

Music, Dementia and Everyday Life within a Community Day Care Setting

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ABSTRACT

This multi-method ethnographic study explores the everyday lives of people with dementia living in the community, cared for by a spouse or family member. It examines three case studies of individuals with early to moderate stage dementia. The latter were attending a weekly day-centre group and this thesis explores their interactions with each other, individual histories, tastes, habits and daily habits. The primary aim of the research was to explore the natural role of music in the lives of these subjects as individuals and as a group. In doing so, this undertaking shows how, in supportive environments, agency and capacity can flourish, leading to constituents of 're-recovery', to use mental health terminology. This highlights some of the important matters that are overlooked where perspectives emphasise dementia as a disease of the brain. By contrast, it illuminates the role of social and environmental factors and their contribution to well-being.

After initial interviews with each individual and in some cases, members of their families, five months of participant observation followed, primarily located in a home-based day care service. The data set was formed from 178 hours of field observations, a number of audio-recordings made during the sessions, and detailed field notes. This study shows that a close-up focus on the minute details of how a person lives their life and 'dwelling' with them for an extended period will illuminate many of the processes that work toward maintaining the well-being of people with dementia and facilitate their revitalisation. Significantly, it was the integration of music within and alongside the everyday tapestries of activities and events which helped create a space for connection and pleasure.

The thesis findings reveal how the participants in this research repeatedly demonstrated expertise and insight, albeit not always verbally expressed, but shown in and through forms of practice as regards what was required for their well-being and how to achieve it. This achievement, however, also relied upon thoughtful and creative collaboration with others (carers, family members, etc.), working alongside the participants for mutually beneficial ends. The thesis concludes that what is required for people with dementia and their well-being does not differ substantially

from what is generally required by humankind, but there are certain skills and modes of co-operative assistance that are necessary to ensure and maintain the well-being of people with dementia.

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ACCOMPANYING MATERIALS

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CHAPTER ONE - INTRODUCTION

Most studies of music and dementia focus on therapy, the brain, peoples' incapacities, specific symptoms and long-term care environments. To date, little attention has been paid to how musical engagement occurs in situ for people who are living in the community. The aim of this research was to explore how music features in the lives of this population and work to understand what music does or can do. The research questions included, 'What shape does everyday musicking take for people with dementia living in the community? Where does it happen, who supports it and what is its significance?' In seeking out answers to these questions, the intention was to describe, explore and provide a more nuanced insight into the phenomena of everyday musicking with this cohort, than had hitherto been considered. In doing so, the objective was also to address omissions, specifically in the music and dementia-related literature.

1.0 Background and Backstory

The country's elderly population is growing. The Office for National Statistics (2013) project that over the next 17 years, the number of people aged over 65 will rise by 48.7% to over 16 million. Furthermore, by mid-2037, the number of people aged over 80 in the UK will double to six million. This rise in the UK is mirrored across the world, with the global share of older people (aged 60 years or over) expected to rise from 11.7% in 2013 to 21.1% by 2050 (United Nations, 2013). Moreover, dementia is predominantly associated with older people. Indeed, the research highlights how in 2013, 815,827 people in the UK had dementia and of this number, 773,502 were aged 65 years or over (Alzheimer's Society, 2014).

With the rise in both the elderly population and diagnosed cases of dementia in the UK, the subject has become a topic of pressing concern for policy-makers. Also responding to this concern is the press, who cover stories on dementia or Alzheimer's disease (AD) with great regularity. The most frequently adopted angle is one of potential preventative measures; for example, looking at the first three weeks of March 2015, there were 23 newspaper articles related to this. Titles included, 'Gout could help prevent Alzheimer's' (The Independent, 4.3.15); 'Middle-age fitness

cuts dementia' (The Express, 5.3.15); 'Gym, diet and puzzles can delay dementia in over-60s' (The Times, 12.3.15); 'How diet, exercise and brain training can delay dementia' (Daily Mail, 12.3.15); 'Epilepsy drug found to slow down slide into Alzheimer's' (The Express, 14.3.15), and 'Pills made from olives could slash the risk of Alzheimer's disease' (The Mirror, 20.3.15.).

Dementia is a frightening and unwelcome prospect for anyone, but frequently, media representations are sensational, highly negative and extremely limited in scope. The common media narrative tends to emphasise an inevitable, swift trajectory, suggesting that until a cure is found, there is little hope of being able to support people with dementia and their families, except by maintaining stasis. If we are to rely solely on medical interventions, then this is a reasonable assumption. However, fortunately, this need not be the case. By uncovering a wealth of individual and collaborative, yet untapped lay expertise, this thesis shows that living with dementia, whilst not without its challenges, does not always equate to poor quality of life; aspects of recovery are indeed possible, with meaning and joy being achievable.

With its focus on everyday musicking, this thesis therefore contributes to and builds upon the literature of three overlapping research fields, namely dementia, music and dementia, and everyday life. As a by-product of this focus, the thesis also highlights how people with dementia are involved in caring for others, with or without dementia; a potentiality that has so far not been addressed in any of the three aforementioned research fields.

This study will begin with an overview of dementia; a term which is defined by the NHS (2014) as a 'syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities'. The term refers to a brain pathology which impairs cognition across several regions, including 'memory, attention, language and problem solving' (George et al., 2011: 419). Subsumed within this umbrella term is AD, commonly claimed to account for 60-70% of dementia cases (WHO, 2012).

Descriptions of dementia have been appearing since 500 AD (Lock, 2013) and until the mid-9th century, the term 'dementia' was broadly applied to people of all ages

exhibiting 'any state of psychological dilapidation associated with chronic brain disease' (Berrios, in Lock, 2013: 31). All similar symptoms present in the elderly were regarded as an inevitable part of the ageing process and were commonly referred to as 'senile dementia'. AD was first classified in 1906 following research by Dr. Alois Alzheimer, who uncovered a cluster of tangles and plaque post mortem in the brain of a 51-year-old female, Auguste D. The woman, who had been under his observation in life whilst living in an asylum, had exhibited 'progressive cognitive impairment, focal symptoms, hallucinations, delusions, and psychosocial incompetence' (Maurer, Volk & Gerbaldo, 1997). Lock (2013: 29) argues that there was a particular drive at this time to establish the 'material component' of mental illness and for Alzheimer, one reason for this was to help reduce any associated stigma. During this period, it was commonly thought that 'mental derangement' was something that some people, particularly the poor, were prone to and Lock hypothesises that Alzheimer wanted to disprove this theory with observable evidence.

The classification of pre-senile dementia as AD was made possible with the advent of the microscope and an enhanced knowledge of brain pathology. Consequently, aspects of brain ageing began to be perceived as having 'visible, specific and identifiable (...) correlates in the brain that could potentially be eliminated through greater reductionist understanding' (George et al., 2011: 420).

It was Alzheimer's colleague, Kraepelin, who nominated the name, Alzheimer as the term for the pre-senile dementia discovery made in Auguste D. However, it is a matter for debate whether Alzheimer was among those who attributed her case to a 'precocious form of senile dementia' (Berrios, in Lock, 2013), as opposed to being a signifier of something more typical. Nevertheless, the 1920s saw further reports of pre-senile dementia, but 'hesitation about its validity as an isolable disease persisted' (Lock, 2013: 37) and for the next 40 years, uncertainty prevailed as to whether it was a normal part of ageing, or a psychiatric or neurological disorder.

The situation changed during the 1970s, when AD emerged as one of the 'fourth or fifth leading causes of death in the United States' (Fox, 1989: 58). There were a number of reasons for this. Firstly in the 1960s, a number of brain autopsies were

performed in the UK, demonstrating the plaque and tangles identified by Alzheimer some 60 or so years earlier. The clinicians maintained that the severity of behaviour alterations in life were directly associated with the amount of plaque and tangles observed (Lock, 2013: 39).

Just as in Alzheimer's time, further advancements in technology were also a factor in refining comprehension of the materiality of the disease. Referencing the development of the electron microscope, Lock (2013) writes: 'For the first time, specific biochemical changes were associated with structural changes made visible by this powerful new instrument (...) a psychological approach to dementia was pushed to one side, to be replaced by a 'new agenda for pathological research' (Lock, 2013: 39).

Political changes were also influential in the reframing of dementia. Fox (1989: 58-59) argues that the reasons for the rapid increase in diagnosis were due to five factors: a) a shift within the scientific community leading to a re-characterisation of the disease as a significant health problem, b) the interest a small group of neuroscientists had in promoting AD, c) the merging of this small group with the focus of the National Institute on Aging (NIA), d) the coming together of the scientists, NIA and recently formed advocacy groups, and e) the efforts made in raising public awareness and lobbying for increased research funding by the advocacy groups and NIA.

This brings us up to the present day and several modifications later made to the Diagnostic and Statistical Manual of Mental Disorders (DSM), where there is still currently no unequivocally determinable set of boundaries which define dementia or AD (Hughes et al., 2006; Whitehouse, 2008; George et al., 2011). Moreover, some behaviours believed to be symptomatic of the pathology of the disease are now known to relate more closely to contextual aspects and the manner in which people with dementia are positioned (Chappell & Penning, 1996). Whilst there is undoubted value in understanding the aetiology of the condition, an exclusive focus on aetiology offers too narrow a lens through which to comprehend the experience of cognitive impairment.

These medicalised aetiologies of dementia are, when viewed from a Foucauldian perspective, redefined as discourses and as such, they are also sites where illness and bodies become subject to forms of power-play. According to Foucault (1973), Western medicine and its perception of 'illness' reduces patients and their bodies to an objectified physical entity, to be probed and examined without recourse to other aspects of the person. The balance of power in such situations significantly favours the health professional; a position further reinforced through the use of language and discourse. Foucault identified that discourse forms a set of rules which specify knowledge and truth in historically variable ways (Biggs & Powell, 2001). The inherent power within the assumption that there is just one version of knowledge or truth concerning health or illness is that it is able to 'destroy(s) the legitimacy of other, competing discourse; just as professional medical opinion might de-legitimize voices arising from folk medicine or informal care' (Biggs & Powell, 2001 p. 6).

1.1 Research Focus; Questions and Clarification

The Foucauldian critique of medicalisation has deep roots in the literature on dementia. For example, in the early 1970s, Brody et al. (1971) described significant positive improvements in symptom presentation among the 'mentally impaired aged', when psycho-social treatments were individualised. They argued that their results gave cause for 'therapeutic optimism' when 'identifying and utilizing the individual's unique traits, personality, history and current potential strengths' (Brody et al., 1971:124). Around the same time, the concept of 'excess disability' was being formed, or as was described at the time, 'the gap between actual function and potential function' (Brody, 1974). This suggests that impairment or capacity deterioration is not absolute.

Notwithstanding the above, it was not until much later that ideas such as this really gathered pace. Indeed, since the 1990s, the call for people with a dementia diagnosis to be re-situated, shifting away from a purely medical gaze to one which is more embedded in local contexts has become increasingly audible (Kitwood, 1993; Hughes et al., 2006; Offord et al., 2006; Whitehouse, 2008). It is with these perspectives that I seek to align; the aim being to subjectify, rather than objectify the participants. In doing so, it is considered how the participants – people with dementia

– can be seen to demonstrate capacity and agency in ways that contribute to their well-being (see, for example, sections 5.4 and 6.5).

Kitwood, in particular, has been highly influential with regard to altering the manner in which people with dementia are perceived, especially with his seminal 1997 work, which asserted that dementia symptoms and their severity were not just a consequence of organic degeneration, but could be hugely impacted by psychosocial factors, particularly the social environment. Echoing this, Harding and Palfrey (1997) also argued that dementia, or AD, was a social construct, with the ‘architects’ of this construction being the medical profession itself.

More recently, Lock (2013) asserted that a continued focus on the physical aspects of the condition and the drive to discover a cure keeps the ‘attention away from social, political and environmental factors’. Lock describes these factors as ‘including poverty, inequality, discrimination, and racism – factors deeply implicated in disease causation. These are variables that thus far have received the least attention in the AD world’ (Lock, 2013, p. 15). I would add to Lock’s list, negative positioning, isolation, loneliness and a lack of quality social interaction.

My research, however, shines a spotlight on some of these social and environmental factors; for example, quality social interaction and positive positioning, demonstrating some of the ways in which they support individuals’ enhanced well-being (see sections 5.4 and 6.5).

It may be that the ‘AD world’ continues to focus more on physical aspects of the condition than any social, political or environmental factors, but I argue that this standpoint is more acute in the music and dementia literature (see section 2.18). The general literature on dementia has increasingly taken on board social and cultural perspectives. It is therefore perhaps slightly ironic that the literature on music and dementia, with some notable exceptions (described below), remains focused for the most part on physical features of the condition, individuals and experimental models. Moreover, the vast majority of music and dementia literature continues to favour experimental research models which focus on the physical aspects of the condition in isolation, failing to take into account the aforementioned social, political and

environmental factors (Sung et al., 2006; Takahashi, 2006; Ziv et al., 2007; Bruer et al., 2007; Raglio et al., 2008; Chang et al., 2008; Sung et al., 2010; Tanaka et al., 2012; Lin et al., 2011; Sung et al., 2012; Chu et al., 2014; Vink et al., 2014).

Likewise, all too frequently, the subjective experience of people with dementia is overlooked, as is any potential for agency. This is described in sections 2.18-2.21 of this thesis. There are, however, notable exceptions, e.g. Hara (2011) and Ward and Peake (2015).

In order to address this gap in the literature on music and dementia, the focus of my research is directed towards environments, capacities, knowledge and relationships, all set against a predominantly musicalised backdrop. More specifically, my objective in this instance is to uncover and endeavour to understand the lay music practices of people with early to moderate dementia, living in the community. With this, my aim is to expose what occurs 'behind closed doors' with this particular cohort in terms of music and to gain enhanced insights into what drives these practices.

Correspondingly, the research questions include: Where does this musicking take place? Who supports it and what is its significance, if any? Furthermore, what is its impact on well-being, if any? My conceptual stance is heavily influenced by ethnographies of music which lie outside dementia-specific fields, i.e. Willis (1978) and DeNora (2000; 2003). For example, attending to a group of 'rockers', Willis explored the significance of social location and micro-cultures as a means of understanding how actors appropriate music to construct meaning. Expanding upon Willis' position, DeNora (2003: 169) focuses on music in everyday life scenarios and posits that music 'gets into' action or is part of a process which helps 'to shape identity, social action and subjectivity'. Taking inspiration from the above studies, the purpose of this project is thus to achieve a deeper and more nuanced understanding of the everyday music practices of this population through empirically based inquiry; an endeavour which will, as never before, span the overlapping fields of dementia, music and dementia, and everyday life.

My account of dementia in relation to music is in contrast with others, where priority is given to deficiencies. My interest is focused on the lay music practices of people with early to moderate dementia, living in the community. I argue that when everyday

music practices are investigated, there is evidence of considerable activity, agency and capacity which, when well supported, can contribute to enhanced well-being.

One point to be clarified is that the progression of dementia is frequently referred to in three stages: early, middle and late. Such references are widely used, both in the general dementia literature and by other related bodies, such as the NHS and the Alzheimer's Society. In her 1974 paper, Hayter distinguishes the three stages by relative and approximate time periods. The first stage, lasting approximately two to four years, is characterised by 'memory loss, time disorientation and lack of spontaneity' (Hayter, 1974: 1460). The second stage includes 'progressive memory loss, aphasia, agnosia, apraxia, a tendency to wander off, and (...) repetitive movements' (1974:1462). This is of indeterminate length. The final stage, with its conspicuous physical degeneration, generally does not last longer than a year. However, the concept of stage theory in dementia is not uncontested and Gubrium (1987) argues that Hayter's presentation of the disease revolves around 'nursing management problems' and as such, demarcates the disease via its impact on self-control. Furthermore, he notes that any assigned stages of the disease are as much about the 'descriptive interests of those concerned with the disease' as the disease itself (Gubrium, 1987: 5). Elsewhere, Gubrium (1986) also argues that there is little uniformity to symptom progression and distinguishing between stages is problematic. For carers, on the other hand, the demarcation of symptom progression can be helpful insofar as it allows them to anticipate future challenges and behaviours (Innes, 2012). Therefore, stages can be useful, as described below, for offering some basic way markers.

The reference to three stages, as I have already stated, is ubiquitous and a more recent example of stage distinction is presented by the Alzheimer's Society (2015). The latter suggest that early symptoms might include forgetting about recent events; being slower to grasp new ideas; losing the thread of what is being said; 'sometimes being confused'; finding it hard to make decisions, and losing interest in other people or activities. Symptoms of the middle stage might include becoming increasingly forgetful; sometimes repeating the same question over and over again; failing to recognise people or confusing them with others; becoming easily upset and angry; behaving in unusual ways, 'such as going outside in their nightclothes'; 'experiencing

difficulty with perception, and in some cases having hallucinations'. The Alzheimer's Society (2015) describes the late stage as involving pronounced loss of memory, with the 'person unable to recognise familiar objects or surroundings or even those closest to them'; difficulty eating and swallowing; incontinence, and 'gradual loss of speech, though they may repeat a few words or cry out from time to time (...) the person may seem to have little understanding of speech, and may not recognise those around them'.

The above terms for the stages of dementia are used throughout this thesis, although, as has already been discussed, terminology is not easy to apply accurately or appropriately. However, I will use terms such as 'early' and 'moderate' here as a guide for the reader to understand where participants lie within a canon of dementia symptoms. Thus, for each of the research participants, terms are used on the basis of their known symptoms and diagnoses. That is not to say I have defined these individuals by their symptoms and presumed these symptoms are fixed, or that they only follow a downward trajectory, but the intention is for the reader to be able to understand how these subjects would be classified according to the canonical medical classification system.

Returning to the focus of this thesis, the social medium of music, embedded within a specific local ecology (i.e. the relevant community) is an ideal vehicle with which to investigate the impact of social and environmental factors on people with dementia. With an emphasis on lay expertise, I am not concerned with organic brain decay, nor what formalised professions (music or health) can do 'for' people with dementia in this scenario. Rather, the desire is to uncover what occurs 'behind closed doors' with this particular cohort in terms of music. I also aim to gain an enhanced understanding of what drives these musical practices; in this regard, the strands of enquiry include the 'What, where, when and how?' of individuals' private musicking within a specific context. Through the respective research framework, I not only seek to shine a light on lay practices, but also to contribute to the legitimisation of the non-medic and his or her expertise.

The non-deficit perspective widens the research and caring foci to incorporate 'questions of subjectivity or intersubjectivity' (Kitwood, 1997) and these are both

areas explored in this research project. My aim is to seek to understand the ways in which quality of life for both the person with dementia and their carer is, or can be, improved. Achieving enhanced comprehension of the subjective experience of dementia will facilitate comprehension of individuals in terms of their capacities, as well as their incapacities, in addition to locating them within their specific socio-cultural contexts. However, the often simplified and sensationalised representations of dementia can override its multiple realities and Beard et al. (2009: 228) observe that 'if approaches to dementia disregard the internal world of those living with it as valid objects of study, then "horrific and monstrous" images of persons with dementia threaten to overshadow the humanity of the individual'.

The word 'carer' also requires some clarification here; the word fundamentally defines a 'person who cares', which is appropriate for this setting. However, I do not find it to be an entirely benign word, as it implies a level of passivity on the part of the 'cared for', which is disempowering. Moreover, the data presented in later chapters highlight how people with dementia also sometimes actively care for others and so the caring is not uni-directional. Nevertheless, the word 'carer' will be used throughout this work for ease of reference, but it must be borne in mind that the term's definition is broadened to include notions of companionship, incorporating 'being with' and supporting a person with dementia. The role of the carer in terms of the 'cared for' is aligned with Kitwood's (1997a: 13) definition, which involves a commitment to 'honour what they do; to respect their unique qualities and needs; to help protect them from harm and danger; (...) to take thoughtful and committed action that will help to nourish their personal being'.

1.2 Thinking Ecologically

What I am interested in is how dementia is managed day-to-day, behind closed doors, away from the gaze of health agencies. More specifically, how might we understand these partially hidden spaces as being ecologies of care? Ansdell describes ecological thinking as 'exploring how people manage to live together more or less successfully within both their natural and their social environment'. Moreover, he explains that 'an ecological metaphor' is increasingly being used to examine 'how

people thrive and sicken, adapt and develop in relation to their ever-changing physical, social and cultural environment' (Ansdell, 2014: 27).

In social research, naturalistic enquiry suggests a concern with the 'real', as opposed to an artificial research environment, such as a laboratory. Indeed 'the naturalistic paradigm treats realities as multiple, constructed and holistic, the knower and the known are seen as interactive and inseparable (Somekh & Lewin, 2005: 132). This is not to suggest such enquiries are without their challenges, but the assumption is 'that phenomena should be studied in their natural setting' (Norris & Walker, in Somekh & Lewin, 2005: 132).

From a care perspective, I am interested in exploring the relational aspects between people and music in everyday life contexts. My aim is to seek to understand the role of music in supporting good, sustainable ecologies of care for people with dementia and their carers. Moreover, I wish to gain a better appreciation of what actually constitutes lay expertise. How do those who have the most knowledge of the person with dementia's self-concept and self-knowledge, i.e. the person with dementia and their familial/spousal carer, incorporate this knowledge into their care practices? How could this specialist knowledge then be harnessed to enhance quality of life?

This focus on the ecology of a caring environment differs from medical foci, which are concerned purely with the 'delivery' of care. The delivery of care model is weighted much more toward addressing specific issues and individual deficits. Indeed, Nolan et al. (2004) suggest that one of the reasons delivery models dominate can be traced back to the strong drive toward client- or person-centred care, which has the individual's well-being at heart.

'It is the application of consumerism to health care, and the promotion of a philosophy that treats people as individuals that has resulted in the emergence of the 'contemporary speak' of person-centred care. Notions of independence and autonomy also infuse related concepts such as 'successful ageing' (Scheidt et al 1999) which underpin the 'heroic' model of the ageing process which depicts ageing as a primarily positive experience. This heroic model provides a counter balance to the deficit model in which ageing is viewed mainly in terms of decline (ref). However, (...) neither the 'deficit' nor the 'heroic' model adequately capture the experiences of most older people.' Nolan et al. (2004: 46)

Indeed, Nolan et al. (2004) contend that autonomy is an inappropriate concept in the care of the elderly, as it ignores any shared societal responsibility for care. They instead advocate relationship-centred care as being a more suitable model.

An exploration of the ecology of care is compatible with this perspective, because it concentrates on how people, things and relationships sustain those living in challenging circumstances. Moreover, such an exploration seeks to understand what can potentially elevate, boost, enhance and strengthen individuals and those who co-habit with them within a particular ecology.

1.3 Beginnings

My own interest in dementia was sparked while undertaking an MSc in community music, during which time I became aware of the work of Eva Götell and her colleagues at Marlariden University in Sweden. Götell has produced a body of work based in long-term care environments which incorporates professional caregivers and nurses singing unaccompanied to their patients with advanced dementia, while undertaking morning care duties, such as washing people, brushing teeth, assisting with getting dressed, etc.

In general, the behaviours exhibited by the residents during these morning care sessions included 'confusion, muteness, resistance and disruptive vocalising' (Götell et al., 2002: 201), but the singing reportedly afforded enhanced connections and well-being for both patient and carer, by facilitating 'implicit understanding without words' and a 'wider and deepened degree of mutuality (...) between patient and caregiver' (Götell et al., 2002: 210). The aspects of this work which particularly inspired me were the seemingly natural and bespoke manner in which singing was subtly incorporated into some mundane, yet potentially unpleasant, daily life episodes, and the value placed on the musicality of the lay 'musicking' caregiving staff. The word 'musicking,' coined by Small (1998), is a derivative of the verb 'to music'. Musicking, therefore, refers to 'taking part in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance' (Small, 1998: 9). The outcomes of such applications of singing employed by Götell et al. (2002) included 'increased patient

competence,' 'elimination of patient resistance' and 'enhance(d) cooperation without disruptive screaming' (Götell et al., 2002: 211).

For my Master's project and dissertation, I undertook to replicate this work. The participants were all at a relatively advanced stage of dementia, but reflecting on my own and Götell's observations, I was prompted to question how music might be similarly adapted for people with less advanced dementia, who live in their own homes and are cared for by a family member.

At the outset of this PhD research, I began thinking of looking at music as an intervention. As my knowledge broadened through reading and experience, however, my position changed and I began looking at investigating music as it occurs in everyday life, but predominantly within a specific community day care setting. The concern of this thesis, therefore, is on community-dwelling individuals with early to mid-stage dementia, and explicitly those residing with family members or spousal carers and their musicking within the abovementioned day care setting. It addresses the manner in which social constructs, at macro-level (more broadly cultural and societally conceived) and micro-level (conceived culturally and socially as more localised, immediate and intimate) affect and either exacerbate or mollify aspects of the condition.

The discussion at the beginning of this chapter demonstrated the continued ambiguities surrounding the understanding of dementia and, moreover, highlighted the shift in received wisdom regarding the underlying causes of the symptoms presented, both pre- and post-onset of the disease. Having aligned myself with those who would conceive of dementia in contextual as well as material terms, the significance of investigating both macro- and micro-constructs in this study became apparent.

The role of positioning is a central concern in this thesis, aligning as it does with the aforementioned impact of macro- and micro-social constructs on the population concerned. Positioning is discussed at length in the Literature Review, as is Kitwood's 'malignant social psychology', which similarly refers to the impact of psychosocial factors, particularly the social environment on cognitive diminishment.

Using the empirical data collected, I was able to demonstrate what capacities and kinds of knowledge which are often hidden can flourish when the context supports them. This thesis, therefore, demonstrates how music can assist in overriding and mediating the influence of impoverished environments or ecologies.

By ascertaining the indigenous place of music in the lives of this cohort, the paper enlarges upon existing music and dementia literature, which is predominantly concerned with music's therapeutic effects, whereby there is a heavy focal bias towards the music itself and what it does or 'causes'. Such a bias implies that music's impact is largely unrelated to other environmental factors and exists in isolation from everyday life; a position closely allied to clinical interventions.

Here, music is examined from the standpoint of what it might afford. The term 'affordance' in this context is heavily influenced by Gibson (1979) and his invention of the word to describe 'an action possibility available in the environment to an individual independent of the individual's ability to perceive this possibility' (McGrenere & Wayne, 2000). In recent years, affordance has been applied as a concept by music sociologists with regard to music's 'resources and its materials (...)' and the 'moods, messages, energy levels (and) actions' which it may influence, and 'which rest on the unique properties of music but which are constituted uniquely within situations of use' (Pavlicevic & Ansdell, 2004: 73). Indeed, DeNora (2002: 21) conceives of affordance, understood in terms of music, as a 'mediator'. As such, affordance is described as highlighting:

'music's potential as an organising medium, as something that helps to structure such things as styles of consciousness, ideas, or modes of embodiment. To speak of music as affording things is to suggest that it is a material against which things are shaped.'

My interest here is to try and understand what 'possibilities for action' (however that action may be described) and modes of embodiment are facilitated by music for the participants of this study within 'unique situations of use'.

Music in fact facilitates numerous routes to enrichment, such as opportunities for action and expression. The distinction between musicking as conceived therapeutically and musicking viewed within the parameters of everyday life is that

the latter is a sustainable practice which does not necessarily rely on professionals or experts to control it. On an everyday basis, for the individuals I was concerned with in this research, musicking can be more fluid, potentially covers a longer time span and occurs with greater spontaneity. The musicking in the everyday lives of these subjects is more autonomous and is not necessarily directed; or at least, the 'musical director' may or may not be apparent, which is not so much the case with musicking in more overtly therapeutic encounters. What is more, the directing role may subtly shift from one person to another.

As I view it here, musicking may have similar aims to music therapy, in that improved outcomes are intended, but the specificity of these outcomes may not be known at the time. My concern is to identify how music and musicking fit into a more complex tapestry of cultural and social practices, in ways that make space for the person and self. In beginning to pursue this matter, I will focus on theories of 'self', starting from the classic work of American sociologist and psychologist, George Herbert Mead (1934).

1.4 Dementia and the Self

There are different versions of 'self' in social theory. Mead (1934) established the idea that the self is essentially composed of two primary components, the 'I' and the 'me'. These are subjective and objective self-conceptions evolving through a reflexive process of social interaction. Both the 'I' and 'me' units are 'made up of interdependent and independent, mutually reinforcing and conflicting parts' (Stryker & Burke, 2000: 286), from which self-concept is derived. Mead's abstraction of 'self' has underpinned more specific conceptualisations applied within the field of dementia studies. For example, Sabat and Harré (1992) understand three dimensions of the self, which incorporate identity and roughly correspond to Mead's conception of the self. However, they are taken further into dementia concerns, distinguishing Self 1 as being representative of personal identity, or 'the continuity of one's point of view in the world of objects in space and time' (Sabat & Harré, 1992: 445) and from where personal agency can derive. Selves 2, on the other hand, are the 'repertoire of personae' or 'cluster(s) of traits' that are 'publicly presented in the episodes of interpersonal interaction in the everyday world' (Sabat & Harré, 1992: 445). The

above authors argue that identity aspects of self (Self 1) lie behind the trait aspect of self (Selves 2). Moreover, Self 1 is referred to using the first person pronoun.

