *Occasional Paper No.8 on Consumer Vulnerability*, available at https://www.fca.org.uk/publication/occasional-

Society have produced various retail, business, utilities and banking and insurance guides,[20] and utilities providers are encouraged to abide by identified standards, such as voluntary British Standard *BS18477: the standard that helps vulnerable consumers.*[21] These well-intended charters are drafted to include some clear statements of intent of how to prepare, how to act, and how to engage with the vulnerable consumer. However, these documents also contain many future-facing recommendations to build a model that is vulnerability-friendly over time. Furthermore, the guidance is voluntary rather than legally binding and uptake has been slow. The Citizen's Advice Bureau, in its report in 2015 for example highlighted this in relation to the British Standard, expressing their frustration.

> *Citizens Advice and Consumer Futures (which was then Consumer Focus) joined with government bodies and the British Standards Institution (BSI), to produce guidance for companies on how to treat consumers fairly. The result was British Standard BS 18477: 2010 'Inclusive service provision – Requirements for identifying and responding to consumer vulnerability' ('the Standard'). Since then we have been encouraging essential goods and service industries to voluntarily adopt the Standard* ***but take-up has been slower than we would like****.* [22] [emphasis added]

This demonstrates the difficulty when businesses are left to self-regulate their response to vulnerable customers.

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papers/occasional-paper-8-exec-summary.pdf, last accessed on 14 February 2021.

[20] Various guides can be found at https://www.alzheimers.org.uk/dementia-friendly-resources, last accessed on 14 February 2021.

[21] Whilst much has been written about BS 18477, access to the document itself is behind a pay-wall, at a cost of £218, available at https://shop.bsigroup.com/ProductDetail?pid=000000000030213909, last accessed on 14 February 2021.

[22] Citizen's Advice (2015) *Treating consumers fairly, Flexible and inclusive services for all,* available at https://www.citizensadvice.org.uk/global/migrated_documents/corporate/treating-consumers-fairly.pdf, last accessed on 14 February 2021.

One of the ways in which to force a shift is to put in place regulation that is binding on all businesses. A charity worker from Alzheimer's Society expressed this well.

> *Charity worker: I think it is definitely moving in the right direction, compared to where things were 5 or 10 years ago, but dementia and awareness of dementia, the removal of stigma,*[23] *is still incredibly low. So I think that it is better generally than it was, but at the same time we are still seeing sectors were there are plenty of issues. So, and from working with these sectors, some organisations are socially minded and will want to work with us, but the most change, as we see it happening, is by regulation, by obligation imposed through the relevant regulator or government department in charge. If it is an obligation it will trickle down, whereas when it is just a recommendation it generally might not happen. And so then you have got inconsistencies...*

In order to encourage regulations to be introduced, a shift in public interest must be achieved, that recognises the importance and urgency of these issues.[24]

10.5 Experiencing challenges around the lasting power of attorney[25]

In England and Wales, lasting powers of attorney are legal documents whereby a person can select attorneys to assist with financial or health-related decision-making. The attorney can then act either immediately with consent, or once the person no longer has capacity. The participants interviewed for this thesis experienced the effects of the lasting power of attorney in both positive and negative ways. Whilst some family members found that lasting powers of attorney were a helpful tool to support their relatives living with dementia, others encountered stumbling blocks along the way.

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[23] For a detailed discussion on stigma and the stigmatisation of persons living with dementia, see Section 9.4.

[24] See Chapter 11, Section 11.3.

[25] Issues relating to the valid formation of lasting powers of attorney are also discussed in Sections 8.4 and 8.5.

Deciding on when to transfer decision-making powers

Beyond the decision of entering into a lasting power of attorney, selecting the relevant lasting power of attorney and then choosing those that will act as their attorney,[26] the lasting power of attorney for property and financial affairs requires the signatory to make a further significant decision. They need to determine *from when* the lasting power of attorney is to be effective. The two options in the form are either (1) with immediate effect, although further consent is then required for each specific act to be undertaken by the attorney, or (2) once the signatory no longer has capacity.

However, as has been discussed in Chapter 7,[27] many people living with dementia experience capacity as a fluctuating event, with varying degrees of ability to make decisions at different times. This fluctuating aspect of capacity is however not taken into account in the lasting power of attorney, both when it is first entered into and subsequently when it is used. Consequently, businesses have no clear guidance as to how to assess capacity to ensure the power of attorney is applied in line with the signatory's wishes. This results in inconsistency of application by businesses to the detriment of the person living with dementia.

This inconsistency in approach by businesses is troublesome, leading to uncertainty for the person living with dementia, their attorneys, as well as businesses or other organisations that are presented with the lasting power of attorney. These two options are examined in more detail below.

Box 1: With immediate effect

From the interviews conducted, it emerged that most signatories had ticked the box giving power of attorney immediately. Consequently, the designated attorneys under the lasting power of attorney expected to be able to act on behalf of the signatory from the moment that the power of attorney was registered with the Office of Public Guardian, without the need for further

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[26] See Section 8.4 and 8.5 for more detail on the challenges in setting up a lasting power of attorney.

[27] See Chapter 7, Section 7.2 on capacity.

paperwork. This is indeed the case as clearly pointed out in the MCA Code of Practice at paragraph 7.32:

> *Unless the donor states otherwise, once the LPA is registered, the attorney is allowed to make all decisions about the donor's property and affairs even if the donor still has capacity to make the decisions for themselves.* [28]

However, because the lasting power of attorney states "*While you still have mental capacity, your attorneys can only act **with your consent***", many businesses wrongly interpreted that as meaning that whilst the signatory has capacity, a further document is required each time the attorneys are to act in relation to a specific task. This is not the case and the MCA Code of practice lists by way of example a very extensive list of activities that the attorney can perform without further consent, covering all usual financial matters. If the donor wanted to specifically restrict the attorney in some way, they would do so expressly in the lasting power of attorney. [29]

In order to counter this difficulty and to provide further clarity, businesses must be educated to ensure they understand when the power of attorney becomes effective. Where the box is ticked to indicate that the power should start immediately with further consent, the attorney acts in a similar capacity to a trustee. This was highlighted in Re Buckley, where Lush J considered the case of a person living with dementia (Ms Buckley) who had signed a lasting power of attorney for property and financial affairs, appointing her niece as attorney. As the niece had spent a significant amount of monies on questionable investments and donations, Lush J was asked by the Public Guardian to consider the revocation of the lasting power of attorney.

Significantly for the purposes of understanding the application of the lasting power of attorney "with immediate effect", Lush J stated in his judgement that an attorney is governed by their fiduciary duties to the donor. [30] Consequently,

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[28] Mental Capacity Act 2005 Code of Practice (2007) London: TSO, para 7.32.

[29] Mental Capacity Act 2005 Code of Practice (2007) London: TSO, para 7.36.

[30] Re Buckley: The Public Guardian v C [2013] EWHC 2965 (COP), [2013] MHLO 13, para 25.

they have an obligation to act in the best interests of the donor (section 1(5) MCA 2005).[31] Lush J specified that attorneys hold a fiduciary position that imposes a number of duties on them. This was expressly explained at paragraph 41.

> *Until such time as the Office of the Public Guardian issues its own guidance to attorneys and deputies on the investment of funds, I would suggest that,* ***as they have fiduciary obligations that are similar to those of trustees****, attorneys should comply with the provisions of the Trustee Act as regards the standard investment criteria and the requirement to obtain and consider proper advice.*[32]

The judgement in Re Buckley makes it clear that the attorney is to be considered and treated like a trustee, acting as a fiduciary in the best interests of the donor. Lush J did make it clear that when acting as an attorney, clear rules and guidance must be followed on how to invest and take care of the property and financial affairs of the donor. At paragraph 20 Lush J stated that

> *There are two common misconceptions when it comes to investments. The first is that attorneys acting under an LPA can do whatever they like with the donors' funds. And the second is that attorneys can do whatever the donors' could – or would – have done personally, if they had capacity to manage their financial affairs.*[33]

For the purposes of this research, the significance of the judgment in Re Buckley is that usually no further written consent is needed from the donor under the lasting power of attorney. An exception to this rule is in relation to the sale of land/property. This was the situation for Garry, who was surprised when the written consent of his mother (the donor) was required on the day that he and his sister were finalising the sale of their mother's house for her. His mother has dementia and to fund the care home, the family home was being sold and a rental property bought. Throughout the sale and purchase process, the lasting power of attorney had been presented and accepted by

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[31] Ibid., para 23.
[32] Ibid., para 41.
[33] Ibid., para 20.

the acting law firm as giving him and his sister authority to act on behalf of their mother.

On the day of completion, the requirement of consent under the lasting power of attorney was raised and it was difficult to obtain his mother's signature, as Garry thought it needed to be done in the presence of an independent, professional person who could certify that she still had capacity.

> *Garry: Recently when my sister bought a [rental income] property [for my mother], we ended up needing to get her [Garry's mum] consent to use her money, which seemed quite strange considering we had the power of attorney. But then we looked it up ourselves and it did turn out we did need to get her consent. So we would probably have to get her a psychologist to now class her as incapable in order for us to now make all decisions…*

This demonstrates the difficulty Garry faced at the time, and the perceived limitations he now feels in using the power of attorney to assist his mother.

In contrast, for Jane, who was in a very similar situation when she and her brother had to sell the family home of their mother living with dementia, the lasting power of attorney was accepted without any evidence of capacity or lack thereof.

> *Jane: My solicitor would ring me up and say "Can you get your mum to sign this paperwork?" and I said "I live 23 miles away, I won't be seeing her till, like, maybe tomorrow. How soon do you need it?" "Oh, we need it today" and I would say, "Well that is not possible. I've got power of attorney, why can't I sign it?", and then they would say, "Oh yes, you can sign it" So we came across all that.*

These two experiences show how arbitrary and confusing it is for both lay people and professionals when using the lasting power of attorney.

Box 2: Once capacity lost

In other cases, the signatory will want to retain sole power to deal with their financial affairs until they lose capacity. Ticking the box that the authority is only passed to the attorneys once capacity is lost should prevent any prior activity by the attorneys. However, as seen above when examining the test of capacity under the Mental Capacity Act, capacity must be decided before each and every decision is to be made. The question therefore has to be asked if it is possible, other than in cases of dementia in very advanced stages, to provide a blanket statement that the signatory has lost capacity.

As was discussed in Section 9.3 above, for many persons living with dementia, capacity is a fluctuating event. Eduard has dementia and he was aware that his capacity to understand, remember and speak could vary greatly.

> *Eduard: Very often.... I mean I can't remember a damn thing sometimes... it comes back. So that is what my problem is.*

Nicole, whose mother lives with dementia, also reflected on the fluctuating capacity.

> *Nicole [talking about her mother's decision making capacity]: And her ability to make decisions will vary, even within the day. For example, at the end of the day she might find it much harder to make a decision. From day to day it will vary.*

From these short extracts it is clear that depending on the day, and even depending on the time of day when a person with dementia is assessed for capacity, the outcome could be very different. These observations were repeated by many of those interviewed.

As pointed out by Herring,[34] the challenge with this test of capacity is that it can lead to situations that are contrary to what the law intended;[35] a person might either be deemed to lack capacity, with others erroneously making

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[34] Herring, J. (2016) *Vulnerable Adults and the Law* Oxford University Press, at 54.

[35] Mental Capacity Act 2005, c.9.

decisions for them, or they may be determined to have capacity, leading to unwise decisions that can be detrimental to the person, but with no recourse to rectify the situation. This is particularly significant if a one-off assessment of incapacity is then used to determine the validity of the powers of the attorney under the lasting power of attorney going forward.

Usage of the lasting power of attorney

The MCA Code of practice describes the function of the attorney under the lasting power of attorney as one that

> *allows and encourages the donor to do as much as possible, and should only act when the donor asks them to or to make those decisions the donor lacks capacity to make. However, in other cases, the donor may wish to hand over responsibility for all decisions to the attorney, even those they still have capacity to make*. [36]

Like trustees, attorneys are required to have regard to the donor's will and preferences, highlighting the need for the attorney to always consider the best interests of the donor when acting as attorney. [37] The MCA Code of Practice sets out a list of activities deemed typical examples of what an attorney under a property and affairs lasting power of attorney would do, including "*buying or selling property, opening, closing or operating any bank account, giving access to the donor's financial information, claiming, receiving and using (on the donor's behalf) all benefits, pensions."*[38]

These examples were typical of what the participants in this research were using the lasting power of attorney for. The data extracted from the interviews shows that the lasting power of attorney was used primarily for communicating with entities with which the signatory had an on-going relationship, such as its bank, its utilities provider and government agencies and departments.

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[36] Mental Capacity Act 2005 Code of Practice (2007) London: TSO, para 7.34.
[37] Mental Capacity Act 2005 Code of Practice (2007) London: TSO, para 7.52.
[38] Mental Capacity Act 2005 Code of Practice (2007) London: TSO, para 7.36.

Kate, whose husband had dementia, showed the lasting power of attorney to his bank and credit card provider. The credit card account was in her husband's name only, and whenever anything needed doing, the bank would insist of him answering security questions, something he could no longer do.

> *Kate: So I sent the lasting power of attorney to them [the bank] and I could deal with all matters after that.*

In other instances, the lasting power of attorney was used for significant transactions, for example as described above by both Garry and Jane for the sale of a person's home.

However, it was also common in the interviewed group to find that the lasting power of attorney had not actually been used, despite it having been created, paid for and registered. This was either because the relevant family members could ask the person to sign any required document without referring to the lasting power of attorney, or because they had access to the person's affairs through other means.

For example, whilst Barbara was doubtful her husband with dementia was still capable of making a decision about the sale of their joint home, she arranged for him to sign the relevant paperwork, which was not questioned by the acting solicitors.

> *Barbara: It was just a question of him signing everything.*
>
> *Interviewer: And the solicitors … never questioned anything?...*
>
> *Barbara: No, they didn't.*

Fiona whose father lives with dementia had spoken to her father's utility provider, explaining the dementia diagnosis and had agreed with them to list her as a nominated account holder/user, circumventing the need for a lasting power of attorney.

> *Fiona: For the utility provider, I just told them that I would help my parents and they added me to the account as a named contact. It is a bit weird really that they would add my name without any security checks!*

Oscar, whose parents both lived with dementia, explained that they had a lasting power of attorney registered, but never actually used it. Instead, he had access to his parents' bank account through Internet banking.

> *Oscar: We never needed it [the lasting power of attorney]. All the banking I did, I did over the Internet. Because we don't go to the bank anymore! So once everything was in place, I didn't really need it any more. I used it [my parents' bank account] quite frugally. I tended to discuss any expenditure with my sister.*

When acting as attorney with immediate effect, the Mental Capacity Act[39] and Code of Practice[40] make it clear that the attorney must always consider the capacity of the donor to make a specific decision, and if not capable of doing so, act in the best interests of the donor.

This was highlighted in many of the interviews, when carers for a family member living with dementia were mindful of the wishes of the person living with dementia. For example, in Section 8.3 Nicole spoke of her mother choosing a little-known cancer charity, and Nicole wanting to support her mother's decision-making, ensuring her mother's will and preferences were followed rather than imposing her own ideas on how the money should be spent. This again highlights the relational aspect of the power of attorney, which allows persons living with dementia to achieve relational autonomy in conjunction with their loved ones supporting them in their decision-making. The lasting power of attorney in such a case can be viewed as a decision-making support tool rather than a substitute decision framework, with family members assisting and supporting their relatives living with dementia.

This was also argues by Harding:

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[39] Mental Capacity Act 2005, s.4.

[40] Mental Capacity Act 2005 Code of Practice (2007) London: TSO, para 7.52.

> *Power of attorney is an essentially relational framework…. In many senses, power of attorney can be understood as an inherently facilitative and supportive legal concept that explicitly supports the relational lives that people lead.* [41]

10.6 Concluding remarks

This chapter has considered two opposite types of experiences by persons living with dementia and their families when looking to terminate a consumer contract. It has explored the experiences of powerlessness, as well as the resourcefulness and ideas for pragmatic solutions and protections recounted by persons living with dementia and their families.

First, the chapter has highlighted the powerlessness experienced by many participants. Participants in the interviews expressed feelings of frustration either because they were unaware of the existence of problematic consumer contracts, or because they encountered legal barriers that prevented them from stepping in and 'fixing' the situation for their family member living with dementia. Many talked of their experiences of cold calling, and the particular challenges this posed, demonstrating that contracts initiated by businesses may be more damaging to consumers living with dementia than those they had actively sought out.[42] The aim in this section was to highlight the vulnerability of both consumers living with dementia and their family members. Family members felt powerless, unable to respond adequately to the assertions by businesses of valid contracts having been formed. If vulnerability was at the heart of the legal system (rather than being seen as the problematic or exceptional situation of a small minority of non-autonomous persons in need of protection) and laws reflected the concept of universal vulnerability, these difficulties to remedy situations for their relatives living with dementia might be lessened.

However, not all experiences were negative and participants shared their experiences of ways in which they worked with businesses to resolve and

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[41] Harding, R (2017) *Duties to Care: Dementia, Relationality and the Law*. Cambridge University Press, at 103/104.

[42] See Section 11.2.

terminate contracts that were not suited or suitable to the person living with dementia. Few of the routes discussed by participants were legal in nature, but rather were practical solutions achieved through communication with the business.

One of the legal solutions participants often mentioned was the lasting power of attorney. However, their experiences varied, and all felt that more clarity and consistency was needed in the way that lasting powers were viewed, understood and applied by businesses. Nevertheless, the data demonstrates that this decision-making support tool allows for persons with dementia to continue to ensure that their own choices (taking into account their families and situations) are complied with. In this way, such persons are able to remain (relationally) autonomous, with family members assisting and supporting their relatives living with dementia.

The final chapter will build on the analysis of the limitations of the law and the problems identified in the interviews to make a number of recommendations that could make a positive difference to the consumer living with dementia and their family members.

Chapter 11 A new framework to protect consumers living with dementia

11.1 Introduction

The aim of this thesis was to critically consider the consequences, legal and practical, that arise when a person living with dementia enters into a contract with a business as a consumer. To that end, it has explored the current legal framework that governs the situation for the consumer living with dementia, in light of the lived experiences in day-to-day consumer situations of persons living with dementia and their family members, supplemented by some less personal but wider-reaching experiences of volunteers and professionals from the charity sector. These experiences have been analysed, taking into account the challenges faced by this group. Internal attributes, such as the cognitive impairment and resulting memory loss or lack of understanding, and external attributes, such as the weaker economic position they face as a consumer, reflect the (compounded) vulnerability of their position.

After a brief overview of the issues identified in the research, in **Section 11.2**, these findings form the basis of a series of recommendations aimed at improving the situation of consumers living with dementia and alleviating some of the issues encountered.

In addition, these recommendations are then applied to the five vignettes that were first presented in Chapter 1. In doing so, the goal is to demonstrate the improvements these solutions would bring to a range of persons, be it persons living with dementia, their families, or society at large.

However, in order to achieve these or similar solutions that put the vulnerable consumer first, a shift needs to take place within society. This willingness to engage is discussed in **Section 11.3**. Finally, **Section 11.4** brings this thesis to a close.

11.2 Analysis and recommendations

The law review chapters analysed the law as it stands today, examining in detail the levels of protection afforded to persons living with dementia when entering into contracts as consumers. The empirical chapters considered experiences relating to capacity, understanding and challenges when considering the validity of consumer contracts.

This thesis demonstrates that there is a general lack of legal protection for consumers living with dementia. More specifically, this thesis has identified the following issues.

1. A lack of protection for those with capacity

In broad strokes, a first overarching theme from the empirical research related to capacity, looking at the experiences of consumers living with dementia and their families in relation to identifying capacity, overlooking capacity, questioning capacity and seeking ways to evidence capacity.

From the legal analysis, it is clear that consumers living with dementia may find themselves within a "jurisdictional hinterland",[1] a space outside of adequate legal protection. This would be the case if they are deemed to have capacity as per the four-tiered test as set out in the Mental Capacity Act 2005,[2] despite having trouble fully understanding or remembering the complex consumer contracts. The law currently only asks if the terms of the contract were clear and transparent, without focusing on whether these disclosed terms were understood by the individual consumer.

As a consequence, when a consumer has capacity to enter into a contract, that contract remains valid, even if its terms or its legal and financial ramifications were not fully appreciated by the consumer due to their cognitive impairment.

2. A lack of protection for those without capacity

The next wider theme looked at knowledge and information. This meant examining the participants' understanding of the consumer contract, as well as their knowledge of the parties to the contract. It also included exploring the

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[1] Re L (Vulnerable Adults with Court's Jurisdiction) (No 2) [2012] EWCA Civ 253.

[2] Mental Capacity Act 2005, s. 3.

perceived risk brought on by a lack of understanding of the illness, leading to the fear of stigmatisation of those that disclosed the disease to their contractual counterpart.