Conversely, Selves 2 is the outwardly directed self; the one that deploys a repertoire of personae. It includes both 'physical and mental attributes and beliefs about those attributes' (Sabat, 2002: 27). Examples of mental attributes could be educational achievements, sense of humour and political persuasion. Self 2 is dependent 'on the social cooperation or consent of others. Without the cooperation of others in the social sphere Selves 2 cannot be constructed at all' (Sabat & Harré, 1992: 446). The focus in this case is more on how an individual coordinates him or herself in the world and how he or she is dependent upon others.

Self 3, in contrast, is determined as the distinctive multitude of social personae people employ in different situations. The existence of these also relies on the cooperation of at least one other person (Sabat, 2002). For example, using the 'dedicated teacher' construct, Sabat (2002) argues that it would be impossible for an individual to maintain such a construct, if there was no concurrence or support from a teacher's students that this was the case.

In their case study on Mrs. F, a 63 year old woman diagnosed with probable Alzheimer's Disease, Sabat and Collins (1999) demonstrate the manifestation of various aspects of selfhood. They point to Mrs. F's use of the personal pronoun and her capacity to recognise 'her experiences as her own and to locate those experiences in psychological space' (Sabat & Collins, 1999:18) as evidence of Self 1. Furthermore, they argue that her acknowledgement of her 'attributes and beliefs' past and present is testament to the presence of Self, 2. Elsewhere (Small, Geldart, Gutman & Scott, 1998; Sabat, 2002; Fazio & Mitchell, 2009; Hedman et al., 2012), the presence of Self 1 has been highlighted as evident from the use of the first person-indexical and other personal pronouns.

More recently, in their discussion of cases of mild and moderate dementia, Hedman et al. (2012) endorse the idea that Self 2 and Self 3 support substantiation. They point to the referencing of personal attributes and life narratives, in addition to

discourses around 'acting as normal as possible', thereby ensuring that people with dementia are 'treated as normal' by healthy others (Hedman et al., 2012: 728).

Sabat and Harré maintain that the cognitive deterioration in Alzheimer's disease does not lead to any loss of Self 1, but only contributes to 'possible losses in self 2'. They argue that,

'given the story lines that are created by caregivers and others the behaviour of the person with dementia may be subject to radical problems of social misunderstanding wherein successful adaptations employed by the sufferers to maintain both kinds of selfhood can be interpreted as symptoms.' (Sabat & Harré, 1992: 448)

Indeed, Sabat (2002) argues that constricting a person with dementia so that they are unable to perform any of their Selves 3 can have significant detrimental effects. To illuminate this, he explains that when someone with dementia finds themselves in contexts where their 'disease-related attributes become the primary focus' (Sabat, 2002: 32), their social persona is restrictively perceived by healthy others as that of a 'burdensome, dysfunctional patient'. This consequently hinders the person with dementia from being able to raise or easily present any of their valued attributes, in which case they become 'defined by others mainly in terms of attributes which are an anathema to him or her' (Sabat, 2002: 35). Consequently, Sabat and Collins (1999) advocate the value of identifying intact areas of social and cognitive function as a means of enhancing the social interplay between the person with dementia and their caregivers.

To further support the above position, it was discovered during interviews with people with early stage dementia that tensions arose 'between how the person with dementia wished to be positioned within society and within their own family and social network, and how others perceive they should be positioned' (Harman & Clare, 2006: 498). This highlights one way in which identity or a sense of self is impacted upon, not only by cognitive incapacity, but also by relationships (Naue & Kroll, 2009). Furthermore, that identity is sustained through the co-negotiation and co-operation of Selves 2.

From the perspective of the chronically ill, Charmaz (1983) argues that a key component of suffering is the loss of self, manifested in reduced liberty, social disconnection and stigmatisation. Furthermore, the affected 'observe their former self-images crumbling away without the simultaneous development of equally valued new ones' (Charmaz, 1983: 168). Clear parallels can be drawn with those with dementia, where notions of self, self-concept and identity are challenged in the first instance by memory incapacity, but consequently, by stereotyping, stigma and social disconnection. Indeed, acknowledging that symptoms may be a representation of need and not solely a consequence of brain decay is endorsed by Kitwood (1997: 31), where 'no one doubts that some abilities are lost during the course of dementia, and that patterns of mood and behaviour are altered. The controversial question is how the evidence should be interpreted'.

Attacks on selfhood and the resulting insecurity over identity best symbolise widespread assumptions concerning the essential self and the individual as a unit actor in society. Dementia highlights the ways in which actors, selves and identities are co-constructed within social spaces, and the ways in which the 'self' can be understood as consisting of different aspects of being, experience and action capacity. Dementia alters the balance in relationships and in order for identities to be realised, greater reliance rests with others to make this possible, highlighting the importance of co-construction in identity maintenance.

It is these interweaving concepts of self and identity and the significance of social cooperation in sustaining them which are developed during this thesis, specifically in relation to engagement with music.

1.5 Identity and Musical Lives

The intertwining of culture and identity clears an interesting space for music within the dementia experience and this, for several reasons. Firstly, music is redolent with cultural references and associations and as such, it commands a significant role in identity creation and maintenance (DeNora, 1999). Following on from this, in relation to the necessity for collaboration in the co-construction of identity, as outlined in the previous section, it becomes evident that music may function, if not exactly as an

identity co-constructor, then initially as an effective identity prompt. Moreover, at a time of instability surrounding identity, music can then operate as part of a community of ongoing identity maintenance practices.

Secondly, music is part of the course of our lives. The journey of a musical life has been broadly mapped out in the literature, beginning with the earliest vocal musical exchanges between mother and infant (Trevarthen, 2000), followed by the spontaneous and at times, quasi-subconscious, musicking in early childhood (Campbell, 1998). This is then followed by the evolution of musical identities beginning to consolidate in adolescence (Lamont, 2002). The concentration of musical personalities sees further development into and beyond adolescence, where music begins to offer resources for self-care in the form of mood regulation, physical entrainment and affirmation of self-identity, or as a technology of the self (DeNora, 2000). In effect, what is initiated in infancy with a mother adapting the way she sings to her infant, as a means of calming, exciting, or riding a wave of existing delight in the child, could be interpreted as the genesis of learning to utilise music for extra-musical ends. Having begun to learn such practices in infancy, we develop, in the Bourdieuan sense, into virtuosos of our own personal music practices and continue to sustain or adapt our identities through musical mediation (Hargreaves et al., 2002).

The mapping of a life in music into the third and fourth ages and the adaptation of musical identities during this period have received limited attention in the literature. Patently, identity is continually negotiated and re-negotiated throughout the course of life and the period immediately following retirement represents a time of potentially considerable identity re-negotiation. That music has been demonstrated as a vehicle for identity creation and maintenance suggests the unrealised value to be gained from its employment during this time, in order to re-vivify previous identities, create new ones and maintain established ones. In terms of dementia, then, the role of music can be seen as a valuable resource, not only as a memory tool, but also for the maintenance of identity. The fact that the onset of dementia and its socially and culturally-mediated consequences most frequently occur concurrently with the post-retirement period accentuates the need for research to address the musicking of this hitherto neglected age group.

In Chapter 2 (section 2.21), the concept of attachment is introduced in this thesis, as defined by Gomart and Hennion (1999), who write about attachment in terms of cultural association (music, art and drugs). They describe how attachment to (or having an active passion for) cultural materials gives rise to opportunities for action and expression. In terms of identity and Self 1, therefore, attachments are fostered in interaction through craft, which can both create and reinforce elements of identity. There is in fact a strong correlation between Self 1 (identity) and its potential to generate agency. This is an aspect of identity and attachment which I explore in this thesis and moreover, it is an aspect yet to be explored within the wider field of music and dementia research. Here, I follow how people can become transformed through the quiet and often tacit work of others, while also showing how people with dementia seek out the things they need and attach themselves accordingly, maintaining their own identity in the process.

1.6 Musical Miracles?

Despite a substantial body of work focusing on music, health and well-being (Clift & Hancox, 2010; Bungay et al., 2010; Hallam, 2012; MacDonald et al., 2012), theories surrounding music in domestic contexts are under-developed and uncomprehensive, not only suppressing alternative accounts of lay expertise and practice, but also the organic and agential employment of music within the domestic environment.

However, the competing narratives which surround music and health/well-being in other settings have a number of dominant strands. Here I will discuss the two most dominant narratives occurring within the diverging and overlapping fields of music, mind and body which have received substantial attention in recent years. These themes pertain to 'music as medicine/music as a detached modifying mechanism' and the dominance of neurological perspectives.

The first example - the 'music as medicine' discourse - has grown in prevalence and builds upon the supposition that music is imbued with intrinsic, yet hidden, 'magic' powers. Indeed, this canon of research proposes that it is the presence of music's 'power' which underscores the generation of short-term changes. The leading exemplar of this school of thought is one experiment which investigated the effect of listening to Mozart on spatial reasoning tasks (Rauscher et al., 1993), whereby it was

subsequently claimed to effect temporary enhancements in the short term; commonly referred to as the 'Mozart Effect'. The above research, which caught the popular imagination, gave rise to the Mozart Effect registered trademark, numerous commercial recordings and additional Mozart Effect type assertions, as detailed here. 'In monasteries in Brittany, monks play music to animals in their care and have found that cows serenaded with Mozart give more milk'; 'In Washington State, Immigration Department officials play Mozart and Baroque music during English classes for new arrivals from Cambodia, Laos, and other Asian countries and report that it speeds up their learning'; at Saint Agnes Hospital in Baltimore, patients in critical care units listened to classical music and it was found that 'Half an hour of music produced the same effect as ten milligrams of Valium'; moreover, Dr. Raymond Bahr, director of a coronary care unit, reported: 'The city of Edmonton, Canada, pipes in Mozart string quartets in the city squares to calm pedestrian traffic, and as a result, drug dealings have lessened' (Campbell, 2009: 14).

The concept of the Mozart Effect has also been applied in clinical and laboratory experiments and as such, has demonstrated that Mozart's music has the capacity to reduce allergic skin wheal responses and in-vitro allergen-specific IgE production in atopic dermatitis patients with latex allergy, whilst Beethoven's music was ineffectual in this sphere (Kimata, 2003). Additional research in the non-human population has demonstrated that common carp were less receptive to Mozart, as his 'Eine Kleine Nachtmusik' was not as effective in encouraging growth, compared to the anonymous 'Romanza Jeux Interdits' (Papoutsoglou, 2010). Elsewhere, however, the music of both Mozart and a contemporary classical composer, Ligeti, did prove to be apparently effective treatments for spontaneously hypertensive rats (Sutoo, 2004; Lemmer, 2008).

These Mozart Effect examples, particularly relevant in the human population, have allowed for some bold claims, yet the lack of any attempt to dissect or acknowledge additional contextual aspects is suggestive of considerable naivety. Indeed, the legitimacy of Rauscher et al.'s (1993) research has been questioned (Chabris, 1999; Nantais & Schellenberg, 1999; Thompson et al., 2001; Twomey, 2002), with a particularly emphatic critique arising out of its exclusion of 'emotional arousal as a causal factor' (Waterhouse, 2006: 221). Indeed, seeking to replicate the Rauscher et

al. (1993) study, Nantais and Schellenberg (1999) compared spatial-temporal performance following either a period of silence or listening to Mozart or Schubert. They further augmented the experimental parameters by including a narrated story as an additional condition. Enhancements were demonstrated, yet they concluded that ‘the Mozart Effect has nothing to do with Mozart in particular’ (Nantais & Schellenberg, 1999: 372), but is more attributable to personal preference, whether in terms of music or narration. Supporting the above findings, Schellenberg and Hallam (2005) discovered a ‘Blur Effect,’ noting that after listening to music by the band, Blur, children demonstrated improved performance at a paper-folding task, compared to their peers who had been exposed to Mozart or a discussion about the experiment, prior to the same task.

In bypassing the impact of emotional, environmental or cultural factors, the implication is that the administering of a ‘shot’ of Mozart will enhance intelligence, but what these discourses actually reveal is a commitment to the idea that music can be divorced from its cultural and social context. Nevertheless, viewing music in quasi-medicinal terms and facilitating direct comparisons with pharmacological interventions is unduly simplistic and neglects to unpack the broad contextual aspects of music, thus limiting the wider relevance of such inquiries.

1.7 Neuromania

The idea of divorcing music from social contexts has gained momentum in neurological research, in parallel with the advent of functional magnetic resonance imaging (fMRI). Since its development in the early 1990s and subsequent access to visual representations of neural activity in response to music, an explosion of research focussing on music and the brain has emerged (Zatorre et al., 1994; Schlaug et al., 2005; Koelsch et al., 2006). Armed with this technological advancement, great excitement has proliferated in the research into how the brain behaves when ‘on music’ (Levitin, 2006). For example:

‘When I hear Rachmaninoff’s Piano Concerto no 3, the hair cells in my cochlea parse the incoming sounds into different frequency bands, sending electrical signals to my primary auditory cortex – area A1 – telling it what frequencies are present in the signal. Additional regions in the temporal lobe, including the superior temporal sulcus and the superior temporal gyrus on both sides of the

brain, help to distinguish the different timbres I'm hearing. (...) Whole new populations of neurons will become active, however, as I attend to pitch sequences (dorsolateral prefrontal cortex, and Brodmann areas 44 and 47), rhythms (the lateral cerebellum and the cerebellar vermis), and emotion (frontal lobes, cerebellum, the amygdale and the nucleus accumbens.' (Levitin, 2006: 91)

Such enthusiasm for brain science with respect to the arts is not, however, universal. Some authors, for example Tallis (2011), have been highly critical of recent fascination with and reverence for this kind of inquiry, to the extent of conceiving it as a 'neuromania'. Tallis argues that explaining and reducing all aspects of human life to their neurological processes is an over-simplification of 'human behaviour to responses to stimuli'. Isolating one response out of context from a whole range of responses removes it from the natural fluidity of life. Moreover, it is Tallis' belief that such a naïve understanding is a deliberate action on the part of researchers to reduce the complexity of both the experimental and analytical processes, failing to address biographical narratives (Tallis, 2011: 282).

An example which highlights the dominance of medical/neurological narratives of music in a dementia context is to be found within the network of increasingly popular community-based singing groups affiliated to the Alzheimer's Society. According to the Society's website, these weekly singing groups use 'singing to bring people together in a friendly and stimulating social environment'. However, the adopted title, 'Singing for the Brain' (SFTB), firmly situates the groups within the medical/neurological discourse, even though at their core, these sessions fully encompass and even celebrate the social aspect of group singing (see Hara, 2011).

Both the Mozart Effect and neurological foci are therefore representative of music being viewed as a set of stimulating organised pitches. They consequently suggest that music, or its potency can be perceived in isolation. However, detaching music from its context might not assist in understanding where its value lies, nor what it may offer, just as analysing any music score might not necessarily enhance any understanding of its social impact. In order to unpack the essential meaning of music for individuals, progress may be achieved with more scrutiny of the interplay between its social, cultural, relational and contextual aspects.

1.8 Naturalistic Enquiries and Local Ecologies

Just as ignoring the contextual processes of music impoverishes the enquiry, the same applies to dementia, as has been highlighted previously. Irrespective of the research discipline under scrutiny, Lincoln and Guba (1985) stress the importance of natural settings; positing that phenomena will necessarily 'take their meaning as much from their contexts as they do from themselves' (Lincoln & Guba, 1985: 189). Existing dementia research has already evidenced the significant impact of the environment on people with dementia. Considering the impossibility of extracting dementia from daily life practices or the social context, the route to enhanced understanding must lie in an exploration of local ecologies.

There is a great deal which is as yet unknown concerning the 'private' care of and support for people with dementia and given the immense disparity of biography, personal characteristics, context and dementia phases, it is likely there will be a commensurate disparity between the potentially unique, even idiosyncratic ways in which people work to maintain stability and adapt to the situation they face. My focus is on investigating the naturally occurring contexts (i.e. not set up for research purposes), where music is situated and on discovering how it is, or may be, incorporated into a set of stability-maintaining practices; not as a quasi-miracle pill or magic bullet, but subsumed within the local ecology it forms part of.

1.9 Summary of the Research Framework

There are a number of themes running through and driving this thesis: the impact of the environment on symptoms and quality of life; the maintenance of self in the face of cognitive losses; the need for research to address local ecologies longitudinally, and areas of lay expertise and knowledge. My research aim is to understand the place of music in the daily lives of people with dementia and those with whom they co-habit - an area of research hitherto unaddressed in the field. I look at this phenomenon both within and beyond one specific community care setting, taking into account the context of individuals' everyday lives. With this objective, I privilege the incorporation of lay musicking practices by, with and for people with dementia; again, this is an aspect of music and dementia research which has not yet received any attention. The purpose of this is to ascertain whether such practices affect the

maintenance of the self and well-being for the person with dementia and their spousal or family carer.

To elaborate on the above statements, the objective is to seek enhanced socio-musical understanding from the polar opposite stance of the one adopted in Mozart Effect-type templates. Instead of seeking to extract music as a 'change agent' from its cultural associations, specific social context and place of personal preference, my intention is to conceive of it as being fully embedded within all three. Similarly, I wish to avoid isolating/divorcing people with dementia from the contexts within which they currently experience music, or have experienced it in the past. By remaining ecologically committed and by uprooting none of the components (neither the music or the person) from what they are inextricably linked with will help uncover what is afforded by music (and other practices), how this occurs, and, moreover, who it is driven and supported by.

1.10 Organisation of the Thesis

Chapter 2, the Literature Review, is divided into two sections. Firstly, I discuss how dementia is currently defined; illustrating where the boundaries are blurred. I include medicalised approaches, such as diagnosis and treatment, in order to both contrast and contextualise my own influences and thinking. The significance of social context and interpersonal interaction are reviewed in relation to Positioning Theory. This Chapter includes literature concerned with the role of the non-professional caregiver, as well as coping strategies. The influence of adult mental health on dementia literature is also discussed.

In the second section I present an overview of the use of music in dementia care literature, incorporating unfamiliar and familiar music applications, active musical engagement and home-based research. Here, I consider and critique the specificities of the contexts in which music and dementia research is situated. Also taken into account is the occurrence of music in the literature on everyday life and its inclusion in health-promoting practices. Actor Network Theory is incorporated within this review.

Chapter 3 is concerned with the methodological issues one is faced with when engaging in research on people with dementia. Personhood is discussed in the research context, as is interviewing, proxy reporting and the increase in investigations which seek to understand the subjective experience of dementia. An overview of Grounded Theory is presented, in addition to an outline of how a modified version is used in this project. Furthermore, issues of consent and the ways in which others have negotiated these are explored.

In Chapter 4, I address the methods used in the present research. This includes setting up the study, obtaining ethical approval, the recruitment of participants and obtaining their consent. Moreover, both the interview process and techniques are discussed, in addition to data collection and analysis. The data sections are covered in Chapters 5 and 6, beginning with the first case study being placed within the respective biographical and musical context. The musicking of this first subject is discussed within the field of observation. The concepts of positioning, personhood and self are subsequently drawn into this discussion. I then proceed to the second case study and explores additional concepts, such as attachment, symbolism and taste. Common ground between the two cases studies is considered.

The primary focus of Chapter 6 is in fact the interaction of one individual with background music in the fieldwork site. As part of this analysis, I return to positioning, personhood and concepts of self. The final section of this Chapter is concerned with a complimentary musical event allied to the fieldwork site. The implications of the musicking which immediately precedes the construction of this event are explored.

In the final chapter, I present and discuss my research findings, drawing conclusions in relation to the overall remit of the research. As well as outlining the limitations of the study, I state its contribution to knowledge. Ultimately, the study's implications for policy, practice and future research are defined.

CHAPTER TWO: LITERATURE REVIEW

This review of the literature is divided into two parts. The first section begins with a focus on how dementia is currently defined and demonstrates where the boundaries of these definitions become unclear. Even though my research framework is not situated within any kind of medical model, medicalised aspects are nevertheless presented here, including diagnosis and treatment, in order to highlight the backdrop against which my own thinking has developed. Moreover, such details are included to illustrate the status quo.

The role social contexts play in supporting a person with dementia is a dominant theme in much of the general dementia literature. This, however, is not the case with literature which is specific to the topic of music and dementia, but it is something I cover in detail in this thesis. Following an outline of dementia treatment models in the UK, the significance of social context and interpersonal interaction are further elaborated on in relation to Positioning Theory. The first section culminates in an examination of the role of the non-professional caregiver and the challenges they are obliged to contend with. The discussion then moves on from this to look at how dementia is managed, by exploring the personal coping strategies developed by, with and for this population.

Part two of this Literature Review centres on music in the literature on dementia care and in the first instance, presents an overview of this literature. An analysis of the specific contexts of music and dementia research, in view of emerging thinking on the topic of dementia, reveals some significant omissions, the implications of which are discussed here. Scrutinising the role of music in the literature on everyday life and its inclusion in health-promoting practices reveals music to be the ideal foundation for the present research.

2.0 PART ONE: DEFINITIONS OF DEMENTIA

To reiterate, dementia is 'a syndrome a collection of symptoms and signs for which there are many causes and which manifests itself in a variety of ways. It is an umbrella term' (Hughes, 2011: 13). AD, vascular dementia, frontotemporal dementia

and dementia with Lewy bodies all fall under this umbrella term. The most common form of the condition is AD, which accounts for approximately 68% of the total UK dementia population (Knapp & Prince, 2007).

Pathologically, AD is characterised by the formation of plaque and tangles in the structure of the brain. These impede the ability of nerve cells to communicate with each other, eventually leading to cell death and brain atrophy (Alzheimer's Society, 2013). However, conclusive confirmation of the existence of this plaque and these tangles and therefore, a definitive diagnosis of AD may only be achieved post-mortem. Brain atrophy can indeed be determined through MRI scans, but as we age, the brain atrophies in any case and so it 'is difficult to be sure what is due to the disease and what may be that person's natural and healthy brain shape and size' (Alzheimer's Society, 2005).

The medical community acknowledges that diagnosis carries with it many complexities and ambiguities. For example, it has been demonstrated that the neuropathological presence of AD does not always correlate with symptomatic representation, particularly in the oldest-old (those over 85) (Snowdon, 1997). Indeed, research has demonstrated that around 50% of 'clinically demented oldest-old' do not possess the neuropathology which would justify their dementia symptoms (George, 2011), highlighting the importance of socio-cultural approaches. Moreover, Brumback-Peltz et al. (2011) demonstrated that 49% of non-demented participants did in fact meet the 'pathological criteria for AD', concluding that there is 'a poor relationship between clinical dementia and neuropathological observations in the oldest old' (Brumback-Peltz et al., 2011: 67).

Therefore, the variety and complexity of symptoms, causes and manifestations are so great that Julian Hughes, Professor of Philosophy of Ageing and Consultant in Old Age Psychiatry at the University of Newcastle, UK has been led to recommend that dementia be re-defined as an 'acquired diffuse neurocognitive dysfunction' (Hughes, 2011: 18); a definition which makes no recourse to any specific physical neuro-anatomical characteristics. It is the literature which engages with the aforementioned contradictions and complexities that I use to inform my research and as such, I have been guided by the premise that symptom presentation is not absolute and does not

necessarily directly correlate with neurological decay. The following sections expand upon these ideas.

2.1 Diagnosis of Dementia – the Complexities

Diagnosis is currently determined by a psychiatric assessment. 'The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)' requires evidence of 'a memory disorder and impairment in at least one additional cognitive domain, both of which interfere with social function or activities of daily living' (ADL). 'ADL impairment has come to define the threshold for the diagnosis of dementia beyond the identification of cognitive abnormality' (Dubois et al., 2007: 734). Outlining the inconsistencies in psychiatric diagnoses, Hughes asserts:

'Clinically and pathologically some people have very clear-cut Alzheimer's disease. However many have concomitant vascular pathology; and cortical Lewy bodies can be found in AD too. At the most objective end of mental illness (that is, in the field of 'organic dementias') it turns out there is no hard scientific boundary between disease and normality. Lines can be drawn but their exact location is a matter of evaluative judgement based on correlations between neuropathology and symptoms and signs. But which symptoms? Which signs? How much forgetfulness is pathological? What counts as normal ageing?' (Hughes et al., 2006: 2)

An earlier and more general critique of the challenges of diagnosing mental illness is underscored in the writings of Szasz, who argues that:

'[m]ental illness is, in a sense, in the eye of the beholder; 'the psychiatrist does not stand *apart* from what he observes, but is, (...) a 'participant observer'. This means that he is *committed* to some picture of what he considers reality—and to what he thinks society considers reality—and he observes and judges the patient's behavior in the light of these considerations.' (Szasz, 1960: 116)

Indeed, it is along these lines that Kitwood similarly proposed that brain impairment is just one of the contributing factors to many dementia symptoms. At this juncture, it is important to highlight that dementia diagnoses cannot in effect just be explained as over-zealousness on the part of the medical profession; individuals and/or their families initially refer themselves to their GP in response to very real concerns regarding changes in memory and perhaps behaviour. It is unlikely to be a step they have taken without some considerable thought.

However, Kitwood proposes that dementia symptoms and their severity are as much a consequence of the impact of psychosocial factors, particularly the social environment, as they are of neurological impairment. Indeed, it was his theory of a 'malignant social psychology' which proved to be the driving force behind promoting person-centred care for people with dementia, particularly those in long-term care (Chen et al., 2009).

Resonant with Kitwood's ideas about the influence of social and environmental factors on dementia symptoms, other scholars have also argued for a rethink of dementia in relation to psychosocial aspects (Sabat & Harré, 1992; Harris, 2002). Indeed, Scholl and Sabat (2008) argue that the manner in which a person with dementia is treated can specifically affect their 'subjective experience, ability to display cognitive abilities that remain intact, ability to meet the demands of everyday life, and quality of life and ability to live meaningfully'. To extend this perspective further, Whitehouse and George posit that:

'Defining brain ageing as a disease and then trying to cure it is at its root unscientific and misguided. In short, Alzheimer's is a hundred year old myth that is over the hill. The entire scientific, technological, and political framework for ageing needs to be reassessed to better serve patients and families in order to help people maximize their quality of life as they move along the path of cognitive aging.' (Whitehouse, 2008: 6)

2.2 Models of Treatment

There is currently no cure for dementia; however, drugs are prescribed to relieve symptoms. These drugs fall into two categories: cholinesterase inhibitors (CIs) for mild to moderate cases of AD and vascular dementia and memantines for more severe stages of the condition (Alzheimer's Society, 2015). The literature has not reached a consensus on the merits of either. The National Institute for Health and Clinical Excellence (NICE) is currently updating its guidance for AD drugs and its position is that clinical trials continue to show benefits, particularly with reference to memantines. The uncertainty surrounding the effectiveness of these has been reduced. NICE continues by suggesting it is confident about making positive recommendations for the use of the latter in mild cases.

In their commentary on the use of CIs in AD, Lanctôt and Hermann (2007) conclude that CIs have a 'significant though modest effect on important outcomes, including global measures and function', which has led to clinical practice guidelines endorsing the use of CIs for mild to moderate AD. The Alzheimer's Society's report, 'Out of the Shadows' (Williamson, 2008) argues that, whilst randomised controlled trials are valuable in evidencing how medication will behave under controlled conditions, their transference to real world settings may be limited. The report continues by referring to the degree of ambivalence which remains over the role of CIs in the light of budget constraints, despite the fact their approval has recently been recommended, albeit purely for those with moderate symptoms. In his foreword to 'Out of the Shadows', the popular novelist, Terry Pratchett, himself diagnosed with early-onset AD, described the CI, Aricept as acting like 'a line of sandbags against the rising tide of unknowing', commenting on the suggestion made by NICE that the changes it facilitates at his stage (post-moderate) are minimal: 'but we don't think so in our house, where those little changes make the difference between a dull day and a fine day. The disease is, after all about small changes, and it may be that individuals may indeed be individual'.

The above discussion demonstrates the complexity surrounding treatment, in the light of multiple concomitant medical, social and ontological security issues, in addition to issues of visual perception (Andrews, 1999). Additional complications to the prescription of dementia drugs involve 'drug-drug interactions' (Aldridge, 2000), or a 'prescribing cascade' (Gill et al., 2005), which can lead to increased incidence of falls, agitation, motor agitation, wandering and dizziness. The misinterpretation of these side effects by clinicians actually represents a new disorder, prompting further medication. A vicious circle then evolves, whereby the new drug causes further harmful side effects and so the cycle continues. Gill et al. (2005) highlight this issue with the increased use of CIs, in addition to arguing that antipsychotic drugs have a tendency to advance incontinence, which in itself is widely regarded as inevitable along the dementia path. Therefore, clinicians may incorrectly view incontinence as a natural progression of dementia, when it may in fact be due to non-compatible drugs and their resulting side effects and therefore, could be remedied. Furthermore, owing to the slowing of the metabolic rate in older people, it may be difficult to calculate dosage (Aldridge, 2000).

Antipsychotic drugs, although initially developed to treat schizophrenia, are commonly prescribed to people with dementia. They are employed to ease aggression; restlessness; depression; psychosis; loss of inhibition; agitation; delusions; anxiety; hallucinations, and sleep disturbance (Alzheimer's Society, 2014). Recently, however, there has been a move to reduce the use of such drugs in dementia care, due to the alarming number and variety of side effects; including:

‘excessive sedation, dizziness and unsteadiness, which can lead to increased falls and injuries, as well as parkinsonism (tremors and rigidity), akathisia (body restlessness), reduced well-being, social withdrawal, accelerated cognitive decline and severe sensitivity reactions.’ (Counsel and Care, 2009)

A recent government report suggested that antipsychotic drugs cause 1800 deaths a year, in addition to 1620 cerebrovascular adverse events (CVAEs) (Banerjee, 2009), e.g. strokes and transient ischaemic attacks.