Even when there is a proven lack of capacity, this will only impact on the contract entered into if the other contracting party knew of that lack of capacity at the time of completion. In a business-consumer situation, where the parties spend little time together, a lack of capacity is likely to go unnoticed.

In addition, whilst businesses are becoming aware of the serious challenges faced by consumers living with dementia, their solution is often to request that their clients inform them of their situation. However, due to the fear of stigma, privacy concerns or because a diagnosis of dementia is either absent, rejected or forgotten, many customers will not provide such information in advance.

3. A lack of legal remedies forcing pragmatic solutions

Finally, the experiences and struggles were explored of persons living with dementia and their family members when trying to disentangle a consumer living with dementia from the contract they had entered into, where such a contract was later seen to be detrimental to that person.

With no legal remedies readily available, persons instead relied on pragmatic solutions outside of the legal framework, such withholding payment, shaming the business on social media, or appealing to the business's better nature and the plight of the person living with dementia.

This section builds on those explorations to put forward a number of recommendations. In Chapter 1, five vignettes were used by way of example to illustrate some of the issues that a consumer living with dementia might face. Short and longer-term 'proposed solutions' below are then applied to the vignettes in order to ascertain how the outcomes might be different if the recommendations and suggestions set out in this thesis were law today.

Recommendation 1: Pre-contractual reflection period of 24 - 48 hours

The ability to dispute or challenge the validity of a consumer contract was an important issue for most of the participants. All had experience of some contracts that turned out to be problematic, mainly because of the cost involved. Time and again, participants talked of bad deals that had been struck, in their minds because of the cognitive impairment brought on by dementia.

Many interviewees felt a certain level of powerlessness in dealing with such situations. Once a contract was signed and goods or services had been accepted, it was difficult for consumers or their families to object to the deal struck, especially if a long period of time had lapsed since the purchase occurred. However, such a time lapse was often due to the disease and the accompanying memory loss. Many families experienced the frustration of seeing money and energy wasted, but felt it was best to simply cut their losses by stopping future contracts from occurring. Few were able to claim money back for contracts already entered into.

Furthermore, most identified that the contracts that were challenged had usually been initiated by a business. This is likely to be something most consumers have experienced. It is these purchases, offered labelled as ‘one-off’, ‘exceptional’ or ‘time-limited’ deals, that will lead to hasty decisions that are later regretted.

If terminating a contract is difficult to achieve and the principle of certainty of contract is to be upheld, it may be more fruitful to review the way in which contracts are entered into. This would result in fewer contracts being created and contested further down the line. This recommendation would consequently alleviate some of the difficulties for vulnerable consumers.

For example, Alice,[3] who lives with dementia, explained that one of the issues she had was that she found it harder to make decisions *on the spot*. As a result, if something was offered to her there and then, be it in a shop, by telephone or on the doorstep, it would be difficult for her to take in all the information and make a carefully considered decision. As a result, she

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[3] See contributions by Alice in Sections 9.3 and 9.4.

recommended giving the consumer time before entering into a contract. She talked about this hypothetically, using the example of a bank teller offering a new product to a consumer.

> *Alice: I think…. I don't think offering a new account over the counter is the right approach. Although having said that, I also think the letters they send out offering new products are not always helpful either for people with dementia.*
>
> *In a way, if it was going to be a genuine benefit to that person, then great. But if it is just another way for the banks to make money… Should they mention it or not? Probably,* ***but they should definitely not be signing anything that day****.*

This is a key point raised by Alice. Being offered something and immediately signing up to that offer means that many consumers will later regret their 'impulse' decision. For a person living with dementia, this short timeframe within which to make up one's mind might prove even more difficult.

As a result, a suggested solution is to introduce a **pre-contractual reflection period**. This new concept would be a time window of for example 24 or 48 hours after an offer was initially made by a business to a consumer, during which time the consumer cannot enter into the contract. The business cannot re-approach the consumer at any time during this time period without resetting the clock, effectively restarting a new 24- or 48-hour reflection period.

In order to ensure that this legal device does not prevent consumers from making wanted purchases of goods and services, this pre-contractual reflection period would only apply to contracts where the business has approached the consumer, rather than when the consumer actively has sought out a business because they need or want certain goods or services. The consequences of this simple change would be significant for all consumers, but especially for vulnerable consumers such as consumers living with dementia. As was seen above, given that it is now understood that a majority of consumers are in some way actually or potentially vulnerable, new rules that better serve all consumers are needed.

Considering the situation of the consumer living with dementia, they would be protected from many contracts from cold callers in all guises. Instead of entering into a contract, for example on the doorstep or by telephone, the business would simply make an offer. That offer can then either be considered and discussed with family members, or might be forgotten, in which case not entering into the contract was the right thing. It would only affect consumer contracts that the consumer did not seek out; most of these are likely to represent impulse buys rather than necessities.

This proposition was put to a charity worker in one of the interviews. They had heard of something similar happening for British Gas customers.

> *Charity worker: British Gas say that if they come to your house and, say your boiler is broken and you have to have a new boiler, or there is a new contract or anything like that, what they will do is leave the paperwork and any information describing what they will do, so the person with dementia can look at it later and also loved ones and carers can come in and see, "Oh, okay, British Gas have been round. They said you need a new boiler, here is the new contract." And I think they give it two days or something.*

However, the concern of the charity worker was again whether this was an internal guideline, which might only apply to one company and might only be enforced by some of their employees, or if this was something more binding on the industry as a whole.

> *Charity worker: Yeah, this is the thing, is it in their process? If it is not in their process, how good is it? Because if one person isn't doing it… it needs to be enshrined, either by law or in a process, ideally law or legislation, so it is mandatory, not optional.*

This statement highlights the concern that, if left to self-regulate, businesses may not consistently apply such rules.

This suggested solution to introduce a pre-contractual reflection period would resolve many issues by ensuring that vulnerable consumers make less of these rash decisions. By delaying the time when the contract can be entered into and putting the onus to initiate the contract on the consumer after a time of reflection, this recommendation is likely to reduce the number of impulse consumer contracts entered into. Such a solution would be helpful for all consumers, regardless of vulnerability or capacity status. However, especially for persons with cognitive impairments or memory issues, such as persons living with dementia, such a system would assist them by ensuring they were protected from all forms of cold callers.

Application to Nita's situation: with the pre-contractual reflection period the contract would be rendered invalid

Looking back at Nita's situation, her savings had been transferred into a high-yielding investment product after a persuasive talk by a (cold-calling) financial sales rep. Whilst it might have been a good deal for some investors, because of cognitive state and limited ability to understand the complexity of the investment, she did not realise that this contract was in fact detrimental to her financial independence. Care home fees needed to be paid regularly and her savings had to be accessible.

With the pre-contractual reflection period in law, Nita could not have entered into the contract then and there. Whilst the sales representative might have left marketing material with prospective clients, it would have been up to Nita to proactively contact the business to set up the contract. A certain amount of time (24 or 48 hours) would need to lapse before the relevant consumer contract could be entered into.

It is likely, given the transient nature of these presentations at the care home, and given Nita's memory issues due to dementia that she would not have pursued this investment opportunity further. If the business representative had pushed the contract through regardless of the legally prescribed reflection period, the contract would have been made illegally and would be void.

Recommendation 2: extension of the eggshell or thin skull doctrine

This long-established rule[4] applies to tortious or criminal law matters. The main premise of this doctrine is that the wrongdoer must "*take their victims as they find them*". [5] Consequently, in a tortious matter, if an accident leads to more serious injuries to the victim due to a pre-existing vulnerability, be that medical, emotional, economic, cultural, or social, the tortfeasor is nevertheless liable.[6] In other words, if they have 'a skull as thin as an eggshell', the responsibility of the wrongdoer is not diminished by this fact. The same holds true in criminal law matters, where the vulnerability of the victim cannot be a factor to avoid liability.[7]

Whilst it is not thought that this doctrine is naturally extended into contract law, it might be said that in some regards this is however the case. For example, even where the contracting party is unaware of the other party's age, a contract will be void or voidable by the minor, despite not knowing of this vulnerability (i.e. the other party's status as a minor) in advance. Similarly, the Mental Capacity Act 2005 at section 9 specifically states that for the person lacking capacity, in relation to necessities contracted for, only a reasonable price will be payable. In this circumstance as well, responsibility to act in the best interests of the more vulnerable party is not diminished or avoided. The weaker contracting party is protected and the contract must be re-written in light of an undisclosed, unknown pre-existing vulnerability.

Irrespective of a person's capacity,[8] some persons will find it harder to understand the terms and conditions of a consumer deal. The experiences of those interviewed demonstrate that relational understanding was also of considerable importance.[9] As was discussed above in Chapter 6, under general contract law principles, only a business' knowledge of the consumer's lack of capacity will determine whether a contract is deemed void. However,

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[4] Vosburg v. Putney 50 N.W. 403 (Wis. 1891); Owens v Liverpool Corp [1939] 1KB 394.

[5] R v Blaue [1975] 1 WLR 1411, Lawton LJ.

[6] Paris v Stepney Borough Council [1951] AC 367.

[7] R v Holland (1841) 2 Mood. & R. 351.

[8] as determined using the four-tiered test under the Mental Capacity Act 2005, s. 3(1).

[9] See Section 9.3.

whilst businesses are requesting that consumers share with them their potential or actual vulnerability, the experiences of those living with dementia, either directly or as a family member of a person with dementia, demonstrate some hesitancy in exposing the health situation of the person living with dementia to businesses. Many experienced the fear of stigma, wanting to keep the disease private to a small circle of trusted family members and friends only. The thought of divulging such personal data to businesses and other organisations was worrying for many. For others it was the refusal to acknowledge any issue that meant that informing of the disease would not be feasible.

In Chapter 7[10] it was suggested that the rule on knowledge of vulnerability or lack of capacity be reviewed and aligned to other situations where the parties accept each other as they are. Currently, remedies are not available to consumers living with dementia when they or the business transacting with them are unaware of the fact that they are living with dementia. As previously mentioned, knowledge of the illness, a person's disability, or their lack of capacity are required in consumer and contract law matters. However, this thesis suggests that the legal doctrine on '*eggshell*' or '*thin skull*' could be applied to a wider rage of contractual situations.

Application to Vishal: the mobile phone contract could be rescinded without penalty

Vishal had forgotten that he had repeatedly entered into identical goods and services contracts. In his case, he had agreed to contracts for five mobile phones. The deadline to retract from the contracts had passed, penalties were payable to break the contracts.