2.3 Medicalisation

The objective of any prescribed drug is either to eliminate or diminish specific negative symptoms; in other words, to address what is ‘wrong’. A driving force underlying this thesis is to subvert this process by exploring what is ‘right’. By this I mean what it takes to ease individual symptoms and enhance well-being, but which is not pharmaceutically derived. Before proceeding to cover what this may include, I will discuss the literature pertaining to medicalisation, in order to further contextualise the medicalised aspects of dementia.

The criticism of ‘the steady expansion of medical boundaries’ (Furedi, 2006), which emerged in the 1970s (Illich, 1976) and continues today (Sharfstein, 2005; Clarke et al., 2010) highlights the drive of the medical profession to incorporate natural life processes within its jurisdiction. The inclusion of dementia within this momentum is partly highlighted by the fact that prior to the 1980s, senility in old age was not considered abnormal (Lyman, 1989); it was only *premature* senility which was viewed as a disease. Considering the medicalisation of dementia, Lyman (1989: 598) suggests that ‘the violation of age norms was the basis for the medical label’. This may be the case, but further scrutiny would suggest that the picture is more complex. The medicalisation of dementia or AD can be seen to coincide with the founding of a

number of AD societies and associations; for example, the UK Alzheimer's Society was formed in 1979, the US Alzheimer's Association in 1980 and the Alzheimer Society of Canada in 1978. Broadly speaking, these organisations were established to raise awareness of the condition and campaign for increased funding for research into what had hitherto been a neglected area. It could be argued that the success of such associations has contributed to dementia being more firmly rooted within the confines of the medical sphere.

Estes and Binney (1989) argue that the influence of medicalisation on ageing, including dementia, is wide-ranging; not only affecting medical interventions, but also policy-making and societal perspectives on ageing. The above authors posit that the power of the biomedical model is such that the research agenda for ageing research is almost exclusively viewed in terms of disease. Moreover, public opinion on ageing is equally affected by the authority of medicalisation and is inclined to view ageing as 'a process of inevitable decline, disease and irreversible decay', rather than highlighting 'the reversible, remediable, and socially constructed aspects of aging' (Estes & Binney, 1989: 594). Referencing McKinlay's (1981) essay on the political economy of illness, whereby he cautions against using all of one's resources to pull 'a seemingly endless parade of people out of a rushing stream without investigating who is upstream pushing them in' (Estes & Binney, 1989; 595), Estes and Binney draw parallels with the biomedicalisation of ageing. Even in the light of the relatively considerable time which has passed since Estes and Binney's paper, much of its message remains relevant today, particularly with regard to the research agenda, as is illustrated by the strap line of the Alzheimer's Society, 'Leading the fight against dementia'. Furthermore, in March 2012, in a funding announcement for dementia research, UK Prime Minister David Cameron called for an 'all-out fight-back' against the disease.

Implicit within the medicalisation narrative is the acknowledgement that medicine has become 'the new repository of truth, the place where absolute and often final judgements are made by supposedly morally neutral and objective experts' (Zola, 2005: 432). Nevertheless, the result of viewing natural life processes - in this case, ageing - in terms of disease has led to narrow treatment models and negative public perceptions. Additionally, Conrad (1992; 2007) has reasoned that medicalisation also

serves as a mechanism for the exertion of social control over generally unacceptable behaviours ('medicalised deviance'), such as madness; alcoholism; homosexuality; obesity; anorexia, and hyperactivity and learning disabilities in children. There are parallels to be drawn with the medicalisation of ageing and dementia, particularly with regard to medically regulating behaviour that deviates from socially accepted norms. However, some of the 'deviant behaviours' are representative of underlying causes of distress for the individual with dementia, which may be allied to organic brain change.

The original thesis of medicalisation particularly focussed on the power wielded by the medical profession and the consequent subjugation of the general population. More recent observations have opined that, although the influence of medicine as a profession has waned, medicalisation still flourishes, albeit with something of a subversion of its driving forces. The emergence of the 'expert patient', in conjunction with an increase in advocacy groups is perceived by Furedi (2006) and Conrad (2005) to be the current driving force behind medicalisation. Furedi (2006: 16-15) suggests that this is due to 'a demand for medical definitions to make sense of existential problems', or 'the transformation of the docile patient into a consumer, or an active patient, in search of a diagnosis.' Additionally, Furedi suggests that broader cultural changes are at play with the subversion of medicalisation, asserting that it is the decline in the strength of the community and 'social solidarity' which have 'heightened the sense of personal vulnerability, creating further opportunities for health-related issues to encroach into the realm of social experience'. Nevertheless, the supposition is that the most important force behind medicalisation and subsequent biomedicalisation today (Clarke et al., 2003) is the dominance and agenda of pharmaceutical companies (Conrad, 2005).

2.4 Positioning

If the dominant view of ageing (heavily influenced by medicalisation), which supposes a process of inevitable and irreversible decline and decay is inaccurate, as indicated by Estes and Binney (1989), then what knowledge is there to support the counter-argument that negative aspects of ageing may in fact be 'reversible, remediable, and socially constructed' (Estes & Binney, 1989: 594). In the following sections, there will

be a focus on some of the factors shown to contribute to maintaining some stability or improvement in dementia symptoms.

In line with other literature on inequality, e.g. in terms of gender or race, the importance of the quality and quantity of relationships in the sustenance of well-being is integral to Positioning Theory, which focuses upon what situates an individual unequally at social or societal levels. Harré and Van Langenhove (1999) argue that the relational nature of social position bestows a powerlessness upon the positioned person. Moreover, they propose that the central aim of Positioning Theory should be a focus:

‘on understanding how psychological phenomena are produced in discourse (...). Not only what we do but also what we can do is restricted by the rights, duties and obligations we acquire, assume or which are imposed upon us in the concrete social contexts of everyday life.’ (Harré & Van Langenhove, 1999: 5)

This is particularly relevant for people with dementia, and one can find many examples where this population is negatively positioned; for example, through the administering of cognitive testing, such as the Clock Drawing Test (Agrell & Dehlin, 1998) and Mini-Mental State Examination (MMSE): the ‘most widely used short cognitive test in clinical practice, clinical research, and epidemiological studies’ (Huppert et al., 2005). In such processes, the position of the individual is immediately compromised by imposing a requirement to demonstrate knowledge retention in areas which are quite often tangential to the person’s daily life, such as drawing a clock, or, in the case of the MMSE, being asked to recall the name of the current Prime Minister (Wind et al., 1997). Hellström et al. (2007) portray a woman with dementia who expressed feelings of humiliation as a result of this assessment process, moreover identifying the MMSE as the cause of much of her distress. Further examples of marginalisation occur when the person with dementia is excluded from consultations regarding their care or treatment, in addition to encountering social situations where a lack of personal agency may be the default assumption of others. Furthermore, over-protective stances adopted by healthcare bodies can contribute to an insidious disempowerment of the person with dementia.

The impact of positioning on identity is outlined by Sabat and Harré's Self 1 and Self 2 concepts, as discussed earlier. The above authors suggest that it is only through the collaboration of others in social scenarios that Self 2 (the 'outwardly directed self, reliant on repertoire of personae') can be produced. They argue that there is the potential for a person with AD 'to attempt to construct a particular persona with another person, but if the latter refuses to cooperate in the constructive process, that persona will not come into existence'. Furthermore, the consequential effect on the position of the person with AD in a social situation will be profound (Harré & Van Langenhove, 1999: 93).

At macro-level, a prime example of people being denied the necessary co-operation to produce a Self 2 can be found in the prevalence of ageism, particularly in the West, and its facilitation of negative positioning. Ageism, defined by Palmore (1999), invokes prejudice, discrimination and stereotyping. Existing on multiple levels, including individual, institutional and societal levels (McGuire et al., 2008), ageism can include stereotypical and negative attitudes, negative labelling and negative language and, within the employment sphere, 'harsher work evaluations' (Rupp et al., 2005). McGuire et al. (2008: 11) argue that at a societal level, ageism and therefore, negative positioning, 'is consistently visible in greeting cards, on television and other media, in humour, and in language expression. Older people are often not visible in the day-to-day life of our society, a form of "ageism by invisibility"'.

Although it is justified that the negative stereotypes surrounding ageing be challenged, McHugh (2003) warns that counteracting negative stereotypes surrounding ageing, resulting in the promotion of agelessness and 'successful ageing', also constitutes a form of ageism. Idealised representations of ageing inaccurately suggest that the template of youth can or should be applied to old age and therefore, 'fail to accord meaning to the third age and beyond' (McHugh, 2003: 180).

The knock-on effect that negative positioning has on an individual can have dramatic consequences. The gradual exposure to ageist stereotypes experienced throughout the course of life becomes internalised before an individual reaches old age and therefore, ageing stereotypes become ageing *self*-stereotypes (Levy et al., 2002;

Levy, 2003). Society is in effect structured to negatively prime an individual to perceive their own aged self, long before that stage of life has been reached. In her extensive output on the subject of ageing and stereotyping, Levy found that negative self-stereotyping affects both memory performance and memory self-efficacy (Levy, 1996; Levy et al., 2002; Levy, 2003). It thus creates a cycle whereby negative stereotyping leads to negative self-stereotyping, contributing to poor performance and as a result, feeding back into the loop of negative stereotyping. Bandura (1989) similarly argues that a negative view of one's own memory has correlative negative consequences, including reduced drive to exercise recall and the avoidance of situations requiring unimpaired memory, leading to reduced autonomy.

In addition to the exacerbation of cognitive impairment, Levy et al. (2002) discovered that negative self-stereotyping brings about a reduction in longevity; individuals with a negative perception of ageing live 7.5 years less than those with more positive views of ageing. Furthermore, Hausdorff et al. (1999), investigating the influence of ageism on the physical functioning of older people, found that ageism had a 'powerful impact on the gait of older persons'. In the above study, participants who 'received reinforcement of positive stereotypes of ageing' demonstrated significant increases in their walking speed.

The combined effects of negative self-stereotyping/positioning and the impact that the 'right' kind of built environment can have on extending cognitive and physical capabilities in ageing have been persuasively documented in the work of Langer (2009). Langer enlisted a number of men in their late '70s and early '80s to reside for one week in a house which had been 'retro-fitted' to mimic a house of 20 years earlier, i.e. 1959. During her experiment, the men were entirely immersed in that time period, in terms of conversation topics, TV and radio programmes, music and literature. Following the end of the week-long experiment in positive positioning, the participants demonstrated improved memory and hearing, in addition to improved joint flexibility and manual dexterity. It would appear that re-positioning the participants so they could re-live a time when they were non-marginalised, fully autonomous members of society facilitated a relatively speedy exit from the force of ageism and negative self-stereotyping by which they had previously been positioned and subsequently, *self*-positioned during the ageing process.

Such situationist work highlights both the role of ecology and the acute importance of aspects extraneous to the brain as an isolated entity. Clear parallels can be drawn here with Kitwood's theories of an enhanced social environment reflecting positively on the severity of dementia symptoms and the need for others to maintain our own positive narrative of self.

2.5 Tacit Knowledge

Implicit within negative positioning or negative stereotyping is a presumption of incompetence. There is, however, a recent body of dementia literature that focusses on the tacit forms of knowledge that people with dementia have. These are forms of knowledge that are not so heavily reliant on demonstrations of cognitive memory. Kontos, for example, has written extensively around the idea of embodied knowledge within dementia and dementia care practices (Kontos, 2003; Kontos, 2004; Kontos, 2005; Kontos, 2006; Kontos & Naglie, 2009; Kontos, 2012; Kontos & Martin, 2013; Kontos, 2014). Kontos posits that restricting any essence of selfhood purely to the brain is to ignore 'bodily sources of agency grounded in the pre-reflective level of experience (which) are fundamental to the constitution and manifestation of selfhood in Alzheimer's disease' (Kontos, 2005: 555). Moreover, she argues that it is important that dementia care practices acknowledge the fact that personal agency and cognitive knowledge are equally about the body (Kontos, 2005). This is a viewpoint which is included within my own research framework. With this focus on capacity, I have explored the subtle cues and clues, which often do not explicitly relate to cognitive knowledge and which people emit in their interaction with each other. These clues, situated predominantly within musicking, demonstrate considerable embodied personal agency, time and time again.

In her 2003 paper on the subject, Kontos references John Bayley's (1999) writings on his wife, Iris Murdoch's memory deterioration in the face of AD. He describes how even when her memory loss was quite severe, she still exhibited 'behavioural instincts' (Bayley, 1999: 75) or 'buried reflexes' (Bayley, 1999: 76). These, Kontos (2003) suggests, can be evidenced by the descriptions of Murdoch's 'social reflexes'; for example, the manner in which Murdoch would greet the postman at the door, or

deal with social situations, where she would, for instance, 'bridge a silence' by asking a question.

Kontos (2003) also highlights the work of Willem de Kooning, the celebrated abstract expressionist artist, who, following an extended period of alcoholism and ill health, developed AD. During the process of his 'advancing dementia', although de Kooning's cognition was impaired, he nevertheless retained the ability to paint. Drawing on both the Murdoch and de Kooning examples, Kontos argues that the body should be perceived as possessing goal-oriented intention, separate from cognition. It is Kontos' supposition that the embodied self can be understood from how 'the body moves, perceives, and behaves' and, moreover, for some (in this case, Murdoch), 'internalized social and cultural practices' remain largely unaffected by impaired cognition. From the perspective of self, therefore, Kontos urges that the body be regarded as central to the 'continuity of our being'.

Hughes (2013) supports the significance that Kontos attaches to embodied knowledge by arguing that particularly in cases where speech is impaired, understanding can be achieved through interpretation of both embodied and tacit knowledge. He describes understanding people with dementia in terms of 'feeling'. His arguments pertain predominantly to communication with those at the more advanced symptomatic end of dementia. Hughes, however, suggests that even where language is fully accessible, words alone do not express the full range or context of an expression. Quoting Wittgenstein (1968, ¶241) Hughes argues that agreement in language use 'is not agreement in opinions but in form of life'. Furthermore, Hughes argues that 'participating in the human form of life can be conceived as an aesthetic act as much as a cognitive one: it is on the feeling side as much as on the thinking side'. In this manner, Hughes (2013) reports how for those who are close to people with dementia, who have impaired speech, there is a form of understanding which is rooted much more in the body; an understanding which includes the 'feelings that emerge between people and the translating gestures and postures.

The focus of my research on capacities, knowledge (however it is determined) and relationships is necessarily engaged with aesthetic understanding and not just

because of the aesthetic presence of music. The time and space of both the ethnographic and longitudinal elements of my research framework have afforded scrutiny of the emergent feelings between people and the aesthetic posture/gesture translation that Hughes describes. As such, this was to move away from cognitive knowledge or understanding and towards an understanding which is more rooted in the body.

2.6 Who Cares? And What Are the Challenges?

To recap the preceding discussion, it seems clear that the experience of both ageing and dementia symptoms can be negatively exacerbated or positively assuaged by social and environmental determinants. This is supported by the social determinants set out in the health literature (Kawachi, 1999; Andrew, 2005). Therefore, it may be observed that dementia, however it is defined, is a shared situation. The significance of who cares and how then becomes that much more pertinent.

Currently, two thirds of the UK's dementia population live at home, with an estimated 670,000 people acting as a primary carer for a person with dementia (Alzheimer's Society, 2011). Furthermore, 60% of familiar carers for people with dementia are a spouse (Benbow & Lennon, 2000) and given that the disease primarily affects older people, the majority of carers will therefore be older people themselves. Quantifying the exact nature of the caring role will reveal that some older carers, particularly those looking after a spouse with dementia, may provide more than 70 hours a week in care, for up to nine years (Glendinning et al., 2009).

Diemling and Bass (1986, in Chappell & Penning, 1996) highlight four specific categories which form the most dominant challenging factors facing caregivers: namely functional dependency; cognitive impairment; impaired social interaction, and disruptive behaviours. Within these groups, potential behaviours highlighted are: confusion; forgetfulness; withdrawal and social isolation; aggression; disruptive behaviour; engaging in inappropriate sexual behaviour; difficulties with activities of daily living (ADL); incontinence; striking out at family members; wandering; screaming; destroying property; being verbally abusive and accusatory; continual

repetition of questions, and emptying drawers and cupboards (Chappell & Penning, 1996).

In addition to these behaviours, there is the issue of 'sundowning'. This is the intensification of agitated and confused behaviours in the late afternoon/early evening period. Its causes are varied - some authors state that it is caused by a disruption to the 24-hour circadian rhythm (Skjerve & Nygård, 2000), whereas elsewhere, issues with vision are proposed as an explanation (Alzheimer's Society, 2010). The brain pathology in AD can cause visual disturbances affecting the regions of motion, depth, colour and contrast: 'a patient can appear to be confused and lost due to a form of motion blindness, as if the world is seen in a series of still frames.' This will cause patients to appear lost, even in familiar surroundings (Solomon, 2005). The decreased light levels at sundown add a further visual hindrance. Additional determinants could be stress and tiredness.

The informal carer engaged in the demanding supporting role described above must also contend with the onerous task of managing and co-ordinating various health agencies (Banerjee, 2009). A review of recent government reports exposes the fact that the lack of cross-agency consistency serves to exacerbate the challenge faced by both the caregiver and the person with dementia. For example, GP records are not currently available to other professionals outside of their practice, thus impeding the level of understanding required by those working in auxiliary roles, which can result in a severe deficiency in the continuity of care (National Audit Office, 2007). Endorsing this view and criticising the sparse uniformity within domiciliary care, the All Parliamentary Party Group on Dementia (2009) have argued that:

'With home visits at irregular times and with different care workers provided for each shift, older people with dementia are most at risk as it is vital they receive consistent, personalised care tailored to their individual needs. Care can be rushed and, at home, even squeezed into 15-minute periods as councils commission unrealistic timeslots and providers attempt to fit care into impractical time scales.' (Counsel and Care, 2009: 5)

Despite these recommendations being made in 2009, the debate surrounding 15-minute care became re-invigorated in October 2013, following the publication of the report 'Ending 15-minute Care' by Leonard Cheshire Disability, which highlighted that 75% of local authorities deliver more than 75% of their care visits in 15 minutes.

Common care tasks required during this time-frame can include providing personal care, such as supporting people as they get dressed, bathe, eat and go to the bathroom. Leonard Cheshire Disability found that for non-frail individuals, the average time needed to complete all these tasks was 40 minutes and 10 seconds. Papastavrou et al. (2007) suggest that, cumulatively, it is the need for 'continuous vigilance' that places such strain on caregivers. Added to this is the perception that the situation will steadily worsen 'in an unpredictable and uncontrollable manner' (Ory, 1999).

2.7 The Impact on the Caregiver

There is a large body of literature that focuses on the impact of caring for a person with dementia. In the case of this study, my concern is more with the individual with dementia and so caregiver literature is not explored in full. However, in this section, a brief overview of such literature is presented, highlighting how my own perspective might contribute to the literature on the situation which faces the carers.

The body of work dedicated to those caring for a relative with dementia has pointed to significant and detrimental effects on the caregiver's health and the overwhelming consensus is that caring for a person with dementia is stressful (Schulz & Martire, 2004). Frequently reported stressors include, 'the progressive impairments in cognition, daily function, and the prevalence of a wide range of behavioral disturbances which can negatively affect carers' self-reported health, illness, as well as medication use' (Ortega & Miranda-Castillo, 2014). 'Burden', a similar and recurring theme, results from 'physical, psychological, emotional, social and financial problems experienced by families caring for impaired older adults' (George & Gwyther, 1986: 253). Indeed, caregiver burden in dementia is not only known to be more prevalent than with other conditions (Schoenmakers et al., 2010), but is also linked to higher levels of medical comorbidity in caregivers (Han et al., 2014).

Psychologically, depression has been indicated as a significant factor with levels of depressive symptomatology being higher in caregivers of people with dementia (Schultz et al., 1990; 1995). Additionally, levels of subjective well-being and physical health are significantly lower in dementia caregivers than in other caregivers

(Brodarty & Donkin, 2009). Russo et al. (1995) found that caregivers of people with dementia and demographically matched controls demonstrated no difference in the prevalence of psychiatric disorders prior to the onset of caring, but there was an increase in such disorders in carers for people with dementia, following the commencement of AD caring. Moise et al. (2004) estimate that in Canada and the US, half of caregivers for people with dementia experience depression and Keicolt-Glaser et al. (1991) found that home-dwelling caregivers were 30% more prone to depression, compared to the 1% of matched controls. Indeed, a more recent report suggests that the risk of a depression diagnosis is four times higher for spouses of people with dementia than for spouses of those without (Joling et al., 2010).

The detrimental impact on physical health amongst carers for people with dementia, who provide more than 20 hours of care a week has been shown to be significant (Hirst, 2004: i), with reports demonstrating that for older carers, there is an increase in infections; predominantly of the upper respiratory tract (Keicolt-Glaser et al., 1991) and 'poor antibody response to influenza vaccine'. This is in addition to reduced resistance to infectious diseases, compared to their contemporaries (Vedhara et al., 1999). Data from a study of 54,412 women showed that specifically for spousal caregivers for people with dementia, there was a correlation between high levels of caregiving burden and the risk of coronary heart disease. This risk was greater than in women caring for other relatives (Lee, Colditz, Berkman & Kawachi, 2003). Indeed, spousal carers of people with dementia have a higher rate of hospitalisation than spouses of those without (Moritz, Kasl & Berkman, 1989). Another cited potential danger for those caring for people with dementia is suicidal ideation (O'Dwyer et al., 2013). The prevalence of detrimental impact is such that this group of caregivers are sometimes described as 'the invisible second patient' (Brodarty & Donkin, 2009).

A concurrent complexity the family caregiver may potentially encounter is the recognition that the relationship they once had with the person they are caring for has changed. In an investigation of close social relationships amongst work colleagues, Chandola et al. (2007) discuss the concept of 'failed reciprocity' and its generation of 'strong negative emotions and stress reactions', suggesting that problems occur when there is an imbalance between output and input. They continue by suggesting that a deficiency in mutuality correlates with all poorer health determinants. Clear

parallels can be drawn with the evolving relationship between the family caregiver and the person with dementia. Research highlighting the stress experienced by carers points to feelings of sadness about changes in the relationship; strain on relationships; friction arising over care decisions; a lack of support; financial concerns; isolation, and anxiety about preparing for the future (Schumacher et al., 2006; Smale & Dupuis, 2004, Bunn et al., 2012). Elsewhere, carers of people with dementia have been demonstrated to be prone to levels of anxiety which are clinically significant (Cooper et al., 2008).

Ultimately, what is often the determining factor in predicting admittance to long-term residential care for people with dementia is the response of their caregivers to the symptoms and not necessarily the symptoms in themselves (de Vugt et al., 2005). However, it would appear that admittance to residential care may not significantly reduce stress levels for carers, as the emotional attachment formed throughout the course of the relationship may be retained, in spite of physical separation. In some cases, caregivers continue in a caring role to demonstrate the sustenance of their love and care (de Vugt et al., 2005).

There is also literature to demonstrate that the negative portrayal of the caring role may not fully and accurately represent all caregivers' perceptions. The Organisation for Economic Co-operation and Development's (OECD) dementia care report states that 'caring for an afflicted loved one, while an unexpected task, is seen more as an accepted responsibility that they wish to be an integral part of, rather than an unwelcome burden' (Moise et al., 2004: 51), adding that 'the reduction in a caregiver's welfare due to the unexpected and stress inducing responsibility of caring for a loved one afflicted with dementia may be offset by the positive experience of being an integral part of the patient's care'. Promoting the less negative aspects of caregiving, Ingebretsen and Solem (1998: 149) argue that in some cases, elements of burden are required 'in order to maintain attachment bonds or to fulfil their obligations. Interventions to take such burdens away, without considering the underlying needs or goals, may interfere with the best interests of the caregiver — and of the person with dementia'. Aspects of the caregiving role which are favourable include:

'a sense of satisfaction, gratification, and pride in the caregiving role; increased sense of mastery, competence, and accomplishment; a sense of purpose or meaning in life; emotional uplifts experienced in caregiving; a sense of reciprocity of care; personal growth; and improved social relationships including increased quality of the relationship with the care receiver.' (Smale & Dupuis, 2004)

Addressing the satisfaction of those caring for people with dementia, Andren and Elmståhl (2005) interviewed 153 family caregivers and reported a high level of caregiver satisfaction. However, it is a complicated picture and the authors of this research emphasise that both satisfaction and stress can and do co-exist. Moreover, Nolan (2001) suggests that the caregiving experience is more likely to sit somewhere between the polarities of burden and satisfaction and in fact changes over time.

Data received from informal caregivers evidence the importance of robust social networks (Haley et al., 1987; Mittelman et al., 2007). Indeed, House et al. (1998: 541) hypothesise that the detrimental effect of not having strong social ties correlates with 'other high profile health risks', such as 'smoking, blood pressure, blood lipids, obesity and physical activity'.

2.8 Coping Strategies

Building upon the research outlined above, the focus is now centred on the literature concerned with coping strategies. Coping strategies, or 'behavioural and psychological efforts employed to overcome, tolerate or reduce the impact of stressful events' (Cooper et al., 2008) are relevant here, not only to add to the scope of this Literature Review, but because they feed into my own study. My research illuminates the subtle strategies people with dementia use to cope, or to enhance their own well-being (see pp. 145f, 167, section 6.1 and pp. 186-187) and I believe that greater awareness of these strategies amongst carers could contribute to their own approaches to coping.

Many authors have attested to the importance of developing effective coping strategies for both the carer and the person with dementia (Milne, Pitt & Sabin, 1993; Nolan et al., 2002; Barbosa et al., 2011; Szabo & Strang, 1999). Cooper et al. (2008) suggest that caregivers use problem-focused and emotion-focused coping strategies (Lazarus & Folkman, 1984), positing that problem-focused approaches may be

successfully employed where situations can be changed, while emotion-focused strategies are more appropriately incorporated when they cannot. Parallels abound between the coping strategies employed in the dementia literature and those used in the more general coping literature and include denial, attempts to regain control, acceptance and making positive comparisons (Norman et al., 2004). Moreover, caregivers who are able to perceive aspects of their role favourably are reportedly better equipped to cope than those who do not (Smale & Dupuis, 2004: 66). Positive perceptions amongst caregivers include the finding, gaining and 'management of meaning', plus 'focusing on caregiver rewards' (Smale & Dupuis, 2004: 66). However, Nolan et al. (2002) argue that despite the number of research strategies targeting caregiver burden, there is little evidence of efficacy. They suggest that this could be the consequence of 'crude interventions' failing 'to capture the nuances of caregiving'.

The coping strategies reportedly employed by people with dementia also include problem-focussed and emotion-focussed coping. For example, Pearce et al. (2002) demonstrated that the coping strategies employed to maintain a sense of self in the face of dementia included striving to maintain past selves, whilst simultaneously constructing new identities and downgrading expectations of themselves. Strategies were employed in collaboration with services, friends and families, but also independently. Dijkhuizen et al.'s (2006) work looking at coping among women with early stage dementia also indicated that success in the realm of identity maintenance was relationship-dependent. Elsewhere, three dominant thematic coping strategies emerged in the work of Preston et al. (2007: 131), which were 'everyday, individual strategies', 'coping in relation to others' and 'personal attitude/approach'. Specific strategies highlighted here were visual prompts (such as keeping diaries and making notes and lists); seeking professional advice; acknowledging the need to interrupt conversations before the fading of a specific thought; continuing to be social; interacting with people in a similar situation; attempting to achieve some perspective on issues, and being positive.

In their research looking at the ways people with mild AD cope with and adapt to changes in everyday life and social relations, Sorensen et al. (2008) found that strategies such as changing activities, attitudes and values were used to maintain

'personal value and dignity'. The authors surmised that some of these strategies were used as a means of combating feelings of powerlessness, in tandem with a reduction in some of their knowledge and skills. In addition, however, Sorensen et al. (2008) suggest that their results are representative of positive and resourceful couples, and the experience of those who are more isolated is likely to be different.

Nevertheless, dementia is perceived, whether as a result of organic neurological decay, life problems, or malignant environmental impact, as generating a ripple effect of need; initially stemming from the affected individual out to those within their immediate proximity, before infiltrating proximate social networks and finally, society at large. The dominant thread running through this review of the dementia literature foregrounds the fact that people with dementia need to be supported in imaginative ways, requiring input at cross-societal levels. Introducing music as a medium to assist in maintaining personhood is one way of advancing this, and sections 2.15 and 2.16 detail the approaches that have been employed.

2.9 The Influence of Adult Mental Health

Over the last 10-15 years, in a bid to change perceptions of adult mental health in terms of projected outcomes, the recovery movement has become an increasingly dominant force. Recovery, as it is framed in the mental health sphere, is not dependent on a complete cure, or even symptom reduction, but is constituted by 'hope, acceptance, agency, peer support, valued social roles and connectedness' (Daley et al., 2013: 522). Parallels can be found within the work of Langer (2009), but also more specifically concerning dementia, within the principles of person-centred care, as championed in the '90s by Kitwood - principles which include a move away from biomedical aspects towards the subjective experience. Person-centred care approaches successfully challenged the commonly accepted paradigm that dementia is a de facto process of continuing degeneration. The idea of recovery in dementia care is now beginning to take hold and several authors have begun to draw parallels between recovery in mental health and person-centred care in dementia (Hill et al., 2010). Indeed, Gavan (2011) suggests that recovery is the successor to person-centred care in that its perspective is both broader and more optimistic in outlook, particularly by virtue of the value it places upon the voice of the individual with

dementia. Additionally, the element of hope in the recovery model contributes to supporting 'facilitative rather than directive care, and enhances autonomy' (Gavan, 2011). However, whilst largely in support of the concept of recovery in dementia, Adams (2010: 629) cautions against the use of the word 'recovery' in this context, citing the potentiality of suggesting 'an unrealistic and often false impression that a cure is possible'. Nevertheless, an underlying applicable focus in the realm of dementia care concerns what it is that people with dementia may be able to 're-cover'.