Under current law, if the sales representative does not know of the disease, and the contracts were entered into validly, no recourse is available other than by appealing to the goodness, decency or reputation of the business.

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[10] See Section 7.5.

With the thin skull doctrine,[11] the business would be obliged to "*take [the consumer] as they find them*".[12] A diagnosis of dementia, even where it is not disclosed to the business, could be considered to be such a thin skull event. Other consumers would – most likely - have remembered to only buy one phone, and would not have committed to so many contracts, but in this instance the consumer had a cognitive impairment that reduced their memory functions.

Consequently, whilst certainty of contract must prevail in other situations where the consumer is an average consumer, i.e. "*a consumer who is reasonably well-informed, observant and circumspect*",[13] in situations where the consumer is instead a vulnerable consumer, this vulnerability must be taken into account, resulting in contracts being voidable at the behest of the consumer or their representatives.

Recommendation 3: extension of the presumption of undue influence

As seen in Section 7.2, undue influence is closely connected to the relational aspect of the parties. Indeed, be it actual or presumed undue influence, much will depend of the special relationship between the parties.[14]

Unless the relationship between the parties was fiduciary in nature,[15] in order to rely on presumed undue influence as a vitiating factor to the contract, it must be shown that one party placed their trust and confidence in the other to safeguard their interest.[16] So far, a presumption of undue influence based on the special relationship of trust between business and consumer living with dementia or a cognitive impairment has not been tested in court. For the person living with dementia, their ability to resist any influence will be determined to a large extent by the progression of the illness and the severity

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[11] See proposed solution 2 above for a detailed description of the thin skull or eggshell doctrine.

[12] R v Blaue [1975] 1 WLR 1411, Lawton LJ.

[13] Consumer Rights Act 2015, s. 64(5).

[14] Goldworthy v Brickell [1987] 1 All ER 853.

[15] In which case undue influence is presumed.

[16] *Credit Lyonnaise Bank Nederland v Burch* [1997] 1 All ER 144 (employer employee relationship).

of their cognitive impairment. As the disease progresses, the person might become more susceptible to the influence of others, and even subtle influences might be considered undue.[17]

In the interviews conducted as part of this project, the reliance and trust placed on the business counterpart in consumer transactions was expressed in numerous cases.[18] This suggests that a presumption of undue influence based on trust should be applied in such cases where the consumer living with dementia relies on the business.

Application to Derek: undue influence when trust and confidence was placed in the sales rep would allow the contract to be voided

After responding to a flyer left with the post, Derek agreed to replace the windows of his home. In addition, he signed up for a loan to cover the cost of the renovation. Whilst all the relevant terms and conditions were read out to Derek and full financial disclosure was provided, Derek may not have been fully aware of the implications of the deal presented to him.

Due to his dementia, Derek was in a position where he relied on the advice of those surrounding him. His cognitive impairment made it more difficult for him to judge who was giving impartial advice, and who might benefit from advising him in a certain way.

Under current law, actual undue influence would need to be proven by Derek and his family.[19] If presumed undue influence were to be extended to those in whom the person with dementia places their trust and confidence, the contract

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[17] Shulman, K., Cohen, C. A., Kirsh, F. C., Hull, I. M. and Champine, P. R. (2007) ‘Assessment of testamentary capacity and vulnerability to undue influence’ *American Journal of Psychiatry* 164: 722–727.

[18] For example, Mary and Helen both experienced a parent with dementia putting all trust in the business when dealing with their payment obligations towards them (in Section 9.2). Garry expressed this in Section 9.3, talking of his mother’s knowledge and understanding of the business and the complete trust she had in them to advise her accurately and in her best interests.

[19] See Section 7.3.

could be declared void[20] because Derek put his confidence, faith and trust in the sales representative who spent time with him and advised him on whether or not to enter into the contract.

Recommendation 4: voiding contracts for lack of capacity

The legal consequences of both capacity and a lack of capacity are different from what the participants in the interviews expected they would be. For example, capacity under the Mental Capacity Act 2005 is presumed and the unwise decisions of those deemed capable will stand. This appeared unfair to interviewees in light of their experiences. Equally at odds with general perceptions of what the law should be was the situation where a person was deemed to lack capacity. Whilst family members assumed that a proven lack of capacity would void a consumer contract, in fact the law requires the contractual counterpart to have known (or ought to have known) of the lack of capacity. Again, the interviews demonstrated confusion and concern about the rules relating to capacity.

These consequences of a lack of capacity need to be reviewed. This thesis argues that a lack of capacity should render a contract void, regardless of knowledge of the other party. As discussed in Chapter 6,[21] capacity is one of four prerequisites for a valid contract. Whilst the other elements[22] will void the contract *ab initio* if they are absent, capacity is treated differently. The reason is to preserve certainty of contract. As discussed in Chapters 6 and 7, case law has enshrined this principle in Hart v O'Connor.[23]

This is however only the case in certain circumstances. As discussed in Section 6.2, in relation to minors, the automatic lack of capacity will indeed ensure that most contracts are deemed void from the outset. This is even when the other contractual party could not identify that the person they were dealing with was under the age of 18.

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[20] See Section 7.2 on undue influence and the possible extension of the principle to consumer transactions.

[21] See Section 6.2 on the four building blocks that make a contract.

[22] Matching offer and acceptance, consideration and intention.

[23] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.

A similar point can be made for adults who lack capacity. This is alluded to in the Mental Capacity Act when expressing the need for some contracts to remain valid.[24] Indeed, current section 7 specifically states that payment of a reasonable price must be paid for goods that are defined as necessities.[25] By stating that some contracts will not be void despite a lack of capacity, it is possible that the legislator thought that other (non-essential) contracts should conversely be void for such a lack of capacity.

Section 7 Payment for necessary goods and services

[Current wording] (1) If necessary goods or services are supplied to a person who lacks capacity to contract for the supply, he must pay a reasonable price for them.

[Current wording] (2) “Necessary” means suitable to a person's condition in life and to his actual requirements at the time when the goods or services are supplied.

[New wording] (3) Where contracts are entered into in relation to the sale of land, the sale of shares or for the purpose of employment or training,[26] the contract is voidable at the behest of the person lacking capacity or their legal representatives.[27]

[New wording] (4) In all other cases, where goods, services or digital content are supplied to a person who lacks capacity to contract for the supply, the contract is deemed void.

Table 11.1 New Wording for section 7 Mental Capacity Act

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[24] See Section 7.2.

[25] Mental Capacity Act 2005, s.7(1).

[26] This wording again mirrors the common law principles available to others that lack capacity, namely minors. A more detailed description is presented in Section 6.2.

[27] This new subsection 3 is outside of the scope of this thesis, but included only for completeness to illustrate how the rules for minors could be mirrored for adults lacking capacity.

The recommendation therefore is to clarify section 7 further by adding new language (which mirrors the principles applied to minors in contract law). Such clarification of the consequence of lack of capacity would assist persons lacking capacity who have entered into contracts, including consumer contracts, that are detrimental to them, financially or otherwise.

Application to Ester: her lack of capacity would have voided the contract

Ester signed exclusive contracts to sell her house with three different estate agents. Not only was she not aware that she had signed contracts for the same type of exclusive service with three different agencies, but she could not remember that she had put her house up for sale. Under current law, it would be up to Ester or her representatives to demonstrate, first, that she did not have capacity at the time of signing the contract,[28] and secondly, that the estate agents knew or ought to have known that this was the case.[29] Two hurdles would need to be overcome to void the contracts that Ester entered into unwisely.

Even if the court were to accept that in Ester's case dementia had advanced to a point that capacity was lacking for these complex decisions, demonstrating knowledge of the incapacity by the estate agents may be difficult to prove. This would be based on the time spent together, although as was discussed herein,[30] many persons living with dementia will ensure that they are not 'found out', by either steering the conversation to topics they are comfortable with,[31] or by being an active listener.[32]

Were the Mental Capacity Act 2005 to be amended to make it clear that contracts entered into by a person lacking capacity are void *ab initio* or

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[28] Presumption of capacity: Mental Capacity Act 2005, s. 1(2).

[29] Hart v O'Connor [1985] 2 All ER 880, [1985] AC 1000, [1985] UKPC 1.

[30] See Section 9.3.

[31] For example, in Section 9.3 Barbara talked about her husband's ability to steer the conversation to topics he feels confident about, masking any issues.

[32] For example, in Section 9.3 Garry explained how his mother living with dementia would be careful to listen and seek to hide her challenges brought on by the disease.

voidable by that person (depending on the type of contract),[33] then one of the two hurdles would fall away. Three *exclusive* contracts were signed in quick succession, and as a result Ester would be in breach of the terms of the agreements entered into immediately. This might be sufficient to demonstrate her lack of understanding of a fundamental term of each of the contracts, clearing the other hurdle.

Overall, this realignment of contract law to ensure that where a fundamental condition of contract formation (namely capacity to enter into a contract) is not met, a contract is not validly formed and any agreement is void (or voidable in certain contexts), would clarify and simplify contract law and be highly beneficial to vulnerable persons in particular.

Recommendation 5: educating businesses on the meaning of the words "with your consent" in the lasting power of attorney

Both the person living with dementia and their families experienced confusion in some situations where further consent was requested by a business following review of a lasting power of attorney.

Lasting powers of attorney provide the following two options for the donor: The donor may select for the lasting power of attorney to apply only when capacity is lacking. Alternatively, the donor has the choice for the lasting power of attorney to be actionable "*As soon as my LPA has been registered (and also when I don't have mental capacity)*". The lasting power of attorney then explains that this means that "*While you still have mental capacity, your attorneys can only act* ***with your consent****. If you later lose capacity, they can continue to act on your behalf for all decisions covered by this LPA.*"[34]

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[33] See proposed solution 1 above and Section 6.2 on void and voidable contracts for minors and the suggestion to align the rules for those lacking capacity to those of minors in relation to contract law.

[34] Office of Public Guardian (undated) Form LP1F Lasting Power of Attorney, Section 5, at 6, available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/600963/LP1F-Create-and-register-your-lasting-power-of-attorney.pdf, last accessed on 23 December 2021.

As was discussed, in fact the lasting power of attorney puts the attorney in to a similar position of that of a trustee, creating a fiduciary relationship.[35] Consequently, separate written forms to document the donor's consent to act in each and every situation are not required.[36]

Application to Jana: a better understanding of the lasting power of attorney would mean that her sons could step in

When Jana asked her sons to step in and take over financial tasks for her, the lasting power of attorney was a sensible way to do so. Businesses need to be made aware of the fiduciary position and not unnecessarily delay or refuse to deal with the attorneys of the donor.

If this was clear to businesses, Jana's sons would be able to liaise with the bank and ensure the direct debits and standing orders reflect Jana's current outgoings. Automatic renewals of contracts, be these with utility providers, insurance providers or other companies providing on-going services or goods, could be monitored and cancelled without worrying Jana unduly. The unnecessary mobile phone contract could be cancelled in line with terms and conditions.

Jana would no longer be put on the spot, asked to remember long forgotten passwords, or confirm the activities her sons were undertaking for her, giving her peace of mind.

Overall, the intention of proposing five recommendations and reviewing these in light of the five vignettes is to demonstrate that there is a different way in which these matters can be approached and dealt with, if there is the will. For this to become reality, there is the need for those in power to want to engage.

11.3 Awareness building and education, a willingness to engage

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[35] See Section 10.5 for a detailed discussion of the fiduciary role of the attorney.

[36] Other than in certain exceptional circumstances (particularly around the sale of land or property) where written consent may be required if the donor still has capacity.

The focus so far has been on whether there are alternative options that might constitute workable legal remedies in the future. However, for such options to become law, there would need to be a willingness to engage with these issues, especially in light of the associated cost to the state as well as to relevant businesses.

A need for change

Many of the problems reported in the interviews can be traced back to a lack of understanding within businesses when dealing with the person living with dementia. As a very first step, before any of the recommendations are implemented, the public generally and businesses specifically must become aware of the issues encountered daily by the consumer living with dementia. Indeed, greater awareness of the challenges for a consumer living with dementia would help to avoid such problems arising. This could include ensuring that those with consumer-facing roles are informed of the disease, the symptoms to look out for, the consequences to be taken into account, and how best to engage with a person who may be living with dementia.

A first step towards understanding and acting positively in relation to vulnerability has been the British Standard BS18477, [37] created in collaboration between Citizens Advice and Consumer Futures, government bodies and the British Standards Institution. However, whilst this standard was published in 2010, in their report in 2015, Citizens Advice Bureau felt that businesses had not engaged sufficiently with the standards set out therein.[38] Training, education and information exchange remains important to ensure business representatives are aware of the issues faced by vulnerable consumers, and the ways in which the business can assist these persons.

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[37] British Standards Institution (2016). *BS 18477: the standard that helps vulnerable consumers*, available at https://memberportal.bsigroup.com/public/2017/january/bs-18477-the-standard-that-helps-vulnerable-consumers/, last accessed on 14 February 2021.

[38] Citizen's Advice (2015) *Treating consumers fairly, Flexible and inclusive services for all,* available at https://www.citizensadvice.org.uk/global/migrated_documents/corporate/treating-consumers-fairly.pdf, last accessed on 14 February 2021; as also described in more detail in Section 10.4.

Kate, whose husband was living with dementia, felt strongly about educating staff.

> *Kate: Public-facing people should be trained to think about issues, especially if it is an older person, a confused person… it is really important that sales persons understand it [dementia]; they really need to be trained on this.*

By providing such training, the aim would be to assist with a shift in focus in contractual law matters.

The cost of engaging

An education programme for businesses that interact with consumers might have some impact, but pragmatically the question must be asked as to how much this can and would actually change things.

When online courses on health and safety are offered by businesses to their employees, these are often taken reluctantly and not considered much past the actual module. This is because such training is often delivered in ways that requires employees simply to be reactive and listen/read about relevant legislation and possible scenarios that might occur. However, such an approach, which is mainly passive for the employees, may reinforce the message that a passive attitude is all that is required. There is the risk that if awareness training of vulnerable adults in consumer matters are provided to employees via an online educational system, that these courses are not as impactful as would be necessary to shift attitudes and perceptions. To be effective, any educational programme on vulnerable consumers should be a continuous process, which can be applied in employees' day-to-day work with customers.

Another problem might be the perceived high cost of compliance with (self-) regulations requiring that all staff become aware of the issues that vulnerable consumers may face. Similarly, if the business puts in place exceptions to their consumer contracts for vulnerable consumers, these exceptions will have to be taught and carry a cost both in terms of time spent in training, as well as potentially the cost of more favourable terms offered to the vulnerable consumer. In addition, rules on (highly) persuasive selling might be curtailed in order to take into account a consumer's vulnerability. This may lead to a reduction in sales and consequently in profits.

While the cost of non-compliance of any of the (self-) regulations, guidelines or recommendations is low, adverse publicity may well be of concern to businesses. For example, the BSI, promoting their British Standard BS18477 on vulnerable consumers, stated that

> *The standard also helps organizations to avoid negative publicity as a result of getting customer service wrong. We have all seen newspaper consumer interest stories about elderly people being treated poorly by utility companies, or recently bereaved people given harsh treatment. While this level of service is seldom deliberate, having processes in place to ensure all customers are treated fairly will help to prevent this damaging publicity.*[39]

This demonstrates the effect that public pressure can have on the implementation of new norms to ensure that vulnerable consumers are treated fairly in light of their circumstances.

Shift in focus: a public interest principle

However, reliance on business (self-) regulation alone will not be sufficient. In order for any meaningful change to occur with regards to the way in which vulnerable consumers, including persons living with dementia, are treated, there needs to be a shift in perspectives more generally. The goal is to find ways in which to encourage support and uptake for legal remedies, such as the aforementioned recommendations. This can only be done if the focus is shifted to one of public interest. The law by its very nature will dictate its rules

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[39] British Standards Institution (2016). *BS 18477: the standard that helps vulnerable consumers*, available at https://memberportal.bsigroup.com/public/2017/january/bs-18477-the-standard-that-helps-vulnerable-consumers/, last accessed on 14 February 2021.

to serve the norm, and then include exceptions (where this is deemed right to do so) for those that fall outside of this category.

As highlighted in Chapter 6,[40] contract law, in its classical position, focuses on an objective approach, with the law aiming to ensure certainty and clarity. The contract is assumed to be entered into between equal partners who both fully understand, have equal power and knowledge, and can make decisions in their own best interests, without the need for any interference by an external authority/regulator. This is the ideal model when viewing contract law through the lens of autonomy,[41] assuming that the autonomous, independent and self-sufficient person is the norm.

However, as discussed in Chapter 3,[42] in relation to consumers, over 50% of all consumers are deemed to be actually or potentially vulnerable due to internal or external pressures.[43] In this current situation, a more nuanced approach that takes into account the actual people transacting may be more helpful to consumers as a whole. In doing so, a shift towards focus on the wider societal, public interest is required.

In order to ensure equal access to business by all, taking into account any vulnerability or difficulty in acting as an able consumer as set out in the Consumer Rights Act,[44] the law needs to step in to protect this 'public interest'. However, the question then needs to consider what public interest covers. There may be an argument that certainty of contract is as much in the public interest as ensuring subjective equality and fairness through rules, regulations and exceptions for different categories of people. As was discussed above in Chapter 5, once people are categorised differently, there is a risk of some of these persons falling outside of a protected category. It needs to be questioned whether that is still in the public interest.

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[40] See Chapter 6, Section 6.2.

[41] See Chapter 5, Section 5.2; and also Consumer Rights Act 2015, s. 64(5).

[42] See Chapter 3, Section 3.3.

[43] FCA (2017) *Understanding the financial lives of UK adults: findings from the FCA's financial lives survey 2017.*

[44] Consumer Rights Act 2015, s. 64(5).

Ultimately, this is a question of rebalancing. The aim is to move from a traditional contract law position to a narrative that is more person-centred. It is in the public interest to consider both the need for contract certainty and to focus on the relationality between the parties to a contract. The particular situations of different parties must be taken into account when identifying effective protective measures. Given the acknowledgment of the potential of vulnerability in the majority of consumers, this needs to be taken this into account when considering public interest. Effective change might come through policy responses.

Where these measures reflect the current public interest to take into account the needs of consumers with cognitive impairment, learning disabilities or disabilities, or going even beyond that, if this would be something public interest would deem useful to all consumers (a majority of which are potentially or actually vulnerable consumers) then in the longer-term, action is needed along the lines of the recommendations herein[45] to ensure that a real difference is made for consumers.

11.4 Aims and limitations

Although small in scale (since it heard the voices of 31 persons based in the South West of England), this research is nevertheless important and representative of the situation that many people living with dementia face. Indeed, the thoughts, opinions and ideas shared by the participants in interviews of their lived experiences and of how they would like to see the future shaped, are valuable and helpful in understanding the challenges faced and the legal and practical consequences experienced in daily life.

This study specifically considered consumers and consumer contracts, and persons living with dementia, and their families or other carers supporting them, were at the heart and centre of this research. In doing so, the conscious and deliberate choice was made not to also approach businesses, the contractual counterparts to the consumer. Consequently, this project has allowed for many of the experiences of stakeholders to be aired and made

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[45] See Section 11.2.

visible. The thesis has given a voice to those who often do not have the power, time or energy to speak up. Valuable insights were gained into some of the challenges faced by consumers living with dementia and their families.

Following on from this research, a valuable follow-up study would be to consider these issues from the perspective of businesses. Crucially, the research carried out in this thesis, identifying the challenges facing consumers living with dementia, will greatly assist in shaping future research aimed at consumer-facing businesses. Understanding the aims, challenges and concerns of the business community when interacting with consumers living with dementia would be an important next step to further understand how such consumers might best be supported.

The current research sought to identify the consequences, legal and practical, when a person living with dementia enters into a consumer contract with a business.

Relevant laws were carefully reviewed to explore the protection afforded to consumers living with dementia. The new data obtained focused on the experiences of persons living with dementia and their family members, highlighting many of the issues encountered. In doing so, it demonstrates that the law does not in all situations adequately protect the consumer living with dementia.

Key findings suggest that there remain many difficulties for consumers living with dementia when entering into contracts. For example, in relation to contract law, the review of relevant laws and empirical data shows that it is too easy for consumers living with dementia to enter into contracts, and too hard for them to break them. This is because a contract can only be set aside if the other party was aware of the consumer’s lack of capacity. However, the data demonstrates that consumers living with dementia may not disclose their health status, either because they are unaware of the diagnosis or for fear of stigma.

In addition, the Consumer Rights Act, which seeks to provide clarity and transparency for the consumer, does not protect the consumer living with dementia. This is because cognitive impairment or memory loss can make it much more difficult for the consumer living with dementia to understand the consequences of the transaction, even where there is full disclosure of financial aspects and other significant terms of the contract.