The majority of the literature concerned with the recovery model and dementia concentrates on professional care; for example, mental health services for older people (Daley et al., 2013); recovery-orientated psychiatric assessment and therapeutic intervention (Jha et al., 2013); dementia care nursing (Gavan 2011); adult psychiatry, and old-age psychiatry (Hill et al., 2010). That professional dementia care services are beginning to consider aspects of recovery is undoubtedly positive, but there is a gap in the literature addressing the application of aspects of recovery in non-professional settings. If 'care' for people with dementia is to be truly holistic, then it would be beneficial if the best of 'best practice' were to be shared, with information flowing freely between the professional, non-professional, medical and non-medical spheres, to include those who work in day centres, or those living in close proximity to the memory-impaired.

Mitchell et al. (2013) call for a rejection of the deficit model of ageing, advocating a move away from the 'tragedy discourse' of dementia, toward a 'discourse of possibility'. They stress that 'alternative discourses challenge what is known and provide new possibilities for being and relating' (Mitchell et al., 2013: 13). Such sentiments clearly embrace the recovery model, which seeks to enhance capacities and support facilitation.

2.10 PART TWO: MUSIC AND DEMENTIA

At its heart, my own research agenda is underscored by a desire to expand upon the body of existing knowledge, highlighting the value of psychosocial approaches. This, as has already been discussed, is a stance which has grown ever more present in

the last 20 years or so in the general dementia literature. However, my intention here is also to counter much of the specific music and dementia research that is heavily invested in medicalised models and perspectives, as demonstrated below. I begin in this section on music and dementia by presenting a broad overview of music in the dementia care literature, including music in live and recorded settings, with both passive and active engagement and with particular reference to singing. The prevalence of addressing aspects of dementia – particularly agitation – via familiar recorded music and its relative consequences is discussed and thematically developed. Additional domains, which have been demonstrated as being positively affected by music, are also outlined.

In order to illustrate what I am working to counter, i.e. a medicalised understanding of this sphere, I move on to critique some representative examples. A dominant motif I address is that of context; for example, the context in which the musical activity occurs and the biographical context in which this music resonates with previous life events all point to a focus on the person, not the disease. Critically, though, in reviewing the ways in which music ‘helps’ people with dementia, the individual as a vital and dynamic component of that context is also considered. With this in mind, I additionally emphasise the tendency of researchers into music and dementia to privilege the perspective of the professional and/or caregiver, to the exclusion of the person with dementia; arguing that to date, music and dementia research has not been sufficiently attentive to issues of personhood and is prone to negative positioning during the research process. These are all ideas I developed in my own research.

2.11 Preservation of Musical Capacity

The literature which focuses on the effects that music-related activities or music therapy can have on people with dementia is substantial (e.g. Millard & Smith, 1989; Clair, 1996; Suzuki et al., 2004; Holmes et al., 2006; Svansdottir & Snaedal, 2006; Chen et al., 2009; Tomaino, 2013; Ray & Fitzimmons, 2014). Implicit memory impairment is the primary deficit in the initial stages of dementia; however, explicit memories, i.e. those not requiring conscious recollection, have been demonstrated to be more durable. Memory for music appears to be particularly enduring, continuing to

outlast other cognitive capacities and memories, even in the final phases of the condition (Smith, 1990; Brotons, 2000). For example, in one study, 10 memory-impaired elderly people demonstrated accurate recall of long-familiar songs (Prickett & Moore, 1991) and elsewhere, Cuddy and Duffin (2005) presented an individual with severe cognitive impairment, who retained the ability to discriminate melody errors in music which was familiar to her. Similarly, a further late-stage dementia case study found that impaired cognitive capacity was no determinant of either the memory of a preferred song, or the ability to sing it (Dennis, 2011), in which case the resilience of a number of learned musical capacities were exhibited, such as timing; intonation; pitch; melody recall; lyric recall; rhythm, and phrasing. Vanstone et al. (2009: 294) conclude that 'memory for tunes and lyrics may be particularly resistant to the ravages of neurologic disorder'.

In support of this is the literature on experienced instrumentalists, which also suggests that musical resilience is present among people with dementia. For example, Beatty et al. (1994) presented a trombonist with AD whose ability to play was unimpaired by his condition. Elsewhere, Cowles et al. (2003) described how a violinist with dementia was able to perform music and also learn, as well as subsequently recall, a new melody. In another study (Crystal et al., 1989), a classically trained pianist with AD demonstrated the ability to continue playing 13 out of 15 pieces of classical music, as originally written, after the opening bars had been played by an examiner. Current understanding of why music is such a durable capacity is limited, although Thaut (2005: 76) suggests that, since memory function is believed to be supported by positive mood states and music is known to induce positive mood, this accounts for its contribution to memory resilience.

2.12 Incorporation of Unfamiliar Recorded Music

The use of recorded background music with people with dementia has received some attention in the literature, with challenging behaviour during mealtimes in long-term care facilities receiving particular focus. At such times, novel music has demonstrated positive effects (Denney, 1997; Hicks-Moore, 2005; Chang et al., 2010; Ho et al., 2011). Elsewhere, Clair and O'Konski (2006) incorporated Rhythmic Auditory Stimulation (RAS), a technique commonly used for people with Parkinson's disease

(Thaut et al., 1996; McIntosh et al., 1997; Howe et al., 2003) into an existing ambulatory programme for individuals with late stage dementia in long-term care. RAS uses rhythmic cues, often in the form of a metronome, 'to facilitate gait characteristics that include an appropriate walking cadence along with enhanced velocity and stride length' (Clair & O'Konski, 2006: 155). Expanding upon a purely rhythmic priority, Clair and O'Konski (2006) included unknown music in a familiar style, with appropriate beats-per-minute, as an auditory cue to monitor gait fluency. The intervention was successful, as patients were observed to require less assistance from staff when walking.

2.13 Incorporation of Familiar Recorded Music

The use of familiar or preferred recorded music is a common thread running through the literature. This is particularly the case with research on agitation; the indicant given most attention in music and dementia research. People with dementia can experience difficulty adapting to changes in environmental stimuli, resulting in agitative responses. Familiar and preferred music has been shown to be effective in reducing agitation. Explanations for the success of familiar music in this context are multiple and include music helping to mask external stressors and dilute unpleasant or unexpected stimuli. Furthermore, the structural aspects of music provide security through the predictability of sound and time (Huron, 2006; Thaut, 2005). The exposure to familiar preferred music facilitates a restoration of self-identity and serves as an instrument of validation; moreover, familiar music offers a 'coherent image of who one knows one is' (DeNora, 2000: 63).

Gernder and Swanson (1993) monitored a small number of patients in a residential health centre at the same time each day (3.30 – 5.00 p.m.) and in a location at the facility where patients spent the majority of their time. They did this to count the number of agitated behaviours occurring during this period. A cassette of music known to have been enjoyed by the participants prior to their admission into long-term care was played from 3.30 – 4.00 p.m. In most cases, instances of agitation were reduced both during and following the music intervention. Similar procedures incorporating preferred music for residents of a care facility revealed a significant decrease in physical aggression and anxiety (Sung et al., 2006; Sung et al., 2010).

A more event-specific application of music was utilised by Ziv et al. (2007) to address agitation at mealtimes. Although the incorporated music had been specifically chosen for its familiar content, it was not known to be specifically preferred by the participants. In addition, the strategic use of both music content and time of day can be found in the work of Ragneskog et al. (2001), who, in addressing the peak agitation times for four individuals, played music they were known to enjoy. There was a reduction in agitation in two out of the four subjects in their sample. Furthermore, recorded familiar music was also shown to both enhance and maintain attention in this group (Gregory, 2002; Thompson et al., 2005).

2.14 Music and Memory

The relationship between music and memory appears to be mutually supportive; not only does the memory of music endure, but it additionally appears that music is able to support memory function. For example, participants in a music therapy session, each diagnosed with AD, demonstrated improved recall of autobiographical details, in comparison with a control group who had been engaged in drawing tasks (Thomson, 2005). Similar improvements in autobiographical memory were recorded by Foster and Valentine (2001). Irish et al. (2006) suggest explanations for music's potency in this area: that it can be attributed to increased arousal and that music assists in concealing other distracting stimuli, allowing for enhanced concentration. More recently, Simmons-Stern et al. (2010) found that when people with dementia were presented with unfamiliar lyrics, sung or spoken, they were able to more accurately recall the lyrics which had been sung, than they could the spoken lyrics.

A good deal of the literature on music and dementia works on the assumption that people with dementia, at whatever stage, possess little agency. This is clear in much of the research outlined above (e.g. Gernder & Swanson, 1993; Sung et al., 2006; Sung et al., 2010; Ziv et al., 2007; Ragneskog, 2001). In these cases, music is 'done' on or to individuals. This type of research seeks to monitor 'responses', which is also suggestive of an acquiescence; the word 'response' signifying, as it does, a reaction to something.

2.15 Active Music Engagement

Much of the literature pertaining to the topic of active music engagement relates to music therapy and the vast majority of these studies involve group music therapy sessions. In general, these group music therapy sessions consist of playing percussion and/or singing familiar songs (Svansdottir & Snaedal, 2006; Takahashi, 2006; Bruer et al., 2007; Cooke et al., 2010). Recorded music is also a feature (Cooke et al., 2010). The range of measured outcomes from the music therapy intervention include: Mini Mental State Examination (MMSE) scores and sundowning (Bruer et al., 2007); cortisol level, blood pressure and 'intelligence' (Takahashi, 2006); activity disturbances, aggressiveness and anxiety (Svansdottir & Snaedal, 2006), and quality of life and depression (Cooke et al., 2010). The effect of group music therapy sessions on each of these desired outcomes has been demonstrated to be positive.

In contrast to the focus on group musical activity, Ridder (2003) concentrated on individual music therapy sessions by singing a repertoire of traditional songs, unaccompanied, to people with advanced stage dementia who exhibited limited verbal capacity. She used singing as a means of entering into meaningful relations with participants, by encouraging responsive communication from them through song. The sessions lasted half an hour and were video-taped. The analysis and coding was undertaken by both Ridder and external assessors. Heart rate data with additional observations were used to further determine the effectiveness of the intervention. The consequence of these one-to-one sessions was a 'catalogue of gestural responses' of varying degrees of quality, in addition to 'emotional valence, receptive participation, sociality, active participation (and) communicative musicality' (Ridder, 2003: 2). It was determined that the singing did have a positive effect on each of the six participants, particularly in relation to responsive communication, compliance and heart rate levels.

2.16 Singing Applications

Active music-making, particularly singing, is similarly embedded within the literature. Beneficial aspects of singing in the general population have been detailed as enhancing emotional affect and immune competence (Kreutz et al., 2004); emotional

balance, heightened arousal and social support (Bailey & Davidson, 2005), and breath control (Clift & Hancox, 2010). However, similar attributes have also been recorded within group singing activities for people with dementia – for example, the SFTB sessions, coordinated by the Alzheimer’s Society (Bannan & Montgomery-Smith, 2008). These structured singing sessions for people with dementia and their carers (formal or informal) have proved highly popular and the authors ascribe their success in part to the social experience of this particular group activity. In her ethnographic study of an SFTB group, Hara (2011) supports this stance, but further suggests that the social reach of SFTB extends beyond the sessions by forming an ‘important node in a larger ‘support network’ for individuals with dementia and their carers’ (Hara, 2011: 53). From a one-to-one perspective, Hara contends that by cuing memories of their ‘pre-illness relationship’, the singing re-activates the relationship between family carers and their relatives or partners with dementia.

Earlier applications of group singing sessions to specifically address the issue of sundowning have demonstrated positive modifications (Lesta & Petocz, 2006). Additionally and elsewhere, participants of a group singing session demonstrated an increase in frequency of positive social behaviours, such as smiling, giving up their chairs for others, affectionate back-patting and holding hands (Millard & Smith, 1989).

Describing the general benefits of singing for people with dementia, Clair (2000) emphasises its contribution to ‘wellness’ through its ability to provide ‘essential comfort and human contact’ (Clair, 2000: 100). It is this kind of essential comfort, mediated through musical human contact, which has been one of the focuses of an interesting body of work that has emerged over the last decade in Sweden from the healthcare academic, Eva Götell and her colleagues at Mälardalen University and the Karolinska Institute (Brown et al., 2001; Götell et al., 2002; Götell et al., 2003; Götell et al., 2009; Hammar et al., 2010; Hammar et al., 2011). By prioritising people in the very advanced stages of the condition, who are living in long-term residential care, they have developed Music Therapeutic Caregiving (MTC), a highly innovative approach to incorporating music into the caring domain. Implemented during the morning care session, a typically stressful time for residents, MTC involves the professional carer singing whilst undertaking caring tasks. Neither the repertoire nor the timing is specified; it is left to the discretion of the carer to introduce singing at

whatever moment they feel is the most appropriate. The approach is progressive in a number of ways. Firstly, it rejects the experimental norms conventionally found in music and dementia research, in that it does not specify how long any music/singing should continue. Those singing are neither therapists nor researchers, but professional caregivers with knowledge of the individuals with whom they are musicking. Furthermore, the fluidity fundamental to the research design affords the caregivers complete autonomy to choose the repertoire and to change it as they deem suitable.

As a consequence of MTC, the authors describe positive outcomes for both caregiver and care-receiver. The residents demonstrated an increase in positive expressed emotions and a reduction in negative expressed emotions and resistance to the carers. The carers experienced increased compliance, facilitating a reduction in narration and thus easing the task in hand. Elsewhere, MTC has been demonstrated to enhance the bond between carer and resident (Dennis, 2011). Ultimately, it is concluded that 'MTC can enhance communication between persons with dementia and their caregivers during caring and can thus increase the mutuality in the encounter, facilitating an interpersonal relation during morning care situations' (Hammar, 2011: 5). Mälardalen University has been so convinced by the results that it has introduced a course in MTC for its nursing staff.

Further scrutiny of the research covered in this section reveals that for those studies involving people with dementia, all are based either in residential settings or day care centres. Given that two thirds of the UK's dementia population (Alzheimer's Society, 2011) live in their own homes, this would suggest something of a gap with regards to harnessing what has been learnt about the effect of music in dementia care, applied in the domestic environment.

2.17 Home-based Music and Dementia Literature

The music and dementia literature related to domestic settings and engaging with people with dementia and their family caregivers is extremely limited. It is not exactly clear why this should be the case; however, a number of factors could account for the lack of studies in this domain. For instance, people in residential care are generally at

the more advanced stage of dementia and as such, this cohort may be viewed as a more urgent research priority. Additionally, once successful negotiation with the relevant gatekeepers has been reached, residential establishments allow for easier access to greater numbers of participants, effecting a comparatively simpler recruitment process, plus homogeneity of the research environment.

The earliest domestically situated music and dementia research I located was by Yasuda et al. (2006) and it concerns an individual who had become reluctant to attend one of his regular day care centre sessions. The individual's wife had resorted to pretending they were going to walk the dog in order to help motivate her husband to leave the house, although she found this an unsatisfactory technique. To assist with this task, three popular songs known to be familiar to the husband were chosen, each with lyrics revolving around nature and 'a desire to travel'. The songs were played on the mornings of the day centre visits, prior to the usually required departure time. Immediately following him hearing the song, messages were played advising him to go for a walk.

Following the initiation of this strategy, the wife reported that her husband was no longer reluctant to leave the house, commenting that 'sometimes, before the end of the songs, he voluntarily stands up and prepares to go out' (Yasuda et al., 2006: 72). An additional and unexpected outcome was that once he was at the day care centre, the staff reflected that he demonstrated a marked reduction in behavioural disturbances, even though they were unaware of the new house-leaving strategy.

In an alternative case study, the same authors describe a music intervention designed for a woman who had begun to substantially reduce her food intake. A digital recorder placed in the pocket of a doll to which the woman had become attached played messages encouraging her to eat; the messages were interspersed with music and periods of silence. A single children's song was used and repeated, the lyrics having been altered and adapted to recommend the woman to eat more. During this music and message intervention, her food intake more than doubled (Yasuda et al., 2006). What is evidenced by both of these investigations is that people with dementia do have the capacity to learn and/or adapt to situations they may be struggling with, but this is seemingly only possible with support.

An even more explicit example of an individual with dementia learning and adapting can be found in the work of Bier et al. (2008). In this case, a step-wise procedure was devised to assist in learning how to use a cassette recorder, in order to enable an individual with dementia to listen to music spontaneously and unaided. The participant was guided through the relevant steps 10 consecutive times. Gradually, support from the researcher was reduced until the individual was able to carry out the required measures without assistance. The procedure was largely successful, as the participant, albeit with additional cues, was subsequently able to autonomously work the cassette player and listen to music.

Elsewhere, in Park and Specht (2009), the time prior to usual peak agitation was targeted to incorporate individualised music in a home-based setting. This research demonstrated that mean agitation levels were reduced after listening to 30 minutes of preferred music before peak agitation. Park (2010) carried out an identical protocol but focused on pain; again, he found that listening to music was effective in pain management, as the reduction in pain was significant.

For the present research, I found just two studies in which active musicking occurred in the home environment (Hanser et al., 2011; Baker et al., 2012), despite searching for the terms 'music dementia/Alzheimer' with either 'community', 'domestic', 'at home' and 'home-based'. Baker et al. (2012) focused on music in a domestic setting, viewed from the perspective of the caregiver. They implemented a six-week pilot of a home-based Active Music Intervention (AMI). This involved singing familiar songs, either unaccompanied or with a CD/DVD/mp3 player. Sessions were requested to last for 20 minutes and post-session, the caregiver was requested to attempt to assist their spouse in recalling associated memories. Caregivers were given the autonomy to apply the music intervention at any point during the week, but the authors requested a minimum of three sessions per week. Potential changes in the caregivers' perceptions of their relationship with their spouse; potential changes in satisfaction experienced with the caring role; moderation of caregiver well-being, and changes in the cared-for spouse, as observed by the caregiver, were to be evaluated. Caregivers testified to experiencing enhanced personal well-being and a

strengthening of their relationship with their spouse. Two out of the five participating caregivers felt that the AMI had a positive effect on their cared-for spouse.

In Hanser et al. (2011), the other active musicking home-based investigation, the stated aim was to 'reduce stress and enhance satisfaction with caregiving, while offering the person with dementia the potential to improve mood and psychological state', through a home-based music protocol. Following interviews with caregivers regarding their preferred music, tailor-made CDs were compiled by a music therapist. Each participant dyad then received an extended training session to discuss ways in which they might engage with the music. Once established, the participants were asked to listen to the music three times a week, during which time they were encouraged to also discuss memories aroused by the music; engage in some gentle exercises to the music; discuss and/or draw images associated with the music; provide rhythmic accompaniment with drums or other instruments, and apply the music strategically to assist with sleep or relaxation. They found that with this experimental approach, there appeared to be an increase in the 'care recipients' and caregivers' perceived levels of relaxation, comfort, and happiness' (Hanser et al., 2011: 15).

2.18 Omissions in the Music and Dementia Literature

I will now use Hanser et al.'s (2011) study as an exemplar to move into a broader critical discussion of the music and dementia literature. Prior to the commencement of the research, consent forms were signed by both the caregiver and the person with dementia. Hanser et al. (2011) describe their participants as displaying 'symptoms in the moderate to severe range of dementia'. However, the distance between the moderate to severe stages of dementia is substantial. This is where the first issue I wish to examine emerges: the ability to grant consent amongst those at a severe stage of dementia is likely to be more challenging than it is for those at a moderate stage. Nevertheless, in this instance, Hanser et al. (2011) does not elaborate on how this was addressed, except to say 'both the caregiver and the person with dementia signed consent forms before any assessments were given or conditions implemented'. I would argue that describing people as inhabiting a dementia

symptom range of 'moderate to severe', but then handling the group as a unified whole, is unsatisfactory.

Moreover, regarding the protocol, the caregivers were fully integrated into the research design from the outset - from being involved in discussions regarding preferred music, to completing self-report measures, both for themselves and on behalf of their family member - to determining how many weekly music sessions would practically be aimed for. Apart from signing a consent form and receiving direction from the music therapist with regard to choices of music methods, the care receiver was otherwise excluded from engagement in the research process. Herein lies a contradiction: all participants were deemed capable of granting consent in the same manner, i.e. by signing a form, irrespective of severity, yet all participants, irrespective of severity, were denied the opportunity to express their musical preferences, or to be actively involved in the research process. Indeed, the caregivers were interviewed regarding their preferred styles of music, favourite selections, and appreciated artists. Caregivers were also asked to assist in determining the music preferred by the person with dementia. A list of approximately 500 recordings of classical and popular music was drawn up, with the caregivers examining the list and selecting music that they and their relative with dementia were familiar with and enjoyed (Hanser et al., 2011: 7).

Moreover, with regard to any effect of the music intervention:

'...caregivers were asked to write anecdotal reports of responses to the music, and interactions with family members. (...) Caregivers rated their own relaxation, comfort, and happiness as well as these states in their care recipients.' (Hanser et al., 2011: 9)

Certainly, for the individuals demonstrating symptoms at a moderate stage, it is not clear why they were not offered greater active involvement during the music protocol. Additionally, although communication with people with advanced dementia is undeniably challenging, it is not unachievable, as McKeown et al. (2010: 29) argue: 'even those in the more advanced stages of dementia, can be engaged in research providing that researchers have a thorough understanding of ethical principles and rules and an ability to apply these sensitively and flexibly in practice.' I would argue that ultimately classifying all participants as a homogenous group does not support

person-centeredness and furthermore, would detrimentally affect the findings, because those for whom the research is designed are not given the opportunity to express their opinions; they are ultimately represented by a proxy.

Hanser et al.'s (2011) study is representative of much of the music and dementia literature, in that persons with dementia are frequently homogenised into a non-specific symptom category. Other examples include Sung et al.'s (2006) investigation into the effects of preferred music on agitation, in which participants are described as 'institutionalised elders', 'diagnosed with dementia and exhibiting agitation'. No indication of symptom severity or consent is given. Suzuki et al. (2004) specify that their participants have dementia of an Alzheimer's type (DAT), or vascular dementia (VD), but do not further clarify an approximate stage. In a construct validation of music-based assessments, Lipe et al.'s (2007) recruitment criteria were that individuals had a diagnosis of dementia, English was their primary language and they had a 'family member or responsible agent to provide informed consent and background information including prior involvement with music'. Similarly, Lin et al.'s (2011) enrolment criteria were for the patient to have been diagnosed with dementia, be over 65 years old and speak Mandarin and/or Taiwanese.

As outlined above, the Hanser study points toward the privileging of either the carer or professional. Relative to this is the significant impact which negative positioning has on people with dementia, as discussed earlier and this is not generally explored within this specific literature, if at all. By virtue of engaging in research with this cohort, the importance of positioning between the researched and the researcher becomes unavoidably propelled to prominence. The issues surrounding positioning with people with dementia, such as presumed assumptions of (in)capacity, (lack of) personal agency, potential marginalisation or exclusion, (non)collaboration and (dis)empowerment, will hugely impact on an individual's responses, particularly those pertaining to the specific remit of a music research project.

Referring specifically to the research context, Dewing (2002, p. 160) argues that:

'The emphasis in seeking and maintaining consent in person-centred research, where nurturing personhood is a primary value, needs to be on right

being. The emphasis is on *being with* another rather than the doing to or doing for. Right *being* cannot be achieved in isolation from others.’ (Author’s italics)

Dewing further describes a ‘moral space’ existing between all those engaged in a research inquiry, reiterating the importance of ‘right being’. Moral space foregrounds the achievement of an interpersonal space, where an exchange of either mutual or ‘free attention’ flows from one protagonist to another (Kitwood, 1990b). In the case of an essentially unequal interpersonal relationship (i.e. pertaining to dementia or childhood), the moral space is maintained through ‘a kind of closeness, but without loss of individuality’ (Kitwood, 1990b: n.p.).

Additional key components which have received considerable attention in the main dementia literature, but which remain relatively neglected in the music and dementia literature, are personhood and person-centred care. Personhood, a ‘standing or status that is bestowed upon one human being by others, in the context of social being (implying) recognition, respect and trust’ (Kitwood, 1997: 8) and person-centred care, or that which remains attentive to remaining abilities, emotions, cognitive abilities, and not to losses (thus contextually positioning the person with dementia within the framework of family, marriage, culture, ethnicity and gender (Epp, 2003) are firmly established tenets within dementia research at large. In essence, these two components, central to a great deal of the non-medical dementia research, all strive towards the same ends: that of positively positioning the person with dementia and seeking to support and maintain their personhood. Nevertheless, a review of the specific music and dementia literature will reveal that many of the methods employed do not optimise personhood, person-centeredness or the ‘moral space’ between the researcher and the participant. Below are highlighted three further significant and relevant areas that the music and dementia literature does not frequently address.

2.19 Time and Place

Zarit and Leitsch (2001: 89) argue that research protocols need to be attentive to magnitude and recommend that ‘identifying levels of adequate dosage will advance the development and evaluation of intervention programs’. In an earlier piece (in Stephens et al., 1990: 244), Zarit suggests that it is unrealistic to expect an eight or 10-week group to have ‘far reaching changes that address all the possible negative

consequences of caregiving'. He gives the example of perceived caregiver burden and argues that this could include physical and emotional strain; role overload; role conflict; role loss, and financial burden. He posits that a brief intervention may facilitate change in some of these areas, but is unlikely to facilitate change in all of them.

In addition, the majority of music and dementia research is short in duration; for example, a review of 18 studies conducted between 2003 and 2012, in which music was used on more than one occasion (typically once or twice a week), found that 15 investigations lasted eight weeks or less (e.g. Millard & Smith, 1989; Suzuki et al., 2004; Svansdottir & Snaedal, 2006; Sung et al., 2010) and seven were for four weeks or less (e.g. Foster & Valentine, 2001; Sung et al., 2006; Ziv et al., 2007). The duration of music exposure ranged from three and a half minutes (Gregory, 2002) to one and a half hours (Denney, 1997), although the most common duration was 30 minutes. While acknowledging that research funds are not limitless, if the aim is to truly comprehend how, why and what type of music may affect this population, the incorporation of music once or twice a week for a month or so represents but a drop in the ocean of understanding.

I have already highlighted the heavy bias towards long-term care environments in this field, but it is an interesting phenomenon which deserves further scrutiny. In the first instance, given that two thirds of the UK dementia population live in the community, the weight afforded to inquiry into care home music interventions is disproportionate. The fact that people in residential care are more likely to inhabit the more advanced stage of the dementia trajectory may have contributed to researchers addressing this population with a greater sense of urgency. Here, an anomaly emerges: acquisition from people in the later stages of dementia should present a comparatively greater challenge, but the canon illuminates that once institutionalised, consent appears to retain less significance for researchers. To reference Dewing (2002), they therefore fail to 'nurture personhood' or fulfil 'right *being*'.

Additionally, many research papers focusing on behavioural issues, such as agitation, give little, if any, description of the distinguishing characteristics of the environments where the music is presented (Ragneskog et al., 2001; Suzuki et al.,

2004; Sung et al., 2006; Sung et al., 2010). Given that people with dementia are known to be highly sensitive to their surroundings, this is an omission. For example, Bakker (2003: 46) reports that dementia alters responses to sensory input. Furthermore, such responses are highly individual and fluid, depending on 'neuropathological changes, sensory loss, time of day, medication management and the social and physical environment'. From the perspective of vision, Torrington and Tregenza (2007) make several recommendations for reducing disturbance amongst people with dementia, specifically in a care home. These include the avoidance of silhouetting against windows due to low-elevation sunlight and the avoidance of uniform lighting, which minimises the contrast between surfaces, thus detrimentally affecting orientation and space recognition. They also highlight that the shiny surfaces, often prevalent in care homes for ease of cleaning can cause discomfort through glare, hindering the perception of surface position. Wong et al. (2014: 34) concur with these arguments, stating that 'dementia disorders are generally aggravated by an age-related decline in sensory perception that affects vision, smell and hearing', which can affect perception. Further support for this assertion comes from Zarit and Leitsch (2001), who argue that:

'features of the physical environment can induce or inhibit behavior on the part of the dementia patient. For example, low lighting, lack of hand rails, uneven walking surfaces, and room size are features of the physical environment that can impede participants with functional health problems. Loud televisions and intercoms and unclear room and doorway designations can exacerbate cognitive deficits. The features of the physical environment in which a program takes place must be considered for their influence on the outcomes of interest.' (Zarit & Leitsch, 2001: 86)

As I view it, the areas of inattention in the music and dementia literature highlighted above are issues I have consequently strived to overcome within my own research project. First of all, I have attempted to do this by engaging with people living in the community, who are, broadly speaking, at a moderate stage of dementia. An ethnographic approach was adopted, which, by definition, signified prolonged time periods spent in the field. This enabled a snap-shot approach and also achieved a richer understanding of both the individuals under scrutiny and the ways in which each engaged with music in an uncontrived setting. Additionally, music was just one part of a local ecology and not artificially included for the participants for the purposes

of the research. Moreover, the angle of the research was to take a broad view of the possible effects of music and not to narrow the focus to specifics, such as agitation.