The four-tiered test of capacity as set out in the Mental Capacity Act may result in a consumer living with dementia being bound by a contract because they are deemed to have capacity, whilst not fully understanding the complexity of the consumer contract terms. This can be problematic in relation to contracts, such as consumer contracts that have financial implications, both for the consumer living with dementia and their family.

The interviews conducted as part of this research shone a light on the relationships between persons living with dementia and their families. These demonstrated that the freedom to make their own choices was linked to their support network. The structural framework, such as lasting powers of attorney, further spoke to the relational decision-making at play.

Recommendations and associated limitations

As a result of the above research, a number of recommendations were made, although these must be tempered by considering the following limitations.

Wider implication of making contracts void or voidable: These recommendations would, if adopted, have a significant impact on relevant contract law and doctrine. It must be acknowledged that such impact may be highly disruptive. For example, the principle of certainty in contract law is a fundamental and essential component, and the risk to businesses of contracts being voided or voidable may be problematic to them.

In practice, this may lead businesses to review their business models and consider to what extent contracts with certain groups of consumers remain commercially viable. This may result in the unwanted situation of certain categories of persons being excluded from entering into contracts. Whilst such an approach would be illegal if contrary to the Equality Act 2010 (if the consumer had a protected characteristic, such as age or disability), in practice this might be difficult to prove and may result in the exclusion from consumer transactions of certain persons. This in turn highlights the further limitation due to the potential lack of access to justice for consumers living with dementia.

Access to justice concerns: In addition to the risk of exclusion in practice of certain consumers, there are likely to also be barriers relating to access to justice, both in terms of legal assistance and legal processes.

A number of reasons will limit access to justice for consumers living with dementia and their families. First, some persons may lack of awareness of their legal rights. It may be difficult for consumers to realise and understand when their rights are breached. This risk may be heightened for those consumers with cognitive impairments, who may be confused about their rights as a consumer, as well as about the resources and support available to them. This lack of knowledge is likely to result in few (if any) claims being made against discriminating businesses.

In addition, the person living with dementia may require the support of others (family members or other carers) to understand and apply their legal rights in a consumer situation. This provides an additional step to access to justice for this group of consumers. Where no clear support system is in place, for example in the case where a diagnosis of dementia has not (yet) been made, access to justice may be further stalled. As was discussed in Chapter 9, in many cases persons living with dementia will not disclose their diagnosis, either because they do not know, do not think to disclose it or are actively hiding their diagnosis from third parties. Without such information, support may be lacking, resulting in a barrier to access to justice.

Finally, the specific symptoms of dementia, as discussed in Chapter 2, make communications in some cases more challenging. This might mean that persons living with dementia may be less able to relay the facts of any incident that occurred with a business. This may make their account of what was said or done less credible, leading to the necessary burden of proof not being met. It may also result in a lack of comprehension of the legal advice given to them and the steps recommended to seek redress.

Whilst these limitations are recognised, this thesis suggests that nevertheless careful and considered steps must be taken over time to assist the person living with dementia when acting as consumer.

11.5 Final concluding remarks

Dementia is a subject that resonates with all of us. Indeed, dementia is and remains a prevalent concern in many people's lives. At the time of writing this, two further legends have been identified as having dementia. Within days of each other, Bobby Charlton announced his diagnosis of dementia,[46] whilst the news fell that Sean Connery had died with dementia.[47]

Dementia continues to move into the mainstream and further enters the consciousness of society at large. However, this awareness alone will not make matters easier or better for people living with dementia. Clear and decisive legal action is needed to assist, not only the popular and affluent stars that live with dementia, but all the other persons with dementia, anonymous and loved by their families and friends, living more modest lives, often relying on small financial sums to get by and continue to live independently.

Where an unwise decision as a consumer wipes out the personal finances and removes that person's independence, legal remedies are required to reverse such circumstances. It is for us as a society to strive towards a more just legal system that recognises these vulnerabilities and considers legal protections for those that will otherwise lose out.

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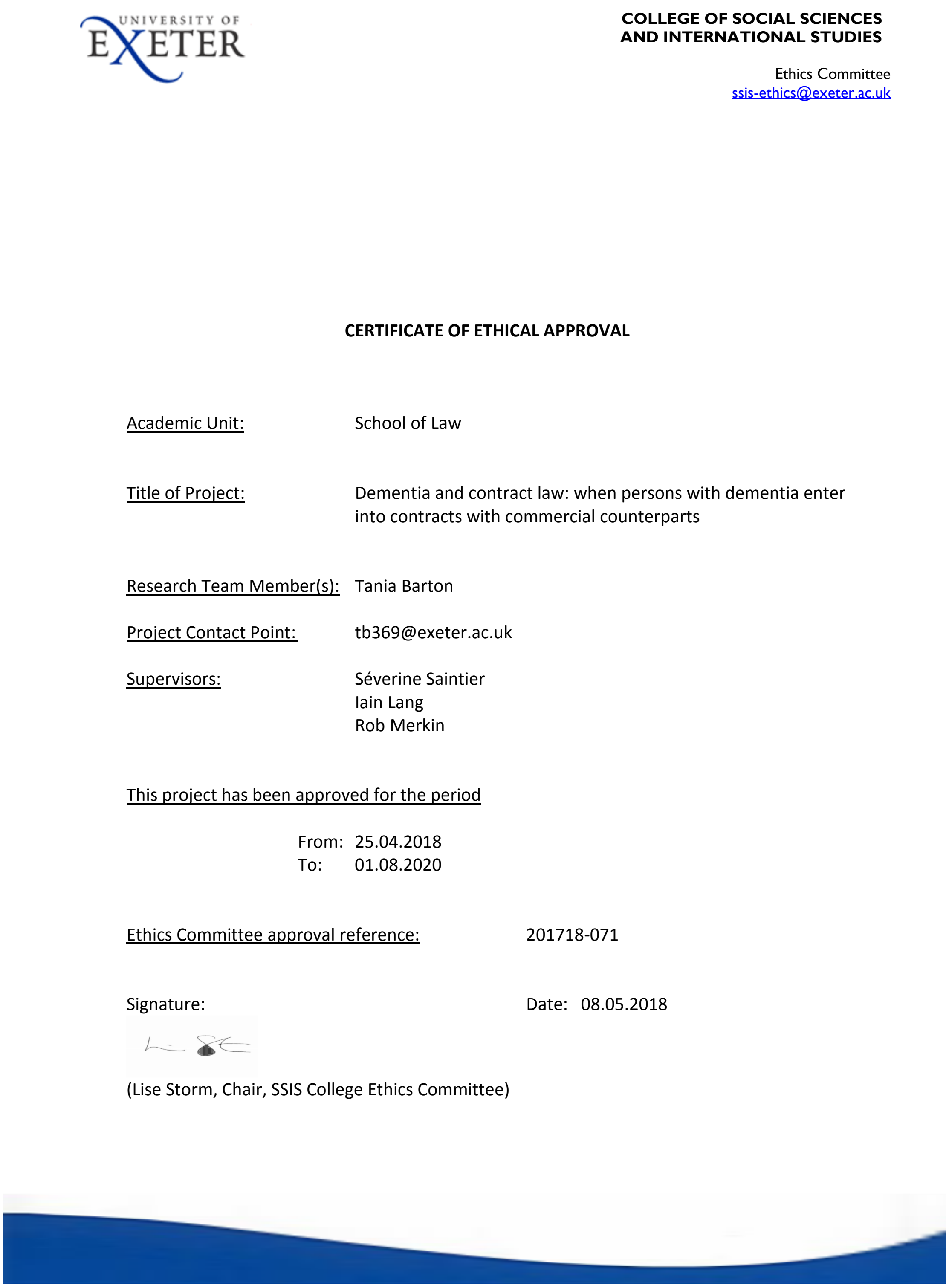
[46] Jackson, J. (2020) *England legend Sir Bobby Charlton is diagnosed with dementia* The Guardian available at https://www.theguardian.com/football/2020/nov/01/sir-bobby-charlton-diagnosed-with-dementia-wife-lady-norma-confirms, last accessed on 14 February 2021.

[47] Pulver, A. (2020) *Sean Connery had dementia, his wife reveals* The Guardian, available at https://www.theguardian.com/film/2020/nov/02/sean-connery-had-dementia-his-wife-reveals, last accessed on 14 February 2021.

Appendices

Appendix 1

Certificate of ethics approval



UNIVERSITY OF EXETER

COLLEGE OF SOCIAL SCIENCES AND INTERNATIONAL STUDIES

Ethics Committee
ssis-ethics@exeter.ac.uk

CERTIFICATE OF ETHICAL APPROVAL

Academic Unit: School of Law

Title of Project: Dementia and contract law: when persons with dementia enter into contracts with commercial counterparts

Research Team Member(s): Tania Barton

Project Contact Point: tb369@exeter.ac.uk

Supervisors: Séverine Saintier
Iain Lang
Rob Merkin

This project has been approved for the period

From: 25.04.2018
To: 01.08.2020

Ethics Committee approval reference: 201718-071

Signature: Date: 08.05.2018

(Lise Storm, Chair, SSIS College Ethics Committee)

Appendix 2

Information sheet and consent form

Information Sheet

I am Tania Barton, a student researcher from the University of Exeter. I am conducting ESRC-funded research on the topic of dementia and contract law and wish to explore what happens in practice when persons with dementia enter into a contract with a business, such as a shop or a bank. This leaflet explains more about the research and what would be involved if you choose to participate.

What is the study about? The aim of the research is to explore what issues arise when people with dementia enter into contracts, which they do not fully understand or remember due to their illness. The aim is hear from persons with dementia, family members or carers of persons with dementia and charities that deal with persons with dementia.

What will taking part in the research involve? Individual interviews will be held, focusing on your experiences, concerns, thoughts and ideas in relation to the issues when a person with dementia enters into a contract with a business, such as a shop or a bank. Interviews will last approximately one hour. With your prior consent, the interview will be recorded.

Who is the researcher? I am Tania Barton, a student researcher at doctorate level, from Exeter University. My supervisor is Dr. Séverine Saintier, from the law school at Exeter University. My second supervisor is Dr. Iain Lang, from the medical school at Exeter University. Together, we make up the research team for the purposes of this research project. The Economic and Social Research Council is funding the study.

Will anyone be identified from the research? No. All participants will be given fictitious names to prevent identification. These fictitious names will consist of the word "Ms." or "Mr." followed by a randomly chosen capital letter (e.g. "Mr. P.") It will be made clear in the reporting that the letters were randomly chosen and do not represent the first letter of the participants' last name. Where necessary other details will be omitted or altered to prevent identification. Description of location may refer to a region only.