My ethnographic focus (as opposed to intervention and assessment) allowed an examination of music in relation to dementia, in ways that focused on how music was done 'by' rather than 'to' people with dementia. I understood the participants as experts of their own musicking and worked to minimise the 'moral space', or rather to reduce the distance between the researcher and the researched. Clearly, any responses to or engagement with music were of significance, but my methodology also facilitated the time and space necessary to bring other corresponding and often complimentary elements to the surface. The aim was to develop a nuanced understanding of the place of music in dementia care, alongside a more holistic understanding of people as social entities with incapacities, but also with considerable capacities.

2.20 Privileging the Professional

Dementia research in the 1980s was primarily concerned with carers' experiences (Innes, 2009:104). However, following on from the work of Kitwood (1993), Sabat and Harré (1992) (as discussed on pp. 15 and 24-26) and Goldsmith (1996), the culture of dementia research began to change. Researchers came to appreciate that it was possible to meaningfully communicate with people with dementia and consequently proceeded to seek the opinions of this population with greater frequency. Now, in the wider dementia research field, i.e. not relating specifically to music, it is common for researchers to engage with people with dementia and not rely on proxy reporting, as had been the case in the past. This is evidenced, for example, in the work of MacRae (2008), who sought to capture subjective experiences of AD and contrast these with popular media representations. Similarly, Beard et al. (2009) investigated how people with dementia actively worked to disprove common negative assumptions.

Elsewhere, Mazaheri et al. (2013) explored people's experiences of living with dementia in Iran.

Likewise, the proxy element is a common feature of research into the realm of music and dementia, in that the music is 'administered' by the researcher, a music therapist,

or a member of the professional staff. With the exception of Góttell et al. and Baker et al. (2012), the lay musicker is almost entirely overlooked. It would, of course, be absurd to suggest that the professional music implementer is insignificant; however, it is precisely the transfer of power from the professional to the lay person which renders the work of Góttell et al. and Baker et al. so innovative. Shedding light on the processes involved in such lay musicking facilitates an emerging comprehension of the level of richness and nuance to be found therein. Transferring the autonomy of the music delivery from the researchers to the professional or familial caregiver enhances the 'moral space' and further privileges personhood. Moreover, lay musickers allow the music intervention to occur more naturally, in concurrence with everyday life and not at a pre-determined time for a pre-determined duration. For a more applied use of research, I would argue that greater attention needs be focused on more naturalistic ways of incorporating music.

Perhaps the most significant omission affecting personhood and the moral space in music and dementia research is bypassing the opinions and perspective of the person with dementia. Evidently, obtaining opinions about a music intervention from people in the late stages of dementia is highly problematic; not least due to the erosion of language, which is a constituent feature of the late stage. However, this is not impossible, as previously discussed and for people whose language faculty is largely intact, it would appear nonsensical to neglect to include their opinion on interventions which are largely designed for their benefit.

Dementia is not, as has previously been established, a narrow, definitive term. Encompassed within the label are not only a number of diseases, but also a variety of symptoms and symptom severities. These can, in turn, be mediated or exacerbated according to environmental factors. In their investigation into the effects of music intervention on older people with dementia, Sung et al. (2006) utilised the Cohen Mansfield Agitation Inventory (CMAI) at baseline and at six weeks as their tool for measuring the success of the music intervention. The CMAI contains a checklist which documents the frequency of a variety of behaviours, including hitting; biting; scratching; spitting; intentional falling; eating/drinking inappropriate substances; general restlessness; strange noises, and the use of repetitive sentences or questions. No doubt this is a useful barometer, but the above authors did not clarify

the severity of the participants' dementia and therefore, it is not clear whether they had the capacity to describe their feelings about the music intervention. This would have been beneficial information either way and if any of the participants were in fact able to express themselves, then neglecting to garner their opinions or feelings reduced them to the status of a 'lab rat'.

Furthermore, Lin et al. (2011) examined the effectiveness of a group music intervention for agitation in elderly people with dementia and were in fact specific about the severity of their participants' condition, stating that 24.49% of their sample had severe dementia, 63.27%, moderate and 12.24%, mild dementia. In this case, therefore, roughly three quarters of the sample would have been able to express an opinion on the music intervention designed to improve their situation, but they were not given the opportunity and once again, the CMAI was the instrument used to gauge the efficacy of the music. This is another example of negative positioning through enforced agential impotency and marginalisation.

Frequently, the literature does in fact demonstrate music's positive effect on this population, but my objective in this section has been to stress that methodologies which are closely allied to the medical model impoverish music and dementia inquiry, particularly methodologies which incorporate snap-shot approaches; conceptualise music as a quasi-pill (e.g. take twice a week for four weeks); privilege the professional or the person without dementia (usually the carer); disregard the opinions of the person with dementia, positioning them as passive patient; and/or ignore the context and environment in which the music is experienced. What the omissions in the literature illuminate is that all too frequently, the manner in which research is conceived removes certain fundamental considerations from the process, namely personhood, experience, subjective opinion, moral space and equality.

2.21 Networks and Attachments

As a contrast to the quasi-clinical focus of much of the music literature outlined above, I now move towards a focus which is more sociologically informed and firmly rooted in everyday life. My criticism of much of the literature highlighted above is that music and the person (with dementia) are conceived of as distinct from each other

when they come into contact, as if there were no interplay between the two. Such a perspective ignores the body of work concerned with the rich interplay between both realms. Before expanding on this specific body of work, reference needs to be made to earlier influences, namely Actor-network Theory (ANT), where actors may be human or non-human.

Gomart and Hennion (1999) argue that ANT emphasises how ‘the capacity to be strategic cannot be assigned to a human actor within a network but should be described as the effect of the association of a heterogeneous network’ and included within this heterogeneous network are non-human elements. Latour maintains that the conjunction between the human and non-human should be understood as actors (Latour, 2005). As Law (2009) puts it, ‘[a]ctor network theory is a disparate family of material-semiotic tools, sensibilities, and methods of analysis that treat everything in the social and natural worlds as a continuously generated effect of the webs of relations within which they are located’.

An important concept of ANT, notes Verbeek (2005), is ‘script’, or the idea that ‘things-in-use can “prescribe” specific forms of action, much like the script of a theatre play’ (Verbeek, 2005:125). As examples, Verbeek cites a plastic coffee cup and speed camera, which, respectively, adhere to the scripts: ‘throw me away after use’ and ‘don’t drive faster than...mph’. Artefacts are not passive and inert entities. They actively co-shape what actors do’ (Verbeek, 2005: 125). Within the world of music sociology, illustrations of these ideas may be seen, albeit not directly with ANT in mind. For example, Willis (1978) and Frith (1987) demonstrate how cultural and aesthetic practices could dynamically be appropriated to produce social life, or (to use the terminology of ANT) the human-non-human (music) network can generate an outcome. These scholars describe, ‘how agents attach connotations to things and orient to things on the basis of perceived meanings’ (DeNora, 2000: 6). Thus, they help highlight, ‘what culture ‘does’ for its consumers within the context of their lives’ (DeNora, 2000: 6).

Referencing ANT and its origins in the field of science and technology studies, Gomart and Hennion (1999) note that such fields focus on modes of action set within the framework of specific networks. Looking to expand such a perspective, Gomart

and Hennion (1999) include a focus on events that 'just occur' and in which amateurs 'are transformed by their attachment to that collective' (1999: 225). Using the examples of music amateurs and drug users, Gomart and Hennion (1999) advise that events as they are experienced by these two groups ought not be simplified to 'an interaction of causal objects and intentional persons' (Gomart & Hennion, 1999: 226), but the 'things' (the music or drugs) should be viewed as a 'locus of an event':

'An event in which 'the user is seized at those very points of asperity (or affordance) that are made possible and relevant by the sophistication of his/her own practices and vocabularies, as well as by the properties of the objects used'. (Gomart & Hennion, 1999:243)

With this project's focus on the music and dementia nexus, it is frequently the music and everyday life literature which I have found to be most informative. Without the constraints of any medical-related influences or concentration on dementia symptoms, i.e. trying to understand what music may do for agitation, for example, such work is free to comprehend people more holistically, without being influenced by the presence of dementia. This is not to say that the dementia-specific aspects are inconsequential with regard to the effect of music. My argument is rather that in order to understand what music may or may not do for people with dementia, progress could be advanced if the dementia aspect was in a sense afforded less prominence and, as per Kitwood (1997), the perception in relation to music was PERSONS-with-dementia, not persons-with-DEMENTIA. One way this can happen is for the dominant focus to shift towards the social world where music is encountered.

What the music and dementia literature does show is that personal musical preference or taste can be crucial to the effect of music on individuals with dementia (Lesta & Petocz, 2006, Ragneskog et al., 2001; Sung, Chang & Lee, 2010), albeit with little analysis of how musical preferences are constituted. With this and the previous paragraph in mind, it is logical to give greater credence to an exploration of what underscores personal musical preferences. Hennion's (2004) work on taste and its acquisition through the attachments people form with regard to music addresses this gap; building on an understanding of non-human 'things', e.g. music, as being part of an integrated actor-network. Indeed, what Hennion's work illuminates is not only the presence of attachment, but also its form.

Attachment may be summarised as that which 'links us, constrains us, holds us, and what we love, what binds us, that of which we are a part' (Hennion, 2007: 109). It is a familiarity with something which is supportive. Moreover, attachments, according to Jones and Boivin (2010) are 'co-mingled' and relational. Comparing attachment with passion, Gomart and Hennion (1999) ally it to addiction and draw parallels between an addictive attachment to music and drugs. It is, moreover, their assertion that such passions or attachments are not passively acquired, but materialise through 'active work' in order to achieve effect or excitement. A time-evolving process, such as attachment therefore motivates action via the experience of living and feeling the attachment. It is Hennion's hypothesis that taste, via attachments, is attributable to 'a collective technique whose analysis helps us to understand the ways in which we make ourselves sensitized, to things, to ourselves, to situations and to moments' (Hennion, 2007: 97). Therefore, in relation to music (and dementia), the concept of attachment points to how and why music becomes integrated into peoples' lives. The conjunction involved in musicking indicates that affordances 'are made possible and relevant by the sophistication of his/her own practices and vocabularies, as well as by the properties of the objects used' (Gomart & Hennion, 1999:243).

As a result, meaning is not only derived from what is attached to music, but, as demonstrated by ANT and music sociology, is bound up with the attachment process. Studying attachments within networks will therefore assist in contextualising both the person and the music (with or without memory incapacity), so that the process of re-coupling or re-situating music more centrally within the context of peoples' lives can begin. The comprehension of both the presence and form of attachment is linked with the existential philosophical perspective of ontology. To elaborate on this, an individual's ontological position is reflected in the way in which they perceive the self and others. 'Ontological security' takes shape in and through the kinds of attachments people form and is dependent on the network of people and things. It is represented by a 'confidence or trust that the natural and social worlds are as they appear to be, including the basic existential parameters of self and social identity' (Giddens, 1984: 375). Giddens further maintains that in common with all other aspects of social life, the maintenance of 'ontological security' is an ongoing accomplishment of lay actors (1976:117). Elsewhere, it is argued that it is within 'the private realm' that the maintenance and recovery of ontological security takes place

(Dupuis & Thorns, 1998). The significance of the private realm with regard to ontological security and this research is that it is a space where the 'secure self' can be attained.

In his work on ANT, specifically in relation to dementia and memory, Schillmeier (2008) argues that a component of dementia is the failure of memory in its role as 'intermediary'. The lack of or confused memory produces 'odd mediators', which make the world 'thinner'. This is where the relevance of music arises once more, because it has the potential to 're-thicken' that which has been 'thinned', through the dynamic process of a person with dementia entering into a network with music. To pursue Schillmeier's reasoning still further, it is possible to see how this is so. The evocation of memory, he suggests, is not so much the production of a 'mental copy of the past', but a dynamic involving the enactment of 'spatio-temporalities of minds, bodies and things constantly re-relat(ing) to each other' (Schillmeier, 2008: 144).

However, I am not necessarily suggesting that music works as an explicit declarative memory prompt through its thickening potential (although at times this may be the case); nevertheless, neither do I believe that, as Born (2005) reminds us, music by virtue of its 'emotive, symbolic, corporeal and material properties' constitutes a mediating resource which can support ontological security. The words 'dynamic' and 'enactment' are significant here, because when the person with dementia enters into a network with music and engages the relating and re-relating conglomerate of spatio-temporalities mentioned above, a degree of ownership of the event occurs. Such ownership can only ever be autonomously acted upon as per the 'ongoing accomplishment of lay actors' mentioned above. Therefore, the elements of the music-actor-network work in conjunction with each other to re-thicken an environment, consequently rendering the world more familiar and coherent, or, as DeNora (2000: 28) puts it, 'musical and textual meaning are interrelated, co-productive; the specific properties of each may be used – by a sense-making observer – to clarify the other'. Ultimately, music can be viewed as part of a 'pragmatics of remembering'; a mediation which, significantly, applies to people without memory impairment who may inhabit thicker, more consistently coherent worlds.

2.22 Music in Everyday Life

The Baker (2012) and Hanser (2011) studies are the only examples of research located for this research which allow for the natural incorporation of music into the everyday life of a person with dementia and their spousal carer, within a home-based setting. Everyday applications of music have been outlined elsewhere; for example, in the 'Music in Daily Life Project' (Crafts et al., 1993), which contains a series of interviews with people, ranging from children to retirees, describing the role of music in their lives. Greater in-depth analysis of daily musicking can be found in DeNora (2000), in which she describes the contexts where people 'use' recorded music and how they regularly flexibly and reflexively appropriate it 'as a means for creating, enhancing, sustaining and changing subjective, cognitive, bodily and self-conceptual states' (DeNora, 2003: 171). This appropriation of familiar music serves as a 'technology of the self'; a device through which one has the means to care for or 'treat' the self.

In his examination of personal stereo use, Bull (2000) also discovered that music was used as a medium for mood maintenance and illustrated the intensely individualised and private nature of the medium. Bull described users who associated their mobile musicking with a sense of 'home' accompanying them throughout the day as experiencing security and well-being. Resonances can be found here with the previously described success of familiar and preferential music for people with dementia and its assistance in the modification of external stressors, via reassuring aestheticisation. Bull argues that the personal stereo transforms time through enhanced experiences and moreover allows individuals to have 'power of control over their experience of time and space (...) by managing their mood and orientation to space through the micro-management of personalised music' (Bull, 2005: 343).

The following quote from one of Bull's respondents highlights this issue of control:

'Well, I think I've come to the conclusion that overall I feel pretty out of control in my life. Stores play music to get me to buy more. Work tells me what to do and when. Traffic decides how quickly I get from here to there. (...) I didn't realize how much I yearn for control and probably peace and quiet. Strange since I'm blasting music in my ears. I think I'm really tired of living on someone else's schedule. The MP3 digital music revolution has given me some control back.' (Tracy 1) (Bull, 2005: 346)

Failing memory and perhaps increasing involvement from health and care agencies may cause people with dementia to experience a lack of autonomy – ‘I prefer to manage than to be managed’ (person with dementia) (Williamson, 2008: 36). The societal constraints so clearly described by Tracy can be viewed as correlative; although not necessarily in terms of urban MP3 player use, her quote indicates where music may ‘fit’ and how it may enhance the daily experience of someone with dementia: ‘through the power of sound the world becomes intimate, known, and possessed’ (Bull, 2005: 350). Users of the iPod describe it as instrumental in maintaining control over their state of mind: ‘a cognitive Sherpa, accompanying them and directing them through the cognitive and physical spaces of their day’ (Bull, 2005: 132). The device is therefore used as a mediator against the fear of ‘their own streams of consciousness and the cognitive states associated with it’ (Bull, 2005: 125).

Elsewhere, the uses of music in everyday life have been explored by North et al. (2004), who tracked the daily music listening practices and experiences of 346 people for two weeks. In line with corresponding research into music in everyday life, the above authors discovered that music was ‘consciously and actively’ used as a ‘resource in everyday life’ (North et al., 2004: 74), but argued that ease of access and pervasive exposure to music has led to it being regarded with a degree of passivity:

‘Music was rarely the focus of participants’ concerns and was instead something that seemed to be taken rather for granted, a product that was to be consumed during the achievement of other goals. (...) Our relationship to music in everyday life may well be complex and sophisticated, but it is not necessarily characterized by deep emotional investment.’ (North et al. 2004: 75)

Further developing this idea of the lay appropriation of music for specific and regulatory ends can be found in the body of work on music as a health technology. Revisiting the mobile music medium, Skånland (2011) concentrates on the MP3 player as a ‘positive life resource for the listener as *user*’ and specifically as a means of coping with stressors in an urban environment. As has been demonstrated in earlier examples, individuals employ music in highly deliberate ways, whether to block out noise and fellow city dwellers, or to create personal solitude. Focusing on the daily commuting experience, Skånland illuminates that her participants viewed mobile musicking as facilitating a transformation of the ordinarily stressful experience

into one that was more tolerable and, therefore, occasionally more enjoyable. Thus, music becomes a successful technology for stress management.

In the case of the elderly population, Hays and Minchiello (2005) revealed the meaning and function of music in older peoples' lives and just like in the younger generations, found it was used as a tool for the construction of self-identity, in addition to 'giving meaning to experiences and emotions'. The respective respondents described having more time to engage with music post-retirement and stated that it contributed to a redefinition of their identity during that period. Within this work, the purely aesthetic qualities of music were highlighted as being particularly significant for those with less mobility, whose access to other forms of beauty, such as nature, had become limited. Inter-personal relationships also appeared to be assisted by music through the 'development, maintenance and communication within relationships', where music acted as 'social glue'. One respondent detailed how she would self-administer music for therapeutic outcomes:

'I'm a pretty healthy lady, but if I'm sick or I've busted my toe, or done something where there's like a sense of deep pain or a chronic pain, my reaction usually is to use music. (...) But to use a favourite sort of chord or to use some majestic sort of combination of musical notes that inspires me, and that does induce well feeling. So of course in effect, it's self-applied music therapy.' (Elizabeth) (Hays & Minchiello, 2005)

This idea of 'self-applied music therapy' is a concept which has been explored by Batt-Rawden et al. (2005), who effectively encouraged individuals with chronic illness to focus on and incorporate their own 'lay-expertise' as musickers, for specific health outcomes. A participatory and collaborative musical procedure was constructed through participants' compilations of personal playlists onto a CD. In directing attention towards the kinds of music they chose and the manner in which they employed them in their everyday lives, the participants were encouraged to utilise a greater degree of reflexivity in the appropriation of music for well-being and health purposes. Thus, a discovery of music's role as a 'cultural immunogen' (Ruud, 2002) and as 'a technology of the self' (DeNora, 1999) was made. Examples of the participants' uses of music included 'as a substitute for sleeping tablets, as a motivational device to "move" out of low moods or depressions, as a model exemplar of where they hoped to be, as a reminder of how they "could" be or were when "at my best"' (Goodall & Ethers, 2005: 281).

Referencing Putnam's work on social capital, Batt-Rawden (2010: 302) details 'technology of self' musicking as constituting a 'bridge'; not between social groups, but 'back to 'normal' cultural participation and to the ways in which an ill person's identity exceeds his or her illness.

It is my view that for those experiencing an attack on their cognition at societal or personal levels and whether through organic neurological degeneration or an impoverished environment, much can be learned from music in the literature on everyday life. The uses of music in everyday life to promote health and well-being through lay practices is a growing body of work which seeks to reject the 'hierarchical model of therapist-client' (Batt-Rawden, 2010). Moreover, when considered in relation to the daily experience of living with dementia, this research canon is a particularly valuable source of information for future community dementia care practices.

The literature reviewed above highlights the fact there is a great deal of room for development and progression within the music and dementia research arena. I am of the opinion that the literature pertaining to this field has not hitherto been sufficiently receptive to developments in other areas of non-medical dementia research and as a result, has fallen somewhat behind the general dementia field. It therefore generally remains too closely allied to the medical paradigm that upholds strong associations with experimental procedures.

By outlining some of the key gaps that my own research seeks to fill, I will start by building on movements in dementia research which promote personhood to a greater degree. This will be achieved by incorporating ethnographic methodologies that avoid 'before-and-after' motifs, since they will be longitudinally situated within domestic environments. The aim is to combine privileging people in context with music in context. In doing so, I will keep an open mind about any potential hierarchies between live, active music-making and listening to background music.

Much has been written about the musical capacities preserved amongst people with dementia, but the cohort I engaged with in this study, situated at the early to mid-

range of the dementia spectrum, will have many capacities from which they can draw. A further research gap I aim to address is therefore the place of music within the broader context of peoples' everyday lives. To more comprehensively address and understand well-being in the lives of people with dementia, music needs to be understood and situated within a rich context of other practices. Lodging music in its naturally and ecologically valid place, within the fabric of the lives of individuals with dementia and their loved ones/carers will allow it to be positioned in relation to a host of equally important cultural practices.

Bull and others, as outlined above, have investigated the lay appropriation of music in everyday life. However, there is similar potential in appropriations of music by, with and for people with dementia, which has not been significantly addressed. For instance, what expertise do people with dementia have and how do they use it to maintain their own well-being, via music or other means? A final lacuna located in music and dementia research, which I seek to rectify here, is the issue of affording greater autonomy and agency to the individual with dementia, rather than perceiving them as passive recipients of care, treatment and therapy. They are, after all, experts in dementia and well-being themselves and I call for a challenge to existing notions of knowledge and expertise, insisting that greater weight needs to be accorded to the discourse and actions of people living with dementia.

CHAPTER THREE: ENGAGING A PERSON WITH DEMENTIA IN RESEARCH – METHODOLOGICAL IMPLICATIONS

3.0 The Current Status

The dominant narrative of dementia, both within academic and popular writing, presents a generally 'monolithic and overall negative' representation (MacRae, 2008), which generally bypasses the subjective experience of people with dementia and focuses predominantly on symptomatic representations and caregiver burden. Although the popular narrative surrounding people with dementia remains extremely negative and exclusionary, in the last decade or so, academic research has begun to address the lived experience of the person with dementia and has exposed more subjective perspectives of it (Phinney, 2002; Phinney & Chesla, 2003; Steeman et al., 2006; Hellström et al., 2007; MacRae, 2008; MacRae, 2010). For example, focussing on technologies outside the home which support people with dementia in their everyday lives, Brittain et al. (2010) demonstrated that peoples' experiences varied. For some, 'outside' was considered therapeutic, but for others, it induced anxiety; either influenced by the fears of others, or their own. The participants explained how everyday technologies, such as in shops, on signs and at bus stops could be useful when navigating outside spaces. However, the subjective experience of modern technologies, such as mobile phones, differed in that for some, they added an element of security, while others felt such devices removed their freedom. In their exploration of the lived experience of early stage dementia, Steeman et al. (2007) found narratives were frequently positive, yet also discovered that individuals struggled to 'remain someone of value' (Steeman et al., 2007: 119). The authors concluded that superficial positivity may be viewed as an attempt to 'counterbalance devaluation' (Steeman et al., 2007: 119).

The subjective experience of those with dementia living in residential care has been explored, indicating that negative expressions include being frustrated, having distressing thoughts and feelings; fear; irritation; experiencing a lack of control, and boredom (Train et al., 2005). Positive expressions incorporated quality social interaction; valuing contacts and friendship; episodes of togetherness; listening to music, and reminiscing. (Clare et al., 2008; Milne & Hibberd, 2011; Train et al., 2005;

Graneheim & Jansson, 2006; Harmer & Orrell, 2008). Further investigations into subjective experience can be found in Lawrence et al. (2011) and Regan (2014), who explored living with dementia from the perspective of ethnic minorities.

In terms of developing my own methodology for this research, with its focus on meaning-making within local ecologies, this literature provides a valuable resource, because it gives due consideration to the voices and capacities of people with dementia. As such, it redresses an imbalance, reducing the negativity and exclusion of earlier perspectives. In the following section, I will discuss what is currently known about the subjective dementia experience, along with relevant issues, set within the context of my own research.

Some examples of the subjective experience can be found in Phinney's (2002: 52) interviews with people with dementia, in which she identifies five thematic strands associated with the subjective experience, namely: 'I can't remember'; 'I worry about getting lost'; 'everything is more difficult'; 'conversations don't always fall into place', and 'I'm sort of oblivious'. A review of qualitative studies focusing on 'the transitional process experienced by those with early stage dementia' (Steeman et al., 2006) describes the experience as being 'highly individualised' and yet concludes that there are a number of common features, some of which correlate with those revealed by Phinney (2002), e.g. 'uncertainty, the importance of autonomy, meaningfulness, and security; and the struggle between self-protection and self-adjustment' (Steeman et al., 2006: 735).

Until recently, a misconception on the part of researchers has led to the assumption that people with dementia have insufficient capacity to comprehend what they are being asked in interviews, which has resulted in the use of proxy reporting in order to assist understanding. However, such assumptions and practices have latterly been subject to critique. For example, in a study by Aquilina and Hughes (2006), a person with dementia presented to her doctor (Aquilina) with mild symptoms. Over time, she proceeded to deteriorate, to the extent that she was experiencing severe hallucinations and was incapable of intelligible speech. It was at this point that the patient was prescribed anti-dementia medication. One month after starting the medication, improvements were observed and the prescribing doctor noted that 'it

was not just remarkable that she was able to speak clearly and lucidly, *but that she was able to describe to him what had been discussed with her husband at the previous appointment when she had been mute and unable to interact* (Aquilina & Hughes, 2006, emphasis in the original). A case such as this highlights the substantial complexity of understanding what living with dementia is like, as experienced from the inside. Furthermore, it demonstrates the fallibility of relying, as is commonly the case, on proxy reporting, to the exclusion of subjective reporting.

Proxy reports have indeed been shown to differ from patient reports, certainly with regard to aspects of health-related quality of life, where discrepancies have been demonstrated (Ready et al., 2004; Smith et al., 2005). Smith et al. (2005) discovered that, when questioned, carers 'could not avoid talking about their own reactions', noting that 'this raises two important issues: that people with dementia can discuss their quality of life along health-related domains; and that their views are not necessarily accurately represented by their family members' (Smith et al., 2005: 126). Similar comparisons between patient and proxy reports on health-related quality of life revealed 'poor to moderate agreement' (Novella et al., 2001), in addition to a greater disparity between proxies and patients on more subjective issues than on more overtly observable ones, such as physical health. In this instance, the authors found a correlation between increased severity of the dementia and an increase in proxy contradiction. They propose a number of explanations: firstly, the propensity for observers to inflate the significance of negative aspects over positive ones; secondly, the impact of the caring burden experienced by family proxies.

It is additionally suggested that possible changes in the person with dementia's self-awareness may account for proxy/patient discrepancy. Of course, it cannot be denied that there are issues with self-reporting; there being the potential for people with dementia trying to 'save face' in their reporting (Ellis, 2009). Nevertheless, Ready et al. (2004) suggest it might be useful to acquire both informant and patient perspectives, since, 'to date, neither source has been established to be superior'. Indeed, it is important to recognise that all accounts may claim equal validity, although all may contain performative elements.

One could argue that contradictions between the person with dementia and their proxy, rather than being a hindrance to understanding, in fact contribute to a richer, more nuanced and more multi-dimensional comprehension of both the subjective and objective dementia experience. However, models for gaining a more accurate understanding of the perspective of a person with dementia ultimately require a greater degree of sophistication.

3.1 Personhood within the Context of Dementia Research

The work of Kitwood has been alluded to many times thus far in this thesis; his theory of malignant social psychology having been hugely impactful on dementia care since the late 1990s. To reiterate: central to his argument about what constitutes good care is the importance of social context and privileging personhood. The concept of personhood can be further clarified by considering it in terms of three distinct levels: the biologic, individual and sociologic (Burton, 2008). Specifically, the biologic is defined as pertaining to all aspects of sentience; the individual is that which comprises personality traits, personal history and values. The sociologic, on the other hand, is that which is bestowed by social relationships. The integrating of each of these disparate parts into the whole of 'personhood' serves to provide a more holistic understanding of each individual in the research process. Fundamentally, personhood underscores the need to avoid 'othering' people with dementia – that is, by refusing to engage with particularly distorted or inaccurate identity representations. The promotion of personhood in research is suggestive of being attentive to what people with dementia 'know' (in personal, procedural, propositional or embodied terms), but may not always be able to demonstrate or communicate.

The concept of personhood in dementia care or research, however, is not entirely benign and the notion of 'bestowing', as in Kitwood's (1997: 8) definition of personhood (i.e. 'a standing or status that is bestowed upon one human being by others') has been challenged as inappropriate (McCurdy, 1998). The equality of the inter-personal relationship becomes destabilised when an authority, such as in Kitwood's definition, is accorded to 'human beings who are envisioned as self-legislating moral agents' (, 2008: 5). Additionally, Bartlett and O'Connor (2007) argue that the apolitical nature of personhood constrains its potency; reasoning that, at

least for those in the earlier stages of dementia, 'citizenship' is better suited to promoting equality. Bartlett and O'Connor posit that for the current cohort, drawing from citizenship, an already established concept within advocacy movements allied to other groups which are marginalised and discriminated against will serve to empower the individual to 'exercise rights and responsibilities'.

However, for those in the later stages of dementia, the exercising of rights and responsibilities becomes more challenging and Post (1995) rejects the idea that autonomy forms the basis of personhood, regarding it as representative of our 'hypercognitive society'. Post in fact calls for a broader conception of personhood, where cognition is not the dominant defining strand. An example of a less overtly cognitive aspect of personhood is to be found in the strength of relationships between people. Inter-relationships are therefore posited as significant contributors to what positively mediates dementia, thus maintaining personhood (Kitwood & Bredin, 1992; Sixsmith et al., 1993). Illustrative of the importance of relationships in positively mediating dementia is the marked deterioration that can occur when elderly people are placed in hospital or residential care. A report by the Alzheimer's Society (2009) showed that 54% of carer respondents reported how admittance to hospital had a significant negative effect on the symptoms of dementia, such as leading to more confusion and less independence. The impoverishment of meaningful relationships when in the custody of a hospital, for example, is clearly highlighted here as being influential on the symptoms of dementia.

On this theme, Kitwood (1997: 37-38) argues that by staying 'close to mundane reality', it becomes clear just how central to the maintenance of good care or personhood 'social or societal, factors' are, including 'locality (...) and the availability or absence of support and services'. Moreover, he also views these components as 'part of the whole process – actually incorporated into the dementing condition for good or ill' (Kitwood, 1997: 38). The idea that the progression of dementia can be mediated by external forces has been conceived of as a 'rementia', or a situation in which there may be a return to lost cognitive and functional abilities in relation to positive approaches to dementia care (Sixsmith et al., 1993). Parallels with the concepts discussed earlier are clear: 'recovery' in mental health and the focus on

'hope - acceptance, agency, peer support, valued social roles and connectedness' (Daley et al., 2013: 522).

The promotion of personhood and consideration of social context can therefore be seen as valid endeavours in the light of the influence they can have on the symptoms of dementia. It is thus remarkable that such little attention is afforded to context and personhood in music and dementia research. For example, investigations into group music-making/therapy demonstrate the absence of these factors. To illustrate, Van de Winckel et al. (2004), Sung et al. (2006), Choi et al. (2009), Sung et al. (2012) and Chu et al. (2014) have all focussed on group music-making and/or therapy. However, in each case, the individuals in the groups are perceived as isolated individuals, who just happen to be simultaneously having the same musical experience. The significance of any inter-personal relationships within the groups, which may then have potentially been enhanced by musicking together, is not considered. Moreover, any impact these relationships and the specificity of joint musicking may have had on the reduction of the negative symptoms investigated in the above studies was also overlooked.

Complementary to the necessary elements for supporting personhood outlined above, Kitwood, citing Post (1995), additionally stresses the importance of 'moral solidarity' in respect of people with dementia, or:

'a recognition of the essential unity of all human beings, despite whatever differences there may be in their mental capacities as conventionally determined. Thus we are all, so to speak, in the same boat; and there can be no empirically determined point at which it is justifiable to throw some people into the sea.' (Kitwood, 1997: 10)

From a research perspective, what is demonstrated by the above discussion is that engaging with people in research into dementia requires a commitment to three related 'spatial' concepts: moral solidarity, 'right being' and moral space. Personally, I understand moral solidarity to involve an action to sustain 'alignment or unity or fellowship' (Harvey, 2007:22), in an endeavour to minimise the gap between researcher and participant. Closely allied to this is Dewing's (2002: 160) concept of 'right being'; defined as 'being with another', as opposed to 'doing to or doing for'. In terms of the current context, I interpreted this to mean achieving a closeness or

minimising the gap, by being attentive to individual capacities, identities and subjectivities. Another of Dewing's concepts, moral space (discussed on p. 69 of the Literature Review) is also relevant here. 'Moral space' refers to the metaphorical unequal interpersonal distance between researcher and researched and the necessity to work towards reducing this distance through an exchange of free-flowing attention (Kitwood, 1990b). Additionally and where applicable, these three terms point to being mindful of the relationships between people within the context of any research investigation.

A commitment to these concepts is not necessarily something which may be achieved within a short timeframe. Moreover, such a commitment not only works to eliminate, as much as possible, the power divide, but also to optimise the starting point from which the research may begin. By this I mean that the people with dementia under investigation must be given a fairer opportunity to represent themselves, in ways they would want and are capable of, given the right support. It is open to question, therefore, why research which is non-medically driven, particularly where it pertains to music and dementia, is not more attentive to these issues. What is the purpose of such research, and who is it really for? Is it really being designed to find ways of improving the lives of people with dementia in valid ways, or is it, as the medicalisation lobby would argue, simplistically looking for a quick fix, where none exists, nor ever will?

3.2 Methodological Approaches

What is evidenced by the above is the need to avoid jumping to conclusions about people with dementia in ways that skip over the highly variable and subtle features which constitute the condition. It is imperative not to 'other' this population, nor presume that they are fully and monolithically incapacitated. Instead, full and holistic attention needs to be paid to the person, which means incorporating a methodology concerned with nuance and detail, achieved through careful observation. To this end, I was influenced by Ansdell and Pavlicevic (2010), who in turn, following the German poet, Goethe (1749-1832) and within the music therapy sphere (although not pertaining specifically to dementia), promote what they call 'gentle empiricism'. They highlight the advantage of employing a qualitative and non-invasive approach in

music therapy research, by rejecting research practices which too readily seek to abstract, catalogue and compare phenomena. Instead, they exhort researchers to remain with and move 'slowly through the phenomena for as long as possible' (Ansdell & Pavlicevic, 2010).

Remaining 'close' to the individuals is reflected, in part, by the longitudinal nature of my work and the extended periods of observation, but it is further complemented by the audio-recordings. This application of slow sociology meant that over time, the respective individuals knowingly or unknowingly revealed more and more about themselves, both in word and deed, illuminating what was important to them. From my perspective, this led to a more thorough understanding of both the individuals and processes at work.

Moreover, in a bid to produce research which is more holistic in nature, as recommended by Ansdell and Pavlicevic (2010), I believe it is important to view and comprehend the cohort under scrutiny in relation to others. If, as has already been described and outlined on p. 26, others play such a pivotal role in supporting personhood and self amongst people with dementia, then it makes sense to include this possibility within the research agenda. Furthermore, the fluid nature of relationships would also point to the validity of proceeding in a gently empiricist manner. Ultimately, the value of this kind of slow sociology is that it supports insights of enhanced nuance with regard to what constitutes quality of life.

3.3 Grounded Theory and Ethnography

Ansdell and Pavlicevic's recommendation of 'idiographic' explanation as 'attending to the individuality of each case and of each manifestation of a phenomenon' points to a mode of analysis that remains close to the details of the research field and respective participants. For this purpose, modified Grounded Theory is highly appropriate.

Grounded Theory was originally developed by Glaser and Strauss (1967) to 'codify explicit procedures for qualitative data analysis and, simultaneously, to construct useful middle-range theories from the data' (Charmaz & Mitchell, 2001). As a method used adjacent to ethnographic research, Grounded Theory can help in both the

clarification and interpretation of the data (Charmaz & Mitchell, 2001). Among other things, Grounded Theory is defined by its receptiveness to 'the existence of multiple realities' and 'the mutual creation of knowledge by researchers and research participants' (Charmaz & Mitchell, 2001). It 'aims to provide interpretive understanding of the studied world' (Charmaz & Mitchell, 2001). As a research method, Grounded Theory offers 'a set of flexible analytic guidelines that enable researchers to focus on their data collection and to build inductive middle-range theories through successive levels of data analysis and conceptual development' (Charmaz, 2005). The simultaneous data collection and specific stages of analysis (initial coding, focused coding, memo writing, memo sorting, memo integration and theoretical sampling) mean that a theoretical understanding emerges as the data is processed and interacts with the data collection in ways which, if not fully 'bottom-up' are certainly not 'top-down' (Charmaz, 2005).

In this research project, I draw upon some aspects of modified Grounded Theory. Specifically, I collected and analysed data concurrently through coding and memo writing, in ways which led to my findings and conceptual categories. I was also greatly influenced by the writings of the distinguished sociologist, Paul Atkinson, who has argued that over the years, Glaser and Strauss' work has come to be misinterpreted in ways that have resulted in the now 'endless, repetitive emphasis on *coding* data' (Atkinson, 2013, emphasis in the original). Atkinson suggests that although coding is a useful way of organising data, it does not directly relate to the 'real work of creative analysis'. By this, he means that excessively rigid conformity to procedure may lead away from the original intentions of Grounded Theory, which were, as he puts it, associated with 'a general description of how any form of social inquiry can be conducted in the interests of generating new ideas, elaborating on existing ideas, and doing so through an attentive reading of data'. Ultimately, Atkinson's argument is that approaching Grounded Theory in too formulaic a way will stifle inspiration. Inspiration, he suggests, is more likely to arise from 'multiple interactions with the field rather than with decontextualized data'. In short, Atkinson warns against losing sight of the unique features of fieldwork through an overly technical approach to analysis. He is thus advocating a form of modified Grounded Theory, which he describes in terms of indexing; highlighting recurring themes and events as a way of making sense of rich data (2015: 59).

The ethnographic and Grounded Theory principles which guided my research were those elements with:

‘a strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them; a tendency to work primarily with ‘unstructured’ data (...); investigation of a small number of cases; analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most’ (Atkinson & Hammersley, 1994 : 248).

In other words, to explore music as a social phenomenon in conjunction with living with dementia, I collected data which were undirected and without specific boundaries. Nevertheless, I approached the analysis in a structured way; indexing data, looking for key themes, observations, processes and forms of meaning-making.

Generally small in scale and situated within everyday settings, ethnography ‘emphasises the importance of context in understanding events and meanings’ (Savage, 2000). Given that the aim of this research is to try and understand individuals’ meaning-making practices for everyday life, whether musical or otherwise, ethnography in tandem with modified Grounded Theory is an ideal vehicle for achieving this. My research framework stands in complete contrast to the models of music and dementia research I critiqued in the Literature Review; models which are not designed to necessarily attend to context, relationships, nuance of process, or fluidity of experience. Moreover, given that there is at present no cure or effective treatment throughout the disease trajectory, it is logical to incorporate a research framework which is broader and more holistic in focus.

Proceeding with the research in a ‘gentle’ manner means that a more nuanced understanding of what it is to live with dementia on a day-to-day basis was achieved. Moreover, the slow empiricism employed meant that a gradual unfolding of extremely subtle processes and lay expertise became apparent; for example, the way in which one particular participant sought out and harnessed a specific musician for the maintenance of her own well-being. This would not have been the case if I had incorporated alternative and ‘faster’ methodologies of data collection. Additionally, I believe that the instinct and subtlety underscoring both process and expertise was

such that even if the participants had been able to convey something of this through speech, a large amount of detail would have been missed and understanding consequently impoverished.

In order to gain an increased understanding of quality of life, the dementia research literature recommends a multi-method approach (Hara, 2011; Frogatt, 1988; Nygård, 2006); specifically the use of interviewing and participant observation. The justification for the use of semi-structured interviews, in particular, is that the interview empowers the interviewee to 'drive' the exchanges (Hara, 2011). Moreover, it is perhaps the most direct route to establishing the perspectives of people in the early stages of dementia. Killick (2001), however, adds a cautionary note by arguing that 'direct questioning can lead to anxiety and increased confusion' (McKeown et al., 2010: 1941). Furthermore, 'what people say may differ from what they do' (Charmaz & Mitchell, 2001: 163); hence the necessity for supplemental or complementary methodological processes, in which case, participant observation allows the observer to scrutinise interaction and behaviour in context and over a longer period of time. In the present research, project participant observation serves to facilitate such scrutiny in a number of different settings, thus helping to contextualise and enrich the data sources.

3.4 What are the Obstacles to Engagement in Research?

Having established the necessity for engaging with people with dementia in research and having set up the methodological framework, I will now approach the practicalities of participant recruitment and participation, outlining a number of obstacles. The first role to be negotiated is that of the gatekeeper. The gatekeeper component encompasses a number of tiers requiring mediation (Hellström et al., 2007). In my own research, these have included the University Ethics Committee; the Alzheimer's Society (Head of Quality and Service Evaluation, Regional Co-ordinator, Locality Manager, Evaluation Programmes Manager, local co-ordinator and local facilitator); Age UK (local services manager, local services co-ordinator, local day care [LDC] host and carer); the Criminal Records Bureau, and spousal/family caregivers. McKeown et al. (2010) acknowledge the absolute subjectivity of gatekeeper decision-making, noting that a successful research proposal is entirely

dependent on how the research and its participants are perceived by the gatekeepers.

Managing the autonomy of people with dementia, while simultaneously promoting their well-being, is challenging. In recognising that there is, of course, a real need to protect vulnerable populations from exploitation, a balance needs to be struck in which issues of protection are not privileged to the exclusion of facilitating full participation in research, detrimentally affecting access to personhood and rights. The subjectivity of authority means that 'overprotective' gatekeepers can potentially fail to fully support people with dementia in making their own decisions about participation in research (McKeown et al., 2010). Indeed, Beadle-Brown et al. (2012: 20) agree, arguing that gatekeepers 'may work from a medical model of disability which creates a culture of dependency and hinders research participation'.

3.5 Consent and Decision-making

The primary issue of concern raised by most gatekeeping organisations encountered in the course of this research was that of capacity to consent and the importance of determining individual capacity or competency in order to ensure that potential participants were able to consent to participation in the research from an informed position; therefore assessing any potential associated risks or challenges. However, a legitimate concern within the relevant literature regards the degree of divergence surrounding definitions of capacity and competency. O'Connor et al. (2009: 11) note that capacity 'denotes a clinical status that is determined by a healthcare professional, while competence refers to a legal status as judged by a legal professional'. These may be the established definitions, but they are also used more broadly. For instance, Royall (2002: 1885) argues that capacity can be allied to intrinsic functional ability, in contrast to competency. This is a state which is 'conveyed' upon an individual. Capacity, therefore, correlates to formal areas of life, 'such as driving, financial management, ability to live independently, testamentary capacity and ability to give informed consent or legal directives' (O'Connor et al., 2009: 11).

The Mental Capacity Act, 2005 (MCA) does not explicitly define capacity. However, in line with the general move (outlined previously) to try and facilitate autonomy for people with cognitive challenges, the Act considers the subjective experience and respects differences between individuals, in addition to any intra-categorical differences. The MCA gives clear guidance as to how best assist an individual in the decision-making process, so that their best interest is respected. The Act is underpinned by the following five key points:

1. Every adult has the right to make his or her own decisions and must be assumed to have the capacity to make them, unless it is proved otherwise.
2. A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
3. Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
4. Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.
5. Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The Act continues as follows:

‘a person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means). The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision’.

The Act considers that:

‘a person is unable to make a decision for himself if he is unable a) to understand the information relevant to the decision; b) to retain that information; c) to use or weigh that information as part of the process of making the decision; or d) to communicate his decision (whether by talking, using sign language or any other means).’

Capacity and its relation to consent is indeed a complex issue; however, voices are challenging the traditional deficit assumption and are pressing for the recognition of both personal autonomy and cognition in the giving of consent (Smith, 2009; O'Connor et al., 2009).

3.6 Consent

Capacity having been established, the next task for the dementia researcher is to support individuals in deciding whether they would or would not like to participate in the research and assist them in reaching a decision from an optimally informed position. The dementia research literature widely endorses the view that consent should be viewed as an 'on-going' process, not a one-off event, focused purely on verbal language as well as non-verbal and behavioural cues (Bartlett & Martin, 2002; Hellström et al., 2007; McKeown et al., 2010). On the issue of informed consent in social research, Atkinson (2009: 21) argues that:

'the nature of the research is so profoundly an emergent property of the processes of data collection and research design, that are themselves emergent, unfolding processes, that it becomes all but impossible to solicit consent to the research that is 'informed' in the sense of being predictable and explicable before the research itself is carried out at all. If the outcomes of an ethnography were entirely predictable, then there would be virtually no point in conducting the research at all.'

Indeed, the inherent unpredictability of action research on people with dementia necessarily involves considerable fluidity and flexibility on the part of the researcher. Moreover, there is the potential for unforeseeable further losses in capacity during the research, due to chest or other infections (Davies et al., 2010). On such occasions, the recommendation is to suspend the investigation until capacity is regained (Davies et al., 2010).

Despite Atkinson's suggestion that maximally informed consent from individuals, with or without capacity complications, is never fully achievable, there is, however, a moral necessity to make it as clear as possible what becoming a research participant will entail for each individual, as far as this is understood by the researcher at the time of making the request. In addition to clearly informing potential participants of what the research involves, it is also a fundamental prerequisite to stress the entirely

voluntary nature of participation and, moreover, to ensure that all the participants are aware of their liberty to withdraw engagement at any time 'without prejudice' (Hellström et al., 2007).

3.7 Terminology

An added complexity is how best to explain the research to potential participants. One issue relates to terminology; in particular how to refer to dementia itself. Some researchers, e.g. Bartlett and Martin (2002), highlight concerns over omitting terms relating to a diagnosis, such as dementia or AD, choosing instead to 'hide' behind terms such as 'memory problems', which have the potential to deceive. They question whether an individual might feel misled if they are unaware that the focus of the study is dementia. By contrast, others do not view the avoidance of the term 'dementia' as problematic. For example, during their interviews with couples affected by dementia, Hellström et al. (2007) did not use the word 'dementia' unless it was first introduced by the couple, preferring to employ the term 'memory problem' in place of other, more loaded terminology. This was the strategy I used in my own research. In all the information documents I produced to communicate with potential participants concerning my study, the term 'memory loss' was exclusively used. To acknowledge Bartlett and Martin's concern about deception, it must be stated that the consequent avoidance of the terms, 'Alzheimer's' or 'dementia' tapped into the local ecological terminology, mirroring the phrases and terms the people I engaged with used themselves. At no point did any of the individuals mention having dementia. As an ethnographer and gentle empiricist, my intention was to tread lightly and avoid introducing non-indigenous language - in this case, into the clinic. Furthermore, I considered that families have the best understanding of their affected family member and it is not the place of a researcher to disturb local ecologies. The term 'memory problems' is essentially an accurate description and since dementia and AD currently have such extremely negative connotations, I considered it to be the most appropriate terminology.

It was therefore decided to avoid using the word 'dementia' during the recruitment process, the interviews with the carer and the interviews with the person suffering from dementia, unless it was introduced independently. As mentioned above, the

reason for this was on account of its stigma and associated negative connotations. Furthermore, for some individuals, their diagnosis had not been clarified, but remained 'suspected', in which case the terminology may not have been strictly accurate for them. Moreover, for the purpose of the interview, any symptoms of 'dementia' were subordinate to my interest in meaning-making and the potential role of music in this. Had the person with dementia demonstrated a desire to discuss their memory, such a debate would not have been stifled; however, none of the interviewees actually introduced the subject, reinforcing the theory that individuals experiencing memory loss do not necessarily define themselves by their incapacities, but by their competencies, as is the case with the rest of the population.

There is also an argument that it is disrespectful to employ and ascribe terminology to individuals which they themselves do not employ or recognise. In some cases, the caregiving spouse explicitly requested that I avoided the terms, 'dementia' or 'Alzheimer's'. For example, one caregiving wife explained that she did not use either of these words with her husband, due to his usual comments when faced with items about dementia on television, namely that it was a dreadful condition, which he hoped he would never encounter. His wife felt that the use of either word would cause him great distress. In all the other interviews, none of the participants with dementia used the terms and only occasionally alluded to memory problems.

For clarification, in two interviews, neither respondent introduced the words 'memory' or 'dementia.' Similarly, with another respondent, the topic of memory was referred to just once: *'I don't do anything now, because I can't remember.'* With regard to the frequency of employment of either term by the carers, two daughters employed 'memory' twice, although omitted reference to dementia at any time and one wife spoke about dementia six times and memory, twice.

3.8 Establishing Person-centred Approaches

'If we come close to the details of how life is lived, hour by hour and minute by minute, we can see many processes that work towards the undermining of people who have dementia.' (Kitwood, 1997: 45)

Here, Kitwood is referring to what he calls, 'malignant social psychology', yet similarly, by paying close attention to the details of how life is lived, minute by minute,

hour by hour, it is also possible to see the processes working towards empowering people with dementia. Indeed, having critiqued at some length in the Literature Review the tendency toward a snap-shot approach to engagement with people with dementia in music and dementia research, I was eager to reject this trend and remain in close proximity to individuals over *extended* periods of time, meaning weeks or days, rather than hours at a time. This contributed to the augmentation of the ecological validity of the research, by more accurately representing the manner in which individuals exist within a natural, if fluid, environment.

To represent the participants/interviewees in as complete a way as possible, I have also included biographical sketches for each of them. The details of the individual biographies were drawn from the interviews, both with the person with dementia and their family carer. Within the realm of biographical narratives, it is understood that the tales people tell of their (and other peoples') lives are subjective; they are constructed entities situated within the specific context of where they are narrated and the specific audiences to whom they are narrated. Furthermore, incorporating biographical detail augments understanding of music in the context and the trajectory of individuals' lives. To a degree, the inclusion of biographical detail works to equalise the power imbalance between the researcher and the researched, although of course, the manner in which the detail is incorporated is subject to editing and the subjectivity of the researcher. Nevertheless, presenting individuals (and their families) just as they present themselves will contribute to reducing the moral space and help 'ensure that participants remain a subject rather than object of the study' (Wicks & Whiteford, 2006: 11).

In addition to the biographies included, I reproduced often relatively extended passages from the interview or participant observation transcripts, towards the same end. I believed that doing so would assist in remaining close to the ideals of 'right being'. The individuals engaged in this process were not rushed to respond during the interviews and neither was this the case when their comments or conversations at the LDC (see below) were brief or succinct. Even when a sentiment was expressed concisely, I incorporate the narrative build-up in order to realise the context and individual as fully as possible. This publicising of the time, patience and

space encompassed within the methodology is uncommon within the music and dementia field.

Moreover, in order to optimise respect for the individuals I was working with, I avoided too readily extracting their words from the context of their discourse. In effect, this meant avoiding editing and abbreviating them for the sake of brevity to illuminate a point. I sought to represent the individual as far as possible in writing, in the same way they presented themselves in person. To do this, I felt it was necessary at times to include lengthy excerpts.

3.9 Case Studies

In order to foreground the subjective experience of dementia and pay due diligence to the principles of personhood, a case study format was adopted here; set within the context of the overall ethnography of an LDC service. By applying this approach, my intention was not to draw broad generalisations between each case, but to demonstrate something of what it is to live with dementia from the point of view of the insider.

Two key issues within case studies are generalisability and typicality. Some case study work seeks to extrapolate observations made from single cases to a wider aggregate, viewing them 'as constituent member(s) of a target population' (Stake, 2000: 23). Other researchers suggest, however, that the importance of context is so great as to invalidate generalisations (Stake, 2000; Guba & Lincoln, 1981). Developing this theme, Schofield (2000: 75), citing Guba and Lincoln (1981), argue that 'fittingness' is a more appropriate term, in that it allows analysis of 'the degree to which the situation studied matches other situations in which one is interested'. As discussed above, the variety of dementia symptoms, both at inter-individual and intra-individual levels, in addition to their emergent links to social context, challenge the research paradigms which seek to draw generalisable conclusions about the factors affecting people with dementia. This being the case, an 'intrinsic case study' approach, seeking to explore specific individual cases for their own sake and highlighting the differences as well as the commonalities, would seem to be most appropriate (Gomm et al., 2000; Saukko, 2003; Stake, 1995). Accentuating

discrepancies and multi-dimensionality in this manner will not only yield greater detail about each case, but could also assist in determining whether there are indeed any cross-over specifics evident in other cases (Schofield, 2000). From this standpoint, it is therefore possible to begin to 'explain causal links from a real-life context' (Yin, 2003: 15).

3.10 Interviewing – Building a Relationship

To qualitatively engage a person with dementia in research is to collaborate in presenting as accurately as possible the subjective dementia experience and perspective. The ultimate objective, therefore, 'is not a quest for a correct answer' (Nygård, 2006), but a desire to acquire increased insight into both the objective and subjective experience of dementia. However, to support a person with dementia in presenting their experiences, the interview process requires careful negotiation. The relationship between interviewer and interviewee is patently important in all qualitative research; however, establishing a rapport is of particular importance with the current cohort (Hellström et al., 2007). Booth and Booth (1994) argue that a greater degree of familiarity is required when undertaking research on people with dementia than is usual in the interviewer/interviewee relationship. Not only will the development of a rapport assist in avoiding unnecessary distress or confusion for the person with dementia, and help avoid this person feeling inadequate, but it will also aid in the reduction of power inequalities (Hellström et al., 2007). Lloyd et al. (2006) stress the importance of developing an 'appropriate interactional style'. Nevertheless, it is suggested that this may not always be natural to those working in research, who might possess limited proficiency and experience in conversing with people experiencing difficulties in language fluency.

James McKillop, diagnosed with dementia himself, has written helpfully on the subject of interviewing and he notes that a demonstration of empathy is desirable, whereas pity is not. He further requests that researchers do 'not appear aloof or give the impression of being condescending', nor 'sit with forms and files'. Moreover, he not only advocates that the researcher retain any personal information imparted from session to session, but also that the initial interview commences with an 'ice-breaker',

i.e. some form of refreshment, or, as per Hellström et al, (2007), a modest gift offering, although cultural context needs careful consideration.

Practical ways in which a rapport can be developed are described in Booth and Booth (1994), who argue that a rapport can only evolve from reciprocal exchanges; recounting that they were satisfied for their study participants to access details of their home address and telephone number; in addition, they were happy to answer questions during the inter-interview period, should they arise. An additional example of reciprocal exchange occurring within my own research was when I was jointly going through a particular couple's CD collection and stumbled across some musicians who were unknown to me. The caregiving wife insisted I borrow the CD, which I did (and I believe it strengthened our rapport). Further aspects highlighted as encouraging rapport are reliability and the importance of being punctual and highly organised (Booth & Booth, 1994). However, the establishment of a rapport is not a static entity. Second interviews may tend towards greater affinity, but the 'good days-bad days' nature of dementia must be taken into consideration here (Pratt & Wilkinson, 2001).

Clarke (2006) similarly notes the importance of developing a good relationship with participants and the inappropriateness of a 'hit and run' approach during the research process, urging the avoidance of 'hygienic representations of research where problems and emotional connections to the research process are ignored'. To this end, Clarke kept a reflective diary and actively approached the participants to discover their reasons for taking part in her study, as well as how they felt about being interviewed and whether they felt 'involved enough or too little'. Whilst she actively sought reciprocity during her interviews, she cautions that, as has been demonstrated in feminist research, there are risks associated with the drive to attain equality between the researcher and researched through the exchange of personal information, which may lead to participants divulging information they regret at a later stage. An additional disadvantage of a close relationship being forged between the interviewer and interviewee is the potential to compromise objectivity (Booth & Booth, 1994).

3.11 Contextual Considerations of the Interview

There are some contextual issues which require consideration when conducting interviews with people with dementia, firstly that of positioning - a concept previously discussed in the Literature Review. For example, carrying out research with people with dementia who are not resident in long-term care in day care settings has the potential to negatively position the researched, whilst strengthening the position of the researcher, particularly if the setting is unfamiliar to the participant. Nygård (2006) suggests interviewing participants with dementia in their own homes to facilitate memory accuracy. For example, in a piece of research undertaken by Nygård and colleagues, to investigate how people with dementia perceived a timer device for their stove, it was found that 'the informant was unable to recall the device when outside the kitchen' (Nygård, 2006: 105). Therefore, the researchers in this instance strove to interview in the kitchen and, where possible, close to the stove. Nygård (2006: 105) maintains that performing interviews within an 'everyday context (...) may provide a reminder and support'.

The persona presented by the researcher also requires careful consideration, as this has the potential to influence participants' accounts. Nygård describes an instance where a study participant misunderstood the researcher's role and instead of viewing them as an individual, who intended to understand more of his (the participant's) experiences, he assumed the researcher was someone who was there to assist him in operating technological equipment. As Nygård stresses, in spite of the research taking place within the context of the man's own home, the persona he wrongly attributed to the researcher would undoubtedly have affected the content of his contributions.

3.12 Coda

In summary, the precedent of fully including people with dementia in the research process is now established and justified in terms of moral necessity. It is also a route to deeper comprehension of the subjective dementia experience. Additionally, the specific methodological route of 'gentle empiricism' (as inspired by Goethe), through case study and the concentrated exploration of local ecologies, has emerged as

being particularly appropriate for this cohort, by virtue of it facilitating due space, time and attention to the process or phenomena under scrutiny.

The access to this trio of ample space, time and attention forms an optimal scenario, allowing for an improved opportunity to really 'get into' the experience of dementia for people with the condition and those with whom they live. However, such a scenario is an ideal and my research to date has taught me there is a great deal beyond the realm of what a researcher can control. Without suggesting that any social research can ever avoid the need for adaptation, dementia research particularly entails a continual negotiation of predictable and unpredictable obstacles and challenges. This can take the form of instigating and maintaining engagement with people with dementia and their families, gatekeeper agendas, capacity fluidity and concomitant illness, thus rendering the potential for unimpeded dementia research improbable. Social research into the dementia experience is therefore a contingent process and the aims and scaffolding of the research project need to be balanced with, or (if necessary) become subservient to the needs and expectations of the vulnerable participants. Indeed, acknowledging the complexities involved in engaging people with dementia in the research process, Dewing (2007: 12) argues that 'a more detailed and open discussion' is required with regard to how practicalities are negotiated. As a contribution to this, I will now detail in the Methods Chapter both the successful and unsuccessful negotiation of obstacles which this research involved, describing their consequent impact.