How will my data be stored? The interviews will be typed up (transcribed) making sure that all identifying details are removed. The completed transcripts will be uploaded to a secure University drive. Only I and my supervisors will have access to the data on the secure University drive. Any identifying information will only exist in paper format and will be stored securely in a locked filing cabinet at Exeter University. Only I will have access to that information. It will be destroyed after three years from the completion of the project using a secure shredding service.

Whose consent is needed and can it be withdrawn? Your individual consent is needed and your participation in the study is entirely voluntary. You can withdraw without explanation any time before or during the interview. You can also withdraw within the year following the interview. If you are willing to take part in the interview then please complete the attached consent form and return it to Tania Barton (details below)

Any questions or worries? If you have any questions at all about the research please contact Tania Barton, School of Law, Exeter University, Devon, EX4 4RJ, Tel 07857805404, email tb369@exeter.ac.uk

If you have any other concerns about how the research is being conducted, then please contact Séverine Saintier, School of Law, Exeter University, Devon, EX4 4RJ, email S.Saintier@exeter.ac.uk

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CONSENT TO PARTAKE IN THE INTERVIEW

Please sign your initials, or make a mark such as a tick, next to each section to demonstrate consent at each stage.

I have read the information leaflet.

I agree to take part in the interview.

I agree for the interview to be recorded [strike through if necessary]

The researcher has explained to my satisfaction the purpose of the study and how the information will be used.

I understand that everything I say will be treated in strict confidence and no comments identifying me will be disclosed outside of the research team.

I understand that my personal details will not be shared with anybody outside the research team.

I understand that the data will not be used for any purpose other than the research and third parties will not be allowed access to the data (except as may be required by the law)

I understand that my data will be held in accordance with the Data Protection Act. It will be held on an anonymous basis for five years and then destroyed.

I understand that I do not need to participate and can change my mind at any time.

I understand that I am able to withdraw from the study without prior notice by not attending the interview or at any time during the interview. During the interview, I can stop the interview at any time at my request if I no longer want to continue.

I understand that I will be offered the opportunity after the interview to review the transcript of my interview. Any changes I suggest to my review will be included in the final transcript.

I understand that I can withdraw after the interview without explanation within a year following the interview.

Name of participant: ....
Signature: ....
Phone number: ....
Date: ....

Signature of researcher: ....

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Appendix 3

Interview guides[48]

A3.1. Semi-structured interview with persons living with dementia

A3.2. Semi-structured interview with family members or carers of persons living with dementia

A3.3. Semi-structured interview with volunteers or employees of charities

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[48] A3.2 is a reproduction of the list of questions produced as part of my Masters in socio-legal research (T. Barton (2017) *What do you mean we have a deal? Considering the concerns of family members when persons with dementia enter into commercial contracts*); A3.1. and A3.3. contain some questions that were already used as part of that same Masters in socio-legal research

A3.1 Semi-structured interview with persons living with dementia

Research Question: *What are the consequences for people affected by dementia, when persons living with dementia enter into contracts with commercial counterparts?*

Pre-interview checklist

- Provide information sheet
- Provide capacity demonstration form
- Ensure consent form is read and signed
- Obtain confirmation that interview can be recorded
- Show ethics certificate
- Ask if there are any queries/issues
- Explain that we can pause or stop the interview at any time

General information

Could you tell me a little bit about you?

- Gender
- Age bracket
- Living arrangements
- Employment status
- When was your dementia diagnosis

Decision-making

This section relates to decisions regarding to every-day activities that you may partake in, some trivial such as what to wear, eat, activities you do, and others a little less so such as financial decisions you make in relation to the home (insurance) or other contracts you may enter into.

- Please talk me through a typical day. What do you do? Who do you meet?
- Do you find it easy or hard to make decisions generally?
- Do you feel your ability to make decisions has changed since the onset of dementia? If so, can you give me an example?

This research is all about looking at when persons with dementia enter into commercial contracts.

- Would you feel happy to enter into a new contract with a business or a bank right now?
- Would you want to discuss the matter with a friend or family member before making a final decision?

Let me set out a couple of scenarios for us to consider together.

Imagine a person with dementia goes to their bank to withdraw money. Whilst at the bank, the bank employee suggests a new saving account. There are advantages to the new account but also costly fees and commissions to be paid.

- Do you think the bank employee is just doing their job?
- Do you think it would be wrong to not suggest the new saving account to a person because they might have dementia?
- Do you think the bank employee should ask if the client has dementia?
- Do you think the person with dementia should be given time to discuss this with a family member or friend?
- Do you think the person with dementia should be allowed to change their mind about the account at any time in the future?

Imagine a person with dementia has forgotten that they already have a mobile phone and has signed up to a second mobile phone contract. Both contracts only come to an end in 2 years' time. The monthly cost for each mobile phone is high (over £50 each) The second mobile phone contract is not needed. To get out of the second mobile phone contract would mean paying an early-termination penalty.

- Do you think the person with dementia should just terminate the second contract and pay the penalty?
- Do you think the sales person should ask if the client has dementia before a mobile phone is sold?
- Do you think the person with dementia should be given time to discuss the contract with a family member or friend?
- Do you think the person with dementia should be allowed to change their mind about the account at any time in the future and terminate the second contract without incurring any penalty?

Capacity (your ability to understand and weigh up information and come to a decision)

- If there was a situation where you were asked to sign a contract by a sales person, and you were not sure of it, would you ask for advice?
- If so, who would you turn to for advice (family member, friend, the sales person, a charity such as Citizens Advice Bureau or Age UK)?
- Would you consider the advice, but make up your own mind?
- Would you be happy to rely on their opinion and take the advice?

Lasting power of attorney

- Have you heard of a lasting power of attorney?
- Have you put one in place?

- Have you used it?
- Was it helpful?
- Was it complicated?
- Anything else that you have encountered?

Dementia guidelines (I am looking to discuss the presence/absence of awareness of dementia and therefore lack of guidelines or usefulness of existing guidelines)

- Have you noticed that some businesses have stickers in their shop windows saying they are dementia-aware or dementia-friendly?
- Does that make you more likely to go into that shop?
- What would you expect from a shop that has such a sticker?
- Have you any experiences with such shops?
- Have you come across companies or local authorities that have, without any persuasion, been very fair and supportive of someone with dementia?
- Do you think a lot of the time companies will act in a fair manner because of the fear of negative publicity?

Catch-all final question

Any other thoughts, concerns or comments on anything we discussed today?

Anything else that I have not asked that you consider relevant?

***

Thank you very much for your participation.

I am going to transcribe what we discussed today and, if you wish, I will send the transcript to you for you to read. If there is anything you want me to change, please just let me know. Any changes you suggest will be included in the final transcript. You can withdraw your participation to the research without explanation within a year following the interview.

A3.2 Semi-structured interview with family members or carers of persons with dementia

Research Question: What are the consequences for people affected by dementia, when persons with dementia enter into contracts with commercial counterparts?

[N.B. Once the relationship of the participant with the person with dementia is established, I would use a more appropriate term (father, mother, uncle, grandmother, etc.) rather than referring to “person with dementia” when speaking to the participant.]

Pre-interview checklist

- Provide information sheet
- Ensure consent form is read and signed
- Obtain confirmation that interview can be recorded
- Show ethics certificate
- Ask if there are any queries/issues
- Explain that we can pause or stop the interview at any time

General information

Could you tell me a little bit about you and your relationship to the person with dementia?

- Relationship
- Gender (participant)
- Age bracket (participant)
- Meeting frequency
- Dementia stage

Decision-making

This section relates to decisions regarding to every-day activities that the person with dementia may partake in, some trivial such as what to wear, eat, activities they do, and others a little less so such as financial decisions they might make in relation to the home (insurance) or other contracts they might enter into.

- In terms of making decisions, what was the person like before dementia (confident/timid/indecisive)?
- In terms of making decisions, did that change with the advance of dementia (examples)?
- Please talk me through a typical day for the person with dementia.
- How long do you think the person with dementia had memory issues or other troubles related to dementia before she/he was officially diagnosed with having dementia?

- This research is all about looking at dementia patients and them entering into contract with businesses.
- Have you come across any examples where the person with dementia had wanted to enter into a contract or actually had entered into such a contract?
- Could you think of a specific example? Please give details of the following:
    - when they came into contact with the business?
    - how they came into contact with business? (telephone, face to face, in a shop, on the doorstep) Were they approached by the business?
    - was there negotiation?
    - was a third party involved?
    - did person with dementia ask for family member's help?
    - did commercial counterpart ask for help?
    - was the contract concluded?
    - was there a financial commitment?
    - was there an attempt to cancel the contract?
    - was it easy for them to get out of the contract?
    - did you have any external advice or help from a charity or public authorities to help you deal with these situations?

What would you like to see changes in the current law?

- e.g. longer leeway to cancel a contract, so that any such contract can be made known to family members or carers and still have time to cancel if it turns out that it is not in the best advantage of that person?
- e.g. should this notice period start from the point when money is collected or from the time when family members become aware of the situation?
- what about the protection of the commercial counterpart: if there is no fraud on the part of the commercial counterpart? What if the commercial counterpart does not realise this person has some cognitive impairments?

Capacity

Imagine the person with dementia wants to enter into a contract and because of the illness s/he wasn't quite capable of understanding the contract or understanding the consequences of the contract in full.

- is it appropriate for them to receive your advice?
- Would you be happy if s/he was receiving advice from a professional carer, or a care home employee or anyone else?
- Do you think the person with dementia would find it helpful to receive your advice?
- Do you think the person with dementia would find it helpful to receive advice from a professional carer, or a care home employee or anyone else?

Lasting power of attorney

- Have you heard of the lasting power of attorney?
- If so, have you put one in place? If not, why not?
- Have you used it?
- Have you used it whilst the person had capacity?
- Was it easy to get her/his consent?
- [If applicable] Have you used it since the person no longer has capacity?
- Was it easy to prove ‘lack of capacity’?
- Who determined ‘lack of capacity’?
- Does the lasting power of attorney work?
- Was it helpful?
- Was it complicated?
- Any unforeseen consequences?
- Anything else that you have experienced that you think it relevant and I have not asked about?

Dementia guidelines

- Have you heard of the Alzheimer dementia guidelines, such as the Dementia-Friendly Financial Services Charter?
- Do you know of any companies that have signed up to these?
- Do you know what impact the guidelines have and what effect they have for people with dementia?
- Have you come across companies or local authorities that have, without any persuasion, been very fair and supportive of someone with dementia?
- Do you think a lot of the time companies will act in a fair manner because of the fear of negative publicity?