CHAPTER FOUR: METHODS

4.0 Setting up the Research

For reasons which I will explain, the journey of this research project was not a smooth one and the final result is slightly unconventional in terms of architecture, but as I clarify here, this unconventional structure can be justified. Setting up the research was a messy and protracted process; changes occurred both in sample and design which were partially due to circumstances and a shift in my own thinking. My research framework subsequently went through a number of adjustments before the final version presented here.

4.1 Introduction and Bare Bones Summary

Initially, it was my intention to undertake a piece of research which sought to investigate the impact of a collaboratively designed music intervention for and by people with dementia living in their own homes, as well as their spousal/family carers. I wished to engage with those who were at the early to moderate stage of dementia, living in the community with a family member or spousal carer. The original research framework comprised two parts; the first was the interview stage, where I planned to interview both the person with dementia and their spousal or family carer. The second part would comprise a home-based, collaboratively designed intervention.

In essence, the research had a Plan A, which was never ultimately realised (for reasons which will be outlined later) and a Plan B. This second plan, described in detail below, became an ethnographic enquiry which explored the natural place of music in the lives of a number of individuals with dementia, via participant observation and over an extended period of time. For the purpose of transparency, the steps in Plan A are presented in Appendix A. Furthermore, Plan A is presented in the Appendix so as not to confuse the reader by outlining the two plans simultaneously. The details that follow predominantly relate to Plan B, but reference is made to Plan A when necessary.

4.2 Ethical Approval

The process of obtaining ethical approval was multifaceted. Firstly, I consulted my supervisor, Professor DeNora, discussing potential issues for concern. Based on these discussions, I then submitted a proposal to the University of Exeter's Ethics Committee, this being comprised of a multi-disciplinary panel. The proposal was accepted, but once it became clear that my research focus and methodology had shifted (see section 4.4), it was necessary to re-submit a revised proposal to the Committee for approval. Approval was subsequently granted. Age UK, the organisation through which the research sample was accessed, encompasses a network of 170 local branches. My research was approved by the relevant local Age UK office. Gaining consent to the research from the participants and their families is detailed in section 4.5.

4.3 Inclusion Criteria and Sampling

There were two essential inclusion criteria for potential participants. The first criterion was that the individuals were within the early to mid-stages of dementia, as defined by the Alzheimer's Society and specified in the introduction on p. 17, but for ease of reference, the symptoms include: forgetting about recent events; being slower to grasp new ideas; losing the thread of what is being said; sometimes being confused; finding it hard to make decisions; losing interest in other people or activities; becoming increasingly forgetful; sometimes repeating the same question over and over; failing to recognise people, or confusing them with others; becoming easily upset and angry, and experiencing difficulty with perception.

It also bears repeating here that when I use terms for the stages of dementia in this thesis, they are merely a guide, for the boundaries are not precisely defined. They also ensure ease of reference, so that the reader can understand the broad severity of symptoms and characteristics presented. As the delineation of dementia stages is imprecise and can only ever be a guide to symptom severity, I have not adhered to strict inclusion criteria, in that the potential participants were not tested for the above symptoms. However, all the participants presented some of the above list and had either received a diagnosis or a 'suspected' diagnosis from a health professional.

The second criterion was that the participants were living at home with a family or spousal carer.

These criteria remained firm throughout the various permutations of my research, but, as elaborated on p. 14-15, with knowledge of the significance of the environment upon symptomatic representations of this population, the setting was also important. In my particular approach, the focus needed to be equally applied to people with dementia and the settings they inhabited. Therefore, in seeking to understand the place of music in the lives of this cohort, the criteria for the project needed to take into account both the individuals and the context.

I chose not to conduct any form of cognitive testing; my interest was not in finding ways to necessarily improve or maintain cognition per se, but primarily to locate and comprehend meaning-making and identity-maintaining activities that are more strongly allied to concepts of well-being, not mental acuity. Moreover, had I pursued a more positivistic route from the outset, there would have been the danger of jeopardising my relationship with the people I was studying. In concordance with this perspective, Beattie (2010: 223) suggests that the nature of qualitative research is the:

‘pursuit of depth, richness and to explore little known phenomenon. Thus, conducting objective tests prior to in-depth interviews could not only preclude this richness, but could inhibit inclusivity and exclude the very individuals we seek to gain knowledge and understanding regarding their experiences.’

Echoing this sentiment, Hellström et al. (2007: 617) found that the use of cognitive testing – in their case using the MMSE – ‘bore no relationship to the ability of persons with dementia to talk about their experiences, and, rather than prove helpful, it was potentially detrimental on a number of fronts’.

As my research is exploratory in nature, the sampling was purposive. In addition, given that I was aware of the research design being time intensive in this instance, my intention was to engage with a small number of participants. Geographically, I deemed it prudent to limit the study to the county of Devon in the UK and I had no predetermined target for gender or age balance. Although the sample was small, the individuals chosen nonetheless corresponded to the criteria previously discussed.

4.4 False Starts

At the outset of my research, I had anticipated recruiting participants from an Alzheimer Society group I had been volunteering with. Over time, I had slowly begun to establish relationships with group members and leaders, but after lengthy and seemingly unending negotiations with the Society, it became clear it would be necessary to look elsewhere for potential collaborators, as time was an issue. Moreover, during this false start period, there had been a gradual shift in my own thinking in response to the literature reviewed. I had been particularly influenced by Tallis (2011), as discussed on p. 32 and gradually became eager to reject the 'music as medicine' perspective, also discussed on pp. 29-31, with which I feared my initial proposal was too closely aligned. I also began to move toward a perspective which aligned itself with positive aspects of being and capacity, rather than deficiencies in dementia. This thinking was informed in part by reading the work of Kontos (2004) and Langer (2009), amongst others. Furthermore, once again influenced by the literature, I started to move away from an interventionist approach and more towards ethnography.

Towards the end of my involvement with the Alzheimer's Society, I approached other national and regional dementia organisations, in anticipation of being able to progress the research further with them. This proved to be a prudent decision. Within one week, I received positive responses from a branch of Age UK and this process is detailed below.

4.5 Recruitment and Consent

In my initial communication with the Age UK local services manager, whereby my research proposal was outlined, I indicated the two essential criteria for potential participants: firstly that the individuals were in the early to mid-stage range of dementia, as defined by the Alzheimer's Society and specified on p. 17 of this thesis and secondly, that they were still living at home with a family or spousal carer. Combining this information with knowledge of her clients and Age UK's range of services, the local service manager recommended visiting two distinct day care services offered within the county, in order to meet clients informally and assess whether any appeared appropriate for the present research. The casual nature of the

meeting would also serve as something of an ice-breaker for those who might be interviewed at a later date.

One of the two services suggested was provided at an Age UK day centre and the scheduled event covered a roughly five-hour time period. The service catered for around 12 people, all with some form of memory problem. Lunch was offered, supplemented by a number of ancillary activities, including playing cards. On the day I attended, the service co-ordinator pointed out potential participants, all playing a card game together at that point. I sat down with them and began to join in their game, in addition to informally joining in their conversation. My engagement with this specific service constituted Plan A and revolved around one informant, Keith. However, this Plan ultimately proved to be abortive (see Appendix A for details). The other service suggested by the Age UK local services manager was their LDC (see Appendix B for a condensed consent procedure for the interviewees from the day centre and LDC).

Catering for a 'hard to reach' or particularly isolated client group, the LDC offers clients the opportunity to become part of a social, yet intimate gathering in a welcoming home environment. The result is more akin to a group of friends getting together than a 'care' service. The LDC is designed for those 'with sight or hearing problems, anxiety, depression and/or memory loss'. It differs from the more traditional style of day care centre, as described in the previous paragraph, in that clients are picked up from their homes by a 'host', who then takes them to the latter's own home.

There are a total of three LDC services in Devon, covering a six-hour time period from pick-up to drop-off and including a hot lunch. I visited two separate sessions, coordinated by the same host, Poppy. The LDC is an intimate service, with each group typically consisting of between five and eight people per session. In the host's home, the sessions fall into one of two routines: in one, the whole group sit around the kitchen table drinking tea, doing a newspaper crossword and chatting. The other group, consisting of older clients, is similarly occupied, but assembles in the living room, with music playing on a stereo in the background. It was from this specific service that my research data were eventually drawn, forming the content of this thesis.

All those present at the LDC and three participants at the day centre were subsequently identified as potentially being appropriate for the research. This was on the basis of information provided by the Age UK local services manager, who knew the individuals and their families, as well as something of their symptomatic histories. The Age UK local services manager had therefore identified these people as fitting the criteria outlined above. My own interaction with them during the first meeting supported the manager's assertion, as these individuals did, for example, demonstrate difficulty recalling recent events; did lose the thread of the conversation; were at times confused, and did repeat questions or conversations. As has already been discussed at length, symptom presentation does not necessarily reflect a materiality of brain decay and so by classifying the above subjects as conforming to an early to moderate stage of dementia, I emphasise here that I did not view this stage as part of a medically conceived and irreversible downward trend; it is merely a statement on how the individuals presented themselves to me.

I did not directly approach individuals at either service about being involved in my research and neither did I discuss the matter with them at any point, in order to avoid coercion. Instead, I handed over a number of relevant information sheets to the service coordinator (see Appendices C and D), which she duly forwarded to the identified parties.

The information sheets outlined my research interest and specified who I wanted to interview and why. The information sheet was designed to assist people in making an informed choice about whether or not to be interviewed. Advice was sought from experienced professionals in the field (Kate Allan, researcher and clinical psychologist focusing on communication with people with dementia, and Celia Smith, an occupational therapist, experienced in working with people with dementia and their families) on the best way to present materials to people with dementia. This pertained to format, design, language structure and colour contrast. The communication with Kate Allan took place via email and in person with Celia Smith. Both offered advice on the best ways of presenting the material, which included making the information sheets visually accessible, by keeping text to a minimum, and using direct language and a large font.

My initial research design included an interventionist approach involving individuals' personal music preferences; however, the first information leaflets distributed made no reference to music, but simply outlined a request for an interview, focusing on the positive aspects of the individuals' daily lives. This was a deliberate strategy, because although the research at this stage consisted of two parts, I did not want to place any emphasis on music and risk bias in the response; nor cloud the issue by including details of the second part at this stage, for individuals who may not have been suitable to approach.

Approximately 10 days after my visits and concurrent distribution of the information leaflets for circulation, I contacted Poppy, the LDC host, and the day centre service co-ordinator to gauge the response. Of those who attended Poppy's sessions, two widows, now living with their respective daughters, expressed a willingness to be interviewed. Moreover, three individuals approached me from the day care centre, each agreeing to be interviewed. It was the day centre engagement which would form Plan A and this is detailed in Appendix A. However, in relation to the LDC, furnished with the relevant telephone numbers, I duly contacted the relevant individuals. In each instance, the daughter answered. I consequently introduced myself, reiterated what had been outlined in the information leaflets and then arranged to interview the respective family carer.

Both daughters expressed a preference for their interview to take place in front of their mother. Furthermore, each of these first interviews was conducted when the mother was not at home, but at their respective Age UK service. Both daughters unanimously proposed that this strategy was the most convenient for them and added that it would facilitate greater fluidity in their particular interviews. This policy complemented my own agenda, in that it permitted further insights into the person with dementia before they were re-encountered. This meant that, if their memory did falter during their interview me, there was the potential for easing the conversation forward, resulting in the experience resembling less of a 'test'. Furthermore, I would be able to prompt conversation around present routines and activities armed with some knowledge of the present format of their everyday lives.

Following the interviews, I initially discounted the intervention part with the two women interviewed from the LDC. In the first instance, this was because one of the women, Eliza, presented with such contentment; exhibiting no obvious signals of distress, anxiety or anger due to her memory problems, I concluded that any encroachment on her life brought about by the research could not be justified in terms of any specific benefit she could experience. The complicated living arrangements and care situation associated with the other female LDC client led me to reason that engaging any further with her in the research was not a viable proposition. At this stage, I continued her line of enquiry with some of the individuals from the day centre (see Appendix A for details). This line of enquiry eventually proved fruitless, because the main informant, Keith, sadly died during the early stages of the collaboration.

Rather short-sightedly, I had not considered this eventuality, especially with such rapidity. 18 months into my PhD, I was then somewhat off course. It was therefore necessary to quickly introduce and incorporate contingent methods to accommodate the ensuing 'changing circumstances and conditions' (Cowdell, 2008: 30) which surrounded me.

It started to become clear that trying to collaborate with this particular cohort can be highly problematic and even if a specified recruitment criterion is met, life is substantially more complicated, with issues other than the cognitive affecting suitability. Although I had anticipated the recruitment of a far larger sample, circumstances and time had transpired against me. However, even with hindsight, I am not convinced there was much that could have been done to alter this course. The slow and painstaking task of working with various gatekeepers, recruiting participants, and then taking into account other additional exclusionary issues as they occur, will always leave the way open to disruption. This highlights the complexities of carrying out real world research and all the more so with the population under study here.

Before outlining who was recruited for Plan B, below, the I will first explain the interview process in detail.

4.6 The Interview

Two main methodological qualitative strategies, namely semi-structured in-depth interviews and observation were used for this study. Charmaz (2006: 29) recommends the use of qualitative interviews in Grounded Theory, by virtue of their flexibility and the way in which they can facilitate 'open-ended, in-depth exploration of an aspect of life about which the interviewee has substantial experience, often combined with considerable insight' (Charmaz, 2006: 29). However, it is important to acknowledge, as do Crabtree and Miller (1992), Denzin and Lincoln (2005) and Alvesson and Skoldberg (2009) that, whilst the interview is a valuable research tool, the process is not unmediated or purely objective. Indeed, Potter (2004: 205) argues that it should not be viewed 'as a machinery for harvesting data from respondents'. An interview is performative and will always be subject to contextual influence. It may well even consist of contradictory elements. It was from this perspective that I came to conceive of the interview as forming the foundation from which to begin to try and understand the dementia experience.

Increasingly, Interviews are widely used in dementia research (Clare, 2002; Clare, 2003; Katsuno, 2005; Surr, 2006; Langdon et al., 2007; Genoe et al., 2010; Moyle et al., 2011), primarily as a vehicle to help give voice to participants' own stories, without resorting to a proxy. Moreover, the flexibility they afford provides access to 'meanings, perspectives, and interpretations (...) embrac(ing) individual differences; sensitivity to diverse forms of expression' (Lloyd et al., 2006: 1387). I used open-ended questions in this case, following Innes' (2009) guidance, who advises that it behoves the interviewer to re-word any questions that interviewees have difficulty in understanding. This will not only help that individual to participate in a meaningful conversation, but will also be a strategy for more effectively representing the subjective experience.

4.7 Interview Topic Guide

A set of questions was devised which were divided into six short categories (see Appendix E). Closed questions were avoided wherever possible, as recommended in the literature, especially Nygård (2006), who argues that when interviewing people with dementia, a focus on mundane and familiar everyday life is useful for eliciting

conversation. Nygård further suggests that open questions accounting for one's specific actions should be avoided. Instead, open questions about what the informants usually do and what they think about particular issues in their daily life may be more appropriate. The literature stresses the importance of maintaining a flexible approach during the interviews, in addition to being able to improvise.

The initial questions here surrounded early biographical details, primarily because (as reports suggest) these memories are likely to be retained with greater clarity than those of the more recent past (Hodges & Graham, 2001; Leyhe et al., 2009) owing to 'memory consolidation (...) through repeated activation of the memory trace' (Graham & Hodges, 1997). I hypothesised that commencing the discussion with topics which were likely to be the least challenging in terms of recall would help assuage interviewee anxiety. Other topics included skills, family, daily life and pastimes. The inclusion of skills as a discussion topic had been held back for incorporation in the second stage, were the relationship to develop that far. However, these topics were just a guide and the interviews were more closely akin to an informal conversation; the intention being for the interviewees to characterise their subjectivity and 'tell their story in their own way' (Clare, 2003: 1020).

4.8 Interview Technique

Proceedings began with the family carer introducing me before either leaving the room or seating themselves in close proximity to their spouse/mother. Each interview then began with me reiterating who I was and explaining the purpose of the visit. On each occasion, I requested permission to record the interview and emphasised that they, the interviewees, were at liberty to terminate the interview at any time, or to decline to be recorded, without the need for justification (McKillop & Wilkinson, 2004). In addition, I stressed that in writing up the research, pseudonyms would be employed. An indication was also given of how long the interview could be generally expected to last.

The necessity for developing and establishing a rapport with interviewees applies across cohorts; however, it is argued that this need is more crucial when engaging with individuals with dementia (Clarke & Keady, 2002; McKillop & Wilkinson, 2004;

Hellström et al., 2007; Hara, 2011). Nevertheless, the process of developing a good rapport is subjective and the means of achieving it is not well documented in the literature. This indicates a tacit assumption that it will almost inevitably be established, as in any other social one-to-one communication.

Hellström et al. (2007: 612) offer a more detailed account of how a good rapport can begin to be established, arguing that 'time is needed to build rapport; and fostering a relationship based on trust, warmth and empathy is a prerequisite if power inequalities are to be reduced'. Additionally, Nygård (2006) stresses the importance of time in the process of building a relationship with a research participant with dementia. McKillop and Wilkinson (2004) usefully provide a list of specific pointers:

- Be among them (*the interviewee*) and do not perch behind a desk
- Look at and talk directly to the person
- Be yourself at all times and do not contrive to be anything other
- Some people have a 'thing' about hospitality and will feel uncomfortable if you do not accept a cup of tea
- If the person with dementia appears to contradict something they said (...) don't exclaim '...ah but you said (...) last time...' We can change our minds, especially if our vision has broadened'

I adopted an informal approach in this research, as recommended by Denzin and Lincoln (2000) and Clare (2002), with eagerness to avoid individuals encountering feelings akin to being examined or tested. The questions were short and in clear language, both in their content and delivery.

4.9 Advantages and Disadvantages to the Joint Interview

Although my intention in this research had been to interview the participants with dementia on their own, it was not always possible or appropriate. Nygård (2006) suggests that the challenges derived from memory incapacity affect the presentation of narrative data and therefore, it may be hypothesised that the presence of an individual with whom there is a shared history could support the relating of particular narratives. In support of this hypothesis, Clarke (2006) cautions that interviews with vulnerable people have a potential to be exploitative if, for example, these interviewees experience an obligation to discuss aspects of their lives which are difficult or cause them distress. The presence of a family carer, on the other hand, supports individuals in the presentation of their narratives, with the capacity to steer

the interview away from controversial areas. Furthermore, the person with dementia is aware that, should their memory fail them, they have an external 'back-up', minimising the potential for interview anxiety.

From a power perspective, Nunkoosing (2005: 699) argues that

'in the interview (...) we can conceive of the various forms of power constantly shifting back and forth between the interviewer to the interviewee. (...) The power of the interviewer rests in his or her authority as a seeker of knowledge and methodological expertise, and that of the interviewee as a more or less privileged knower.'

It is indeed accurate to lend the interviewee 'privileged knower' status. Nevertheless, in this particular situation, the person with dementia is more vulnerably situated within the dyad. Therefore, the presence of family members during the interview could be argued as redressing this balance to some degree.

On the other hand, the primary disadvantage of interviews with people with dementia in the presence of family members is the potential for the person with dementia's voice to be lost, defeating one of the main aims of the research. These unplanned quasi-joint interviews, in some cases almost become quasi-proxy reports, as family members, with all good intentions, answer for their mother/wife/husband, not allowing enough time for the person with dementia to respond to questions intended for them. Indeed, Innes (2009: 119) argues that researchers need to be cognisant that 'any account that is presented, where perspectives and experiences are shared, is not a quest for a 'correct' answer, rather an attempt to hear what research participants have to say about aspects of their lives'.'

In the first stage, each individual was interviewed once and as previously stated, each interview with the carer was undertaken in the absence of the person with dementia. However, interviews with the person with dementia varied with regard to the number of others present. All the interviews took place in the home of the interviewees. This arrangement did not occur as a result of any specifications from either party, but was agreed unanimously through the emergence of a common assumption that it would be preferable for all concerned. The length of each interview

was in the region of 30 minutes for the individuals with dementia and 30-40 minutes for the carers. The interviews began between 11 a.m. and 11.30 a.m.

4.10 Plan B

Following Keith's death, by necessity, I turned my focus towards Eliza, one of the women interviewed from the LDC group. I had previously discounted her as a potential participant for the second part. The reason for this was that my underlying intention of my research was to effect positive change through a music intervention, but Eliza and her family appeared to be managing Eliza's memory frailties well, without any of the typically associated daily living challenges. However, Keith's death compelled me to scrutinise Eliza's and her family's interview responses from a different perspective. The interviews evidenced fragments of musicking in her daily life, indicating potential value to be gained through further exploration of this phenomenon.

A modification to the second strand of the research was now necessary. The primary aim of the interviews in the first part had been to discover where, when and what the positive times in a day/week for individuals with early to moderate dementia living in the community were, ascertaining how they were achieved and moreover, gauging how or if music played any part in these. Now concentrating on Eliza, this remained my aim, but furnished with some knowledge of the place of music in her life, i.e. 'Where, when and how?' I sought to explore this further, embedding the enquiry within the context of where her musicking took place. The subtle transition in research focus now added elements of ethnomusicology, described on the Society for Ethnomusicology's website (2016) as:

'the study of music in its cultural context. Ethnomusicologists approach music as a social process in order to understand not only *what* music is but *why* it is: what music means to its practitioners and audiences, and how those meanings are conveyed.'

This is in addition to the ethnographic foundation of the enquiry, which is discussed in section 3.3. This allowed me to concentrate my research more acutely on the cultural context of music and its social processes. In doing so, my aim was to avoid, as far as

possible, artificial research situations, and observe social life in the practices of everyday life.

A modified research design was devised, with verbal agreement from Eliza's daughter, to determine an indefinite and on-going observation of Eliza at the LDC, in addition to other scenarios where music was a feature. This was so as to focus on her talk and practice. I deemed the inclusion of participant observation to be an appropriate strategy, owing to its ability to foreground more subtle contextual aspects, such as emotion and embodiment (DeNora, 2004). This approach is particularly suitable for people with dementia, for whom verbal communication may not always flow with ease.

The once a week LDC sessions attended by Eliza usually involved three other women, although these other women were not intended to participate in any focused observation. Consent from all was achieved in three ways. Firstly, prior to the start of my regular attendances at the weekly LDC group attended by Eliza, all the women were given a consent form by Poppy (see Appendix F). When Poppy gave out the forms, it was intended for the women to take them away, digest them, discuss them with someone else and then return them signed or unsigned, as appropriate. What actually happened was that Poppy explained what the forms were about and all the participants decided they wanted to sign them straight away. The second step was that before my arrival at each session, Poppy would remind the women about my visit and explain the purpose of it as well as what I would be observing and recording, therefore verifying that everyone was happy with my presence. The final step was to take place on my arrival, whereby she would go through the same process, explaining who I was, why I was there and verifying that all were happy for her to record the session. It should further be mentioned that the recording device was placed in the middle of the coffee table, around which everyone was seated. The device was attached to a small tripod stand (around 10 cms high) which, when added to the further 10 cm height of the recording device, was conspicuous. Its conspicuousness proved to be useful, as on several occasions those attending would enquire as to what it was, having forgotten an earlier explanation. This was an ideal opportunity to re-verify that everyone was still satisfied with the recording/observing situation contributing to the on-going consent.

I timed my visits, which took place in Poppy's house, for around 10 minutes after the arrival of the women, so that they were settled in position with their tea or coffee. This was usually once they had begun doing a crossword as a group, led by Poppy. Consent was sought by Poppy at the start of the first session, attended by all the women before I arrived. Poppy explained that my visit was for research purposes, outlining something of the research, without singling out any individuals. She verified that all were happy for me to join them. Concordant with the on-going consent recommended in the dementia research literature (Bartlett & Martin, 2002; Dewing, 2002; Hellström et al., 2007; Dewing, 2007; McKeown et al., 2010), this procedure was repeated on each subsequent occasion I attended any of the LDC sessions. There was never any objection to my presence and typical jokes frequently made included, 'Ooh, are we going to be famous?' or 'You're not going to get much out of us'.

I was present at the relevant LDC sessions for the entire duration of each session and joined in the crossword, chats, lunch and other activities, including knitting and darning, immersing myself in the cultural milieu where I was situated - seeking to obtain 'marginal native' status (Freilich, 1970). My first observation session was 20th June, 2012 and my last, 21st November, 2012, resulting in a total of 16 sessions.

By way of a 'thank you' and to mark a definitive end to this involvement, I organised an additional farewell day-out 'jolly'. The group were picked up as usual by Poppy and then brought to my house for morning coffee. At the previous week's session, the invitation had been discussed and Poppy informed me of how, on the day before the outing, when she had gone to pick up one of the women involved to take her to another session, the woman had shown Poppy the outfit she was intending to wear the next day, presumably denoting happy expectation.

Following morning coffee, we all took a short ride to the coast. It was a sunny, if cold day and a short walk followed. After this, we all went to a fish and chip restaurant. It was an establishment the group had been to before on another occasion and therefore, I knew it to be easily accessible for all. Poppy informed me that on the drive home, everyone expressed how much they had enjoyed the experience.

A prominent musical feature conspicuous during both the interview with Eliza and her daughter was the significance of regular congregational singing. It was an aspect that Eliza had spoken of with great enthusiasm and consequently, in my discussion with Eliza's daughter about the potential for long-term observation at the LDC, she approached me with regard to joining Eliza at church on some occasions. I had a telephone conversation with her daughter regarding this, whereby she articulated satisfaction with me joining her mother and family at church, indicating she would verify it with her mother, which she did and two church dates were duly arranged. When I then met them at church, Eliza got out of the car and introduced herself, but did not appear to recognise me. On walking into the church, I discreetly asked Eliza's daughter if I could introduce myself once more to her mother, as well as explaining my reason for being there. Eliza's mother replied she had already explained the situation to her mother, adding that she did not think the information had been retained and had consequently changed strategy that morning, deciding to introduce me as a friend of the family. Feeling uncomfortable with the deceit, I reiterated my willingness to explain the situation to Eliza, but her daughter affirmed she was satisfied with the situation and moreover, she was satisfied her mother was happy with it too, which she felt was sufficient. My attendance at church with Eliza and her family allowed me to closely observe her musicking in context.

4.11 Additional Consequential Materialisations

Although Petula, the other LDC interviewee, was also present at the LDC sessions where Eliza would be observed for the study, she was not intended to feature as a focus. However, over time, it became clear that music was of significance to her and gradually, Petula's musicking progressively became more central to the respective inquiry. The data gathering process foregrounded Petula's close affinity with one musician in particular and so Petula became the second participant.

As further vindication of the gentle empiricist approach, some three months or so after commencing observation at the LDC sessions, Poppy (the host) suggested I attend her 'Tuesday Group'. Recently, a new client, Joe, had started to come and Poppy envisaged him as a potential interviewee. As Petula also attended this Tuesday group, I proceeded to go there, in conjunction with the existing 'Wednesday

Group', for another six weeks. I also contacted Joe and his wife in the manner which was customary by now, namely through an information leaflet supplied by Poppy. Although the request for an interview was not declined, neither was it acknowledged. Moreover, although I would very much have liked to interview Joe, both he and his wife were experiencing some health frailties and my instinct was not to pursue the matter any further. However, consent to observe Joe was obtained as part of the 'Tuesday Group'.

The consent process for Joe firstly involved Poppy further explaining to both Joe and his wife (in addition to the information leaflets already supplied) what this would entail and for what purpose. Secondly, it involved Joe agreeing to sign the observation consent form (see Appendix F). In addition, discussions had begun within the group about the singing which took place on the car journey home. Realising that such singing was likely to be significant, the potential for recording these moments was added to the consent form.

My original reason for attending the newer Tuesday Group had been primarily to assess Joe; however, after it became apparent that an interview would not be forthcoming, I continued to attend for another five weeks with unspecified motives. It was at this time, with the consent of all concerned that I began to audio-record both the Tuesday and Wednesday sessions. In transcribing these recordings, it became apparent that Joe, with great subtlety, almost constantly engaged with music within the LDC context and as such, Joe, along with Eliza and Petula became the third and final case study.

I nevertheless acknowledge that complete uniformity with regard to acquiring consent was not achieved, in that an opportunity to interview Joe and his wife did not materialise in the way it did for both Eliza and Petula. Ideally, this would not have been the case. I am confident, however, that meaningful consent was obtained from Joe to observe him. This confidence is based on the repeated consent sought on each possible occasion via Poppy and subsequently, myself. Recently, researchers have begun to write about the messiness and complexity of ethics and informed consent, both in ethnographic research (Atkinson, 2015) and in contexts where 'vulnerable' research participants are involved (Ansdell & DeNora, forthcoming).

The complexities of consent for people with dementia who do not reside in long-term care are perhaps the reason for the comparable rarity of community-based music and dementia research. Expecting to always achieve homogeneity of consent when undertaking 'real world' research with this population is arguably naïve. Recognition of this reality validates my approach here, however unorthodox it might appear.

I was with Petula between January and November of 2012 at the same weekly Wednesday LDC sessions attended by Eliza. However, for a period of six weeks from September 2012, I supplemented the Wednesday sessions with the Tuesday sessions (hosted in the same environment by the same person), which Petula also attended. The reason for adding the extra sessions was to observe how Petula might behave in, or react to a different context; albeit one which resembled the original sessions where I had been observing her. It was also to observe Joe. The Tuesday Group was mixed-sex, but the Wednesday Group was exclusively female. The Tuesday group was also larger and noisier, typically including five to eight people, in comparison with the four who usually attended the Wednesday session.

The total number of hours I spent with each of the participants varied considerably. For example, a total of 88 hours was spent with Petula at the LDC sessions, in addition to one 30-minute interview. The result was a total contact time of 89.5 hours. I was with Eliza at the LDC over the six-month period for 64 hours, plus a 30-minute interview and two 45-minute church visits, representing a total of 66 hours' contact time. I was present with Joe for six sessions at the LDC, totalling 24 hours' contact time.

In an ideal world, the variation in contact time would not have been so great, but flexibility in 'real world research' is important, as supported by Altrichter et al. (2002: 130), who argue that:

'while it is important to attempt definition and clarification, it is also important to acknowledge that action research must remain open for ongoing consideration since confining it within narrow, restrictive definitions could serve to inhibit constructive conceptual development.'

Petula attended the LDC twice a week, not just once, like Eliza and Joe. This meant that I had the opportunity to spend more time with Petula than with the other two. I

consequently decided that even though there would be a discrepancy in the amount of contact time spent with each individual, in the interests of gathering rich data, I would take advantage of such an opportunity. Joe's contact time was the most limited, because not only did he only attend the LDC once a week, he declined to be interviewed and surfaced late as a significant informant in the data-gathering process. All the participants and informants featured in this thesis were given fictitious names. Additionally, some identifying details have also been altered to ensure anonymity.

4.12 Additional Actions as Opportunities Arose

As discussed at the beginning of this chapter, the research process was not a smooth one in the present study and modifications to the research design occurred along the way. Some of these were down to practicalities, i.e. the death of Keith; others were an effort to make the most of unforeseen opportunities which emerged during the fieldwork process. This section describes the latter and involves two further LDC attendees, F and D.

All members of the LDC had signed a consent form for the observations and recordings. I got to know both F and D well during my time at the LDC. They had never been approached to be interviewed, primarily owing to their living arrangements. However, F in particular, was observably engaged with and moved by music during his visits to the LDC, as well as other art forms, including visual art and poetry. This was evidenced by his regular and enthusiastic singing at the LDC, discussion about and evidence of his own artwork, and occasional poetry recital. On several occasions, Poppy had explained to me how the car journey home had become a group sing-song, due to F. Poppy and members of the in-car singing group had discussions about the potential of recording one of their journeys to capture the singing phenomena. All agreed and an analysis and discussion of this is presented in a later chapter. One point to note is that there was not enough room for me to actually accompany them in the car and so Poppy recorded the journey on my behalf.

The Table below details the interviews, i.e. the length of each; how many were embarked upon; with whom; where, and at what time.

Table 1. Interview log for LDC attendees plus additional contact time

<i>Pseudonym of informant and age at time of interview</i>	<i>Diagnosis</i>	<i>Interview time and length (duration varies according to either how talkative or taciturn interviewees were)</i>	<i>Solo or joint interview</i>	<i>Location of informant interview</i>	<i>Pseudonym of carer/s interviewed or present at interview</i>	<i>Interview Length (duration varies according to either how talkative or taciturn interviewees were)</i>	<i>Additional time spent with informant during Part Two</i>
Eliza, 96 (LDC)	GP diagnosis of 'suspected' dementia	11.30 a.m. 32 minutes	Solo	At her kitchen table, by the Aga.	Julie (daughter)/ Nigel (son-in-law)	40 minutes	64 hours in total at LDC; 1 ½ hours (two church visits)
Petula, 78 (LDC)	Dementia of a non-specific type	11 a.m. 33 minutes	With two daughters present, who eventually joined in	In her living room	Andrea (daughter 1)	28 minutes	88 hours in total at LDC

Joe, 86 (LDC)	Dementia of a non- specific type	No interview secured					24 hours in total at LDC
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4.13 The Local Day Care Service (LDC) and Poppy's Craft

For further context, the LDC is described here in greater detail. The LDC service, designed for a 'hard to reach' population, is a more intimate and bespoke day care service than is generally typical and this is deliberate, as it is a service which is essential for clients who find larger groups and more institutional settings difficult to manage and who require a more 'family' orientated, 'home-from-home' service. It provides for people who are keen to get out and about and enjoy some company during the week, who need to learn to find companionship again, and for those whose anxieties can only be catered for in the intimacy of a domestic environment. The service also provides valuable 'time off' for families and carers of guests.

Both the LDC groups I observed were hosted by the same individual, Poppy. Her groups typically consisted of between four and eight people per session. The sessions had a clear trajectory, which had evolved with careful and deliberate steering from Poppy. I have detailed the components constituting the LDC with some specificity from start to finish, in order to realise a full contextual understanding and ground the analysis more deeply within the action site.

I observed both the Tuesday and Wednesday LDC sessions and there were subtle differences between these. The Tuesday Group was the larger of the two, containing a core collection of seven individuals. Owing to the size of the group, on these occasions, Poppy's husband assumed the role of support worker. The overall framework of the session was relatively structured, beginning with the car journey. Clients were collected by car from their homes, either by Poppy or her husband, both of whom stating a tendency to listen to Classic FM on the radio during this period:

‘Sometimes [local radio] for local interest but mainly Classic FM because it always felt like the right pitch – it has so much well known mainstream classical music which is probably recognisable and familiar to most clients. It doesn’t have to be on very loud and the intention is that it is also (hopefully) pleasant company for patiently waiting clients.’ (From section of interview with Poppy)

On arrival at Poppy’s home, the individuals would make their way to the living room. Poppy has an array of animals, consisting of a goat, three cats, three dogs and periodically, various litters of puppies. Three concurrent facets are then set in motion upon arrival: firstly tea and biscuits are offered around, music is put on the stereo and then the group are led in completing a newspaper crossword by Poppy’s husband. Having experimented with various newspapers, the *Daily Mail* crossword was found to be the most suitable:

‘It does appear to have the right kind of degree of difficulty, mixed in with some really easy ones which get us going for that level. I mean any other, *The Times* quick one or *The Telegraph* quick one, they’re too difficult, so you’ve got to have it so you can... so that’s how we started off and then from that we then realised that there was the word game and it tends to be in the morning that it’s rather wordy oriented.’ (section from written communication)

Following the crossword, the group then once again embark, led by Poppy’s husband, on another word quiz from the same newspaper. This activity gives Poppy the opportunity to retreat to the kitchen to cook lunch. Background music is generally put on from the outset and continues throughout this morning session. The word quiz is undertaken and then lunch is served. The word quiz, also taken from the *Daily Mail*, includes categories of scoring which change, depending on the difficulty of the quiz; for example, 15 words might be average; 25, good, and 30, very good. There is a running joke about whether the group is average, above average, below average, good, etc. Following lunch, the group returns to the living room with Poppy leading the afternoon section of the proceedings. This may involve general conversation led by Poppy, some general knowledge questions, or a music quiz. At the end of the session, the clients are driven home.

The structure of the Wednesday session, which has a core of four regular female attendees, is similar to the above; although Poppy is without a support worker on these occasions and in the pre-lunch slot, must juggle cooking with engaging with the

women in a crossword, chat or activity. Activities observed included knitting, darning and making bread.

The organic aspects, weaving their way through the structured aspects, evolved partly by design and partly through a gradual and imperceptible metamorphosis. The group dynamic is co-constructed by the group members and Poppy. For example, lunch is a feature which Poppy views as highly significant:

‘Quite often [menus are] thought up on the hoof depending on my mood and the time I have available to prepare ahead. I try to think of mainstream meals that are familiar and popular with all. Nothing too adventurous! Good puddings are essential though and really important - I think they are capable of evoking strong/fond childhood memories and can be facilitators of great conversation!’
(Section from written correspondence)

There are some parallels to be found here with Proctor (2013), where during group music therapy sessions in a mental health community centre, food was observed to impact both upon people’s interaction and their musical participation. Indeed, Proctor noted that food was a facilitator of conviviality.

Below, Poppy further explains how she works to make lunchtime meaningful for those present; for instance by protracting conversations and introducing topics for discussion:

‘The meals have become a major part though (...) well I think it’s almost the single most important thing of the whole day. I mean Age UK would probably say it’s good they have a hot meal, and my point is, of course, that goes without saying, but the fact is for a lot of them, they live alone, they never eat with anybody anymore. They always would have been brought up to eat at a table to sit together and have conversation and we never ever rush that, in fact if anything I try and protract it as long as I can because I think it’s amazing what comes out over a meal table; I mean we find that as a family, amazing (...). With the, certainly the Tuesday group we get into current affairs – I mean it might be what do they think about the voting age going down to 16 (...) all sorts of things, but I know I think ‘Ooh must ask them about that, what do they think about that?’ Not as complex as ‘What do you think about staying in Europe or not?’ But it’s certain things that they can contribute towards and so forth (...). Lively general chat that we can all contribute to, or all for those who don’t necessarily participate it still goes in but it’s a nice bit of banter, it’s friendly, it’s... you know... and just because we’ve finished the first course doesn’t mean to say we immediately whip the plates away and then get the pudding out as soon as possible, and sometimes when we’ve finished pudding we actually sit there for quite a long time and carry on chatting, if

that's what people are still doing, and I think it's a really important part of life, eating together (...) it's lovely, it's healthy, it's hearty it's... you know... it's important, so that has become a good hour's session out of the day.' (*From section of interview with Poppy*)

The above section illuminates the process through which Poppy constructs a 'pleasant family mealtime' environment, but it also demonstrates that, as in any corresponding scenario, success cannot be achieved without cooperation from those present. Poppy's clients are therefore complicit in the action of creating a meaningful mealtime experience. They demonstrate tacit know-how and an unstated understanding of the situation, with what is required to achieve the desired outcome, both for themselves and for Poppy. Her narrative not only demonstrates that her clients act as co-collaborators with her in this, but that there is compatibility of outcome: 'We never rush that [conversation], in fact if anything I try and protract it; it's a nice bit of banter; when we've finished pudding we actually sit there for quite a long time and carry on chatting; I think it's a really important part of life, eating together.' In a sense, what is effective for the clients is effective for Poppy. This leads back to the issue of 'moral space' raised in the Literature Review. It is apparent that Poppy adheres to the principle of 'right being', as opposed to 'right doing' discussed in the work of Dewing (2002), in that she very much takes her lead from her clients. She allows them to subtly dictate the proceedings and as such, stays 'with them', rather than 'doing to them'. Indeed, Hughes (2013: 348), acknowledging Wittgenstein, states that 'understanding entails grasping a form of life' and I perceive this to be what Poppy is describing here: her understanding of the individuals in this scenario is informed by empathetic awareness.

Uncovering what occurs during (as well as before and after) the LDC session foregrounds the question: What is it that constitutes 'good care?' How is 'good care' constructed and by whom? Moreover, is 'good care' even the correct terminology? Would 'effective collaborative guardianship' be more appropriate? Care is inherently suggestive of an unequal relationship and perhaps what occurs at the LDC is more egalitarian than the term 'care' would suggest.

In fact, collaborative guardianship is not confined to elderly individuals who are experiencing memory loss; it is more or less a process unfolding between all friends,

colleagues and acquaintances on an almost continual basis. This is not to infer that friendships are completely benign, as there is undoubtedly also friction, irritation, disappointment and challenge which can occur simultaneously, yet I believe that by working as some kind of subverted computer malware, i.e. functioning unnoticed in the background for positive ends, collaborative guardianship unfolds almost continually. That the LDC contains small groups, further limited both in number and geography for the car journeys, is the key to its success. Moreover, in the context of frail elderly people living with the multiple issues of losing their memory, as well as perhaps their hearing and physical immobility, while at the same time potentially enduring pain, the size of the group offers an optimal environment in which tangible relationships/friendships can be cemented and collaborative guardianship can thrive.

To conclude this scene-setting section, the response given by Poppy to a written communication will be included, where I asked her to provide her own definition of her role as an LDC host:

'I see my role as much more than is expected of me at Age UK. But it is important to stress that this is my choice. I feel passionately that I don't want to just be a 'holding operation' for my clients. I want to effect change and improve the status quo and I will do this through which ever means I can. If I feel at the end of the day that my clients are laughing and chatting, animated and interactive in general terms then I have achieved something so worthwhile. Many of my clients experience physical and mental isolation and emotional neglect. It is my hope that the time they spend with me on a Tuesday or Thursday is a marked contrast and that they might feel like life is worth living again. I suppose you could say that I use a variety of 'tools' to help me achieve this end but they don't relate to defined structures or directives. For example, aware that the 'older' generation learnt poetry by rote as children we have often dipped in to the Oxford Book of Verse and found some favourite poems that are familiar to most, Wordsworth's Daffodils for example. Interestingly this also leads on to unexpected pathways such some as reciting Burns together. Then of course there's the recitations of Kipling and Shakespeare sonnets – amazing! He is always so chuffed to have the opportunity/platform to do this!

Music though is the best resource of all. It never ceases to amaze me how it can facilitate comment, enjoyment, reaction and emotion and is a brilliant way of connecting with memories that still exist. I revisit the same music on a regular basis (I think familiarity is key) – songs from the 40's for example which are evocative. Gilbert and Sullivan on the other hand provides (in smallish doses!) a great and energizing contribution to the dynamic of the group and allows certain individuals to shine and perform!

Because the job is home based the 'props' that I have to hand are immeasurable. A willing dog or cat can make a huge contribution to an individual on any one day as can the hectic comings and goings of the family which many of the clients love to hear about. Familiarity heightens the sense of belonging and improves the outcome every time. Practical tasks are important too – peeling sprouts or runner beans or table laying can be really valuable activities.'

4.14 Analysing the Data

The Grounded Theory approach has been used in previous dementia research. For example, in their longitudinal study of carers' experiences of caring for people with dementia, Lin, Macmillan and Brown (2011) chose it because of its potential to 'generat[e] new perspectives from familiar phenomena'. Daly et al. (2013) also used Grounded Theory as a means of understanding how informal carers of people with dementia manage alterations to relationships within their social worlds. The authors posited that the suitability of this method lay in its ability to facilitate 'systematic conceptualisation of (...) latent social patterns' (Daly et al, 2013: 502). Elsewhere, Cooney et al. (2014) argued for the use of Grounded Theory in dementia research, owing to its potential to 'focus on understanding human behaviour, interaction and response to events or activities in its context'. Although in this research I have not strictly adhered to the rules of classic Grounded Theory (Glaser, 1978; 1998), I have nevertheless applied it in a modified form as the basis for analysis, as will become apparent in the subsequent sections.

Data collection and data analysis were carried out simultaneously and continued for the 10-month duration of the fieldwork. The data sets can be divided into three distinct, yet related, individuals or groups. These comprise the case studies on Eliza and Petula, as well as Joe's activities in the context of the LDC and the occurrence of singing in the car. I decided to include Joe, because of his explicit engagement with music during the sessions. With regard to Joe and the singing in the car, the presentation of the analysis would constructively be viewed as relating specifically to context, but in relation to the preceding case studies. I contend that this sheds further light on how or why context is so significant in dementia care and the place of music within it.

The data sets can be divided into a number of sections. The first data set consists of the interview; the second, observations and field notes, while the third comprises the audio-recordings. I immediately transcribed each interview verbatim on completion and this was made possible by the fact they were audio-recorded, with the permission of the participants. At each field note visit, either at the interview or in the LDC observation session, I took field notes and later wrote them up. The audio-recordings made at the LDC were lengthy, some being around four hours long. In the first instance, I indexed the recordings every five minutes. This means the action or inaction occurring at 5-minute intervals was listed. I then went back over and noted down snippets of conversation going on at these points. Gradually and over time, I transcribed large sections of conversation or action verbatim, where these were pertinent to the themes being developed.

Over the period of the research, I listened to the recordings many times over, either in part or in full and therefore became well-acquainted with them as data resources. It was through regularly listening to the recordings that the true significance of the phenomena of Joe and his musicking in context emerged, as well as the importance of the singing in the car. Remaining close to the data meant that unexpected phenomena emerged which would otherwise have gone un-noticed, had the 'gentle empirical' approach not been maintained, as discussed earlier and advocated by Pavlicevic and Ansdell (2010). The first step in analysing the data was then to undertake open line-by-line coding. This was in order to gain a detailed sense of all emerging concepts in considerable detail. During the line-by-line coding, I was able to name and categorise events, actions, opinions and phenomena.

Next, I focused on coding. Based on the earlier codes, this course of action sees the researcher deciding which initial codes are most logical to pursue and categorise in analytical terms (Charmaz, 2006). These focused codes were then finally consolidated into a final or core code, which represented 'the central phenomen(a) of the study' (Corbin & Strauss 1990: 424), around which the 'story' of the thesis was hung. A process which was concurrent with the coding was my use of memos. Memo-writing, according to Charmaz (2012) is the intermediate step between coding and writing a first draft.

There were a number of recurrent themes, emerging within data from single participants. For example, the theme of ‘asylum’, which emerged with Petula’s musicking, both at the LDC and at home and Joe’s LDC musicking came to highlight the important and varied ways in which people with dementia actively yet subtly use music for their own specific ends. Moreover ‘asylum’ as a theme fed into another aspect, contributing to the overall ‘story’ of this thesis, namely the significance of ‘lay expertise’.

The process of selective coding involves the consolidation of categories around a principal category. Corbin and Strauss (1990: 424) suggest that such categories, arrived at through a reflexive process, form the ‘core’ categories which ‘represent the central phenomenon of the study’. The ‘final codes’ outlined in the Table below represent the selective coding in this study.

Table 2: The Coding Process

	OPEN CODES	FOCUSED CODES	FINAL CODES	COMMONALITIES BETWEEN SOME OR ALL
ELIZA FROM INTERVIEW	Importance of activity; dislikes being alone; very lonely childhood; loves gardening, joy in seeing things grow; love of church and singing therein; has played piano her whole life; a prolific knitter; unsure of whether has grand/great grandchildren; prominence of growing up on a farm; significance of animals in her childhood – cow milking; childhood was predominant referential feature	Occupational importance; church – significance of singing and socialising	Lay expertise of E at home; positive positioning at home and church; significance of church context in terms of lay expertise; freedom of expression	LAY EXPERTISE FREEDOM OF EXPRESSION

<p>ELIZA FROM INTERVIEW WITH FAMILY MEMBERS</p>	<p>Never listens to music; inaccurate sense of time; piano remains important but prefers to play with daughter than solo; dislike of being alone; joy at great grand-daughter's weekly visits; 10 minute estimated memory length; joy of cooking but needs assistance now; church-going enjoyment; out of character behaviour at family parties; E shows some confusion regarding her current living arrangement; significant negative change in E during short hospital stay; enjoys gardening but less participation now</p>	<p>Maintaining continuing occupation; church (socially and musically understood)</p>	<p>Assistance required to maintain selves. Lay expertise of her family in supporting this, their tacit knowledge</p>	<p>TACIT KNOWLEDGE</p>
<p>ELIZA FROM CHURCH VISIT/OBSERVATION AT LDC</p>	<p>Love of church and singing; importance of socialising at church; significance of being active; significance of daily domestic occupations; does not sing to background music at LDC; will sing if music presented at LDC is live; desire to demonstrate pianistic ability; enjoys a 'good old shout;' love of animals now and in the past</p>	<p>Church; socialising; occupation; animals; live musicking</p>	<p>Continuity throughout life course; personhood and self - how they are maintained by and for E; her tacit knowledge; rituals (church context/occupation); agency and autonomy; where is meaning found? Association of pleasures; ontological security; embodiment</p>	<p>MAINTENANCE OF PERSONHOOD AND SELF RITUALS ASSOCIATION OF PLEASURE ONTOLOGICAL</p>

				SECURITY
PETULA FROM INTERVIEW	Multiple references to war time childhood; many siblings; has always been very practical sewing/growing veg/knitting; love of Andre Rieu (AR); her father was a violinist, she a pianist; disappointment that her own children/grand children aren't musicians; life is quite boring; enjoys being with family	Significance of the past; AR focus; family influence on musical taste	Attachment to past and AR Selves; positioning	
PETULA FROM INTERVIEW WITH FAMILY MEMBERS	Andre Rieu; enjoys watching her dog have fun; her love of dancing; work at making their Petula laugh with banter; P's pride in her father's violin-ship; violin in loft dilemma; P's irritation if AR CDs/DVDs out of place; joy at going to nurseries and allotment; had been keen gardener, situation doesn't support this now; love of being around family hustle and bustle; misery when detached from this for a period last year; frequent iterations to family of questioned self-value	Strong attachment to AR; vicarious enjoyment of her dog; significance of the past; attachment to AR related materials.	AR representative of 'home'	
PETULA FROM OBSERVATION	Andre Rieu, only listens to AR now; love of dancing; love of	Musical taste, influence of parents on;	Association of pleasures; musical taste;	

AT LDC	violin; growing up in a musical household; joy at travelling into London for work; father as violinist; father's violin still in loft, dilemma of what to do with it; circumstances prevented P from continuing her own piano playing following marriage	prominence of violin in discourse; attachments; links between past musicking and AR	her strong identification with her current musical taste (AR) and links to self; musicalized attachment to the past; ritual; flow; ontological security; expertise in seeking out AR as place of asylum for solace and reassurance; embodiment.	
IOE FROM OBSERVATION AT LDC	Making special; freedom of expression; singing dominance; role as singer within the group; engagement/disengagement within the group; quipping; confidence increase; significance of background music	Sub/consciousness; absorption/flow; vitality; freedom of expression; autonomy; roles; non-compartmentalised music; lay expertise (Joe and Poppy as DJ)	Asylum; vitality; freedom of expression; valued and varied roles; personhood; level of confidence and within group security achieved	VITALITY ASYLUM SECURITY/CONFIDENCE POSITIVE POSITIONING/ VALUED ROLES CARING FOR BACKGROUND MUSIC

4.15 Song Analysis

As the Table above demonstrates and as is detailed in subsequent chapters, Joe's singing was a regular feature of his time at the LDC. Eager to represent his particular musicking as accurately as possible and within context, I decided to conduct quasi line-by-line analysis of one particular song (see 'Downtown' Analysis in section 6.5), on the grounds it would be productive. I ascertained that this would assist the reader in comprehending the manner in which Joe used music, both for his own and other people's ends within the timeframe of one song. Although this one song example provides the vehicle for a micro-analysis of Joe's (and others') action, the song analysis is also representative of elements of Joe's musicking, situated more broadly within the context. For example, the song highlights how he switches between using music and quipping to humorous effect, depending on what comments are going on around him (i.e. about drinking tea) and perhaps more significantly, how he subtly yet deliberately draws his colleagues into the song, joining him in a humorous climax.

4.16 Data Gathering and Analysis

The first stage of data gathering was the interview. As already outlined, the interviewees were selected through a number of avenues. It was through me being introduced to one particular LDC group that I subsequently became a regular attendee at the LDC, consequently becoming a participant observer and making additional field notes post-session. Some months later and with the group's consent (detailed later), I then began to audio-record entire LDC sessions I attended.

The analysis of the second data set, the three and a half to four-hour recordings of the LDC sessions included indexing and partial transcription. The richness of the data was such that I indexed the recordings at two-minute intervals. This was done to set out an outline of what was occurring every two minutes throughout each session. Sometimes, these two-minute junctures would land in the middle of a period of silence and sometimes, at a moment of action. I logged these two-minute occurrences and where there was a discussion or action I deemed to be of some potential significance, I transcribed it in full, for as long as it lasted.

Some discussions or actions immediately struck as being noteworthy and were therefore transcribed/described in full in the two-minute indexing process. In some instances, however, I wrote, e.g. 'discussion on growing vegetables', 'talk of wasps', 'F talking about something that happened to him as a boy', 'Great British Bake off chat' and so on. Should any of these have emerged as being significant later on, I could have returned to them and transcribed them in full for further analysis. In this way, I came to know sections of the recordings in great detail, having listened and re-listened to them on many occasions.

I categorised themes and concepts, based on the interviews, their codes, my observations, field notes, recordings and transcriptions. I found the LDC recordings to be particularly invaluable, both for enhancing understanding and as central to the conclusions I ultimately drew from the process. Through the iterative process of listening, transcribing, and listening again and again, my understanding of the individuals became much more nuanced than would have been the case without the recordings, long after I had ceased to attend the LDC sessions. A marked example of this is the manner of Joe's singing, which did not appear to be of any great importance in the first few listenings, but became significant over time. Furthermore, without the recordings, I could never have captured or comprehended the extent to which Joe sang. I initially indexed Joe singing 'Downtown' in full (see Table 3), in order to comprehend him as a solo singing unit. However, my repeated listenings foregrounded just how intricate this specific situation was and what he was giving to others with the music.

Nevertheless, this analysis was a continual process, not only produced through repeated exposure to the recordings, but also by me attending conferences and seminars and reading publications and papers.

CHAPTER FIVE: MUSICKING IN EVERYDAY LIFE

5.0 Prelude

This section describes the case studies on Eliza and Petula, both of whom I first encountered at the same Age UK LDC service. These case studies present the different ways in which two people with dementia use music in their everyday lives. What is their motivation? How is their musicking sustained? Moreover, what is the significance of their everyday music practices in terms of quality of life? Answering these questions brings us back to the concepts discussed in the Introduction and Literature Review of this thesis, including personhood, lay expertise, the significance of context, and positioning. I begin the discussion here with Eliza and move on to Petula, highlighting any links or divergence which occur between the two. The amount of detail for each varies and was dependent on the information they volunteered. Also incorporated into the biographies are details of previous musical experience, where this was known.

This chapter will demonstrate how music ‘helps’ individuals as well as highlighting some processes of appropriation and consumption. I thus demonstrate how these particular individuals became attached to music and with particular reference to the music and dementia sphere, I aim to show the way for future and more person-centred research through specific and gently empirical case studies. I make no claims to generalisability, but propose that there are things which might be recognised, if we only knew how to look for them and these things are highlighted. Some of the concepts covered here and outlined in the first paragraph of this section are necessarily picked up again in the next chapter, to further reiterate the significance of everyday musicking in different contexts.

5.1 Back Stories

The central tenet of this research is the importance of context: the context of music in the life of the individual; the context in which music is now experienced from a social relational perspective; the context of the musical environments the individual inhabits, and the context of the individual, in terms of who they are and how their histories and

environments have shaped the above. It is therefore of manifest importance to incorporate as much biographical detail as was made available to me, in order to enhance contextual complexity, as outlined in the Methods Chapter.

The narratives each of these individuals, told and re-told about themselves during our time together, represent their subjective experience of living. In other words, through the narration of their past and present lives, individuals have autonomy to substantiate an identity which differs from what may have been ascribed to them as ‘people with dementia’ (Bender & Chesterton, 1997). Concurring with this perspective, Robertson (2010: n.p.) suggests that ‘the narratives of older people with dementia reflect their active struggle to find meaning in terms of realising their sense of self within a social world that largely defines them as different and out of the ordinary’.

5.2 Eliza

To briefly re-cap, my initial contact with Eliza, who was 96 at the time, occurred at Poppy’s house, during one of the weekly LDC sessions she attended. I subsequently interviewed both her daughter and son-in-law together and then on a separate occasion, just Eliza. Each of these interviews took place in the home they all shared.

Eliza’s family had deduced that her memory had begun to cause serious concern about four years earlier; although in her daughter’s opinion, it was the death of Eliza’s husband’s eight years previously which had precipitated a noticeable deterioration. When asked in our interview if Eliza had been diagnosed with any specific memory loss condition, her daughter responded:

‘A couple of years ago I took her... well we were particularly distressed about it weren’t we? We thought oh this is getting really bad. I took her for a ‘routine’ and I said to the doctor should we have it officially diagnosed? And the doctor said ‘well, she is 96 what do you expect? What are you going to gain from it?’ And I thought nothing really, so why put her through that? So she hasn’t been officially diagnosed. The doctor probably doesn’t realise, because she performs really well when I take her to the medical place – [chuckles] – and you wouldn’t realise talking to her sometimes.’

Although Eliza has not been formally diagnosed, her daughter confirmed that her GP concludes she has a ‘suspected dementia’. Biographically, in both our interview and

during the time we were together at the LDC, Eliza's narrative talk focused almost exclusively on her childhood and teenage years. Significantly, she omitted to discuss most of her adulthood, including her husband. The main reference she made to her adulthood was in connection with her son, despite the fact she also has a daughter. The dancing she enjoyed in her youth was often recalled, but she was disinclined to recall or discuss the competitive dancing she and her husband had pursued up until around 20 years previously; some details of which were provided by her daughter.

Eliza grew up on a farm and continues to live in the village where she was born. She was an only child, over which she frequently expressed regret. The following comment comes from a group conversation at the LDC:

'I'd have given my eye tooth to have had a brother or a sister, anybody to have shared life with. (...) Don't ever envy an only child. It's the most lonely life.'

At around the age of 14, Eliza left home, finding employment as a home help in a town 25 miles away. During our interview, she detailed her enjoyment of those four and a half years spent living away, predominantly by virtue of there being other young people in the house; a situation she described as akin to a second family. Also during our interview, she discussed the outbreak of war, precipitating a return to her village to work on the farm for the war effort. While working away, she had learned to drive and was duly called on to drive