- Do you think it is unfair or do you understand that vulnerability will only kick in when the condition is medically diagnosed?
- Have you registered the person with dementia as a vulnerable person?
- Why? Why not?

Catch-all final question

Any other thoughts, concerns or comments on anything we discussed today?

***

Thank you very much for your participation.

I am going to transcribe what we discussed today and, if you wish, I will send the transcript to you for you to read. If there is anything you want me to change, please just let me know. Any changes you suggest will be included in the final transcript. You can withdraw your participation to the research without explanation within a year following the interview.

A3.3 Semi-structured interview with volunteers or employees of charities

Research Question: What are the consequences for people affected by dementia, when persons with dementia enter into contracts with commercial counterparts?

Pre-interview checklist

- Provide information sheet
- Ensure consent form is read and signed
- Obtain confirmation that interview can be recorded
- Show ethics certificate
- Ask if there are any queries/issues
- Explain that we can pause or stop the interview at any time

General information

Could you tell me a little bit about you and your relationship to the person with dementia?

- Position within charity
- Gender (participant)
- Age (participant)
- Experience with dementia

Decision-making

This research is all about looking at dementia patients and them entering into commercial contracts.

- What is your day-to-day experience with persons with dementia or their family members or carers?
- Have you been asked for advice about situations regarding a person with dementia? If so, can you explain?
- Have you been asked for advice about situations where a person with dementia has entered into a contract? If so, can you explain?
- Have you been asked to assist or advice on what to do? If so, can you explain?
- Have you been asked if you had a template letter or form to help the person deal with a contractual matter?
- Have you come across any examples where the person with dementia had wanted to enter into a contract or actually had entered into such a contract?
- Could you think of a specific example? Please give details of the following:
    - when they came into contact with a business?

    - how they came into contact with business? (telephone, face to face, in a shop, on the doorstep)
    - was there any negotiation?
    - was a third party involved?
    - did the person with dementia ask for a family member's help?
    - did the commercial counterpart ask for help?
    - was the contract concluded?
    - was there a financial commitment?
    - was there an attempt to cancel the contract?
    - was it easy for you to get out of the contract?
    - did you have any external advice or help from a charity or public authorities to help you deal with these situations?
- What would you like to see changed in the current law?
- e.g. longer leeway to cancel a contract, so that any such contract can be made known to family members or carers and still have time to cancel if it turns out that it is not in the best advantage of that person?
- e.g. should this notice period start from the point when money is collected or from the time when family members become aware of the situation?
- What about the protection of the commercial counterpart if there is no fraud on the part of the commercial counterpart?
- What if the commercial counterpart does not realise this person has some cognitive impairments?

Capacity and lasting power of attorney

- Have you heard of the lasting power of attorney?
- If so, would you recommend its use?
- Have you seen it used in practice and has it helped?
- Can you tell me more, such as whether it is easy to use, if it helps, etc?
- Have you advised on completing a lasting power of attorney?
- Have you advised on an existing lasting power of attorney?
- Have you had personal experience or feedback on the ease to use a lasting power of attorney?
- Any unforeseen consequences?

Dementia guidelines

- Have you heard of the businesses signing up to self-regulating dementia guidelines, such as the Dementia-Friendly Financial Services Charter?
- Do you know of any companies that have signed up to these?
- Do you know what impact the guidelines have and what effect they have for people with dementia?
- Have you noticed that some businesses have stickers in their shop windows saying they are dementia-aware or dementia-friendly?
- What would you expect from a shop that has such a sticker?
- Have you any experiences with such shops?
- Have you come across companies or local authorities that have, without any persuasion, been very fair and supportive of someone with dementia?
- Do you think a lot of the time companies will act in a fair manner because of the fear of negative publicity?
- Have you heard about registering a person with dementia as a vulnerable person?
- Would you advise registering a person with dementia as a vulnerable person?
- Why? Why not?

Catch-all final question

Any other thoughts, concerns or comments on anything we discussed today?

***

Thank you very much for your participation.

I am going to transcribe what we discussed today and, if you wish, I will send the transcript to you for you to read. If there is anything you want me to change, please just let me know. Any changes you suggest will be included in the final transcript. You can withdraw your participation to the research without explanation within a year following the interview.

Appendix 4

Scoping review, list of selected journal articles

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Appendix 5

Themes emerging from new data

Themes and sub-themes

Change in person living with dementia

- Unnoticed
- Noticed
- Labelled differently
- Age
- Character traits
- Eccentricities
- External circumstances
- With hindsight
- Confused
- No confidence
- Overconfidence

Change in family member

- Carer
- Parent
- Son/daughter
- No change
- Financial decision support
- Financial decision substitution
- Responsibility for financial decisions

Reversed roles

- Helping with decision making
- Taking over decision making
    - * by spouse
    - * by grown-up child

Living independently

- Financial decisions made
- Financial decisions questioned
- Problems arising from financial decisions made
- Financial decisions

Contractual decisions
    * by post
    * by phone
    * on doorstep
    * at shop
    * by internet
Blank cheques/purse

Worry

Worry about restricting decision making
Worry about safety
Worry about fraud/abuse
Worry about accusations of abuse

Business cold-calling

On doorstep
By phone
By post
By email
Approached by person living with dementia
Business cold calling

Capacity

Fluctuating capacity
Capacity considered
Capacity less important that safety

Knowledge of contract

Of choosing between deals
Of cost
Of value of money
Of the other party
Confidence in other party
By person living with dementia
By carer/family member
Confidence in ability to make good decision
Confidence in ability to understand terms
Family member unaware of contract
Family member unaware of cost

Knowledge of consumer

- At shop
- On phone
- Informing business
- Bank
- Insurance (pet, travel)
- Hiding symptoms
- Of business/company

Self-knowledge by person living with dementia

- Unaware of dementia
- Refusal to acknowledge dementia
- Refusal to share with others
- Open about dementia
- By person living with dementia
- By family member
- Educating others

Knowledge (compliance with contract)

- Passwords
- Phone systems
- Internet
- Automatic renewal

Stigma

- Fear
  - * by person living with dementia
  - * by family member
  - * of ‘mental’ illness
- Assessment of capacity
- For lasting power of attorney
- For wills
- By self
- By doctor
- By solicitor
- By family friend
- Informally
- Formally
- Lack of assessment

Forms of disclosure

- In person
- Check box
- Pin/symbol on person
- Sign on door

Preparing an LPA

- Need
- Making LPA
    - * Alone
    - * Professional
    - * Family member
- Use
- No use
- Use
    - * original
    - * photocopy
    - * certified copy
    - * without further consent
    - * with further consent
- Cost of LPA
- Difficulty in preparing LPA
- Difficulty in getting LPA signed by person living with dementia
- Pressure to have LPA

Application of LPA

- Immediate effect
- Once capacity lost
- Did not mention
- Further consent needed
- Could act
- Paperwork
- Used for
- Credit card provided
- Solicitors
- Government agencies
- Utility providers
- Not used for
- Banks internet banking
- Signing in person

Acted a attorney without LPA

Terminating contract

Penalties
No penalties
Money lost
Reputation
Goodwill
Withholding money
Unable to terminate contract

Powerlessness

Costly contract
Unaware of contract
Unaware of how to return
Tied to contract
Financial abuse

Suggestions

Longer cancellation period
Pin/flower/symbol
Tick box
Education

Concerns disclosure of dementia

Fraud/abuse
Unscrupulous persons
Forget to disclose

Appendix 6

Post-script

First encounter

The first time I met a person living with dementia was as a child in the 1980s, living in the suburbs of Paris. Old American family friends were in town, as the husband, in his 70s, was still working as an entertainer on a touring ice-skating show. We got a phone call one day, hours before they were to visit us at home that afternoon. “We’ve lost Janet.” John told us. “Oh, I am so sorry for your loss”, my mother replied, speechless at the suddenness. “No, no”, John replied, “she is lost – lost in Paris.”

Janet had been separated from her husband as they were boarding a metro close to the Champs Elysees. Whilst John stood on the metro heading eastward, Janet had missed stepping into the carriage and stood distractedly on the platform. By the time he got off at the next station and asked the station guard to inform the previous station of the situation, Janet was no longer there, most likely carried outside of the metro station with the crowd of tourists and commuters, pushing their way into the street.

Finding a woman in her 70s, speaking only English, with dementia, in Paris, could have been a difficult task. Luckily, after (just) three hours, the police found her, happily wandering through the Tuileries gardens, with the napkin of a restaurant in her pocket and a name, telephone number and a series of drawings on that napkin. We found out that she had had a coffee, paid for by a patron of the restaurant. She had chatted to staff and tourists and all accounts were of “that charming, if somewhat confused, American woman”. She seemed unperturbed by the events, happily greeting us all. That night as we all sat together to watch the ice-skating show, I remember thinking about her inability to memorise events – aged ten, the focus was on the advantage of being able to see the show every night, like for the first time.

Close encounter

30 years later, my mother developed dementia herself. The positive aspect I had seen as a child was soon replaced by the heartbreak of seeing a loved one's health deteriorate. In losing crucial cognitive function, my mother became paranoid and would often make irrational decisions based on her perception of her environment, tainted by the lack of information that arose from her memory loss and her inability to fully understand the implications of the offers made to her by sales reps.

As a commercial lawyer, I had seen countless contracts, from standard terms and conditions to negotiated deals, and everything in between. But the issue of the person living with dementia entering into contracts with businesses as a consumer only struck me when I saw my mother time and time again enter into agreements for goods or services she did not need, would not remember getting, or could not afford to keep. Cancelling those contracts was however often a struggle. Commercial counterparts would point to the airtight provisions that left no room for the consumer to be released from the agreement, once statutory windows of opportunity (such as a two-week reflection period in which to change one's mind) had passed. In most cases, no consideration was given to the fact that she lived with dementia.

This made me want to research the complex relationship between dementia and contract law, and specifically the situation when a person living with dementia, as a consumer, enters into a contract with a business.

List of cases

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Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67

Allen v Rescous (1676) 2 Lev 174

Al Nehayan v Kent [2018] EWHC 333 (Comm)

Atlas Express v Kafco (Importers and Distributors) Ltd [1989] 1All ER 641

Ayes v Hazelgrove (QB, 9 February 1984, unreported)

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Convention on the Rights of Persons with Disabilities (2006) United Nations 2515 UNTS 3

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Mental Capacity Act 2005, c.9 (read together with Mental Capacity Act 2005 Code of Practice (2007) London: TSO)

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Safeguarding Vulnerable Groups Act 2006, c.47

Sale of Goods Act 1979, c.54

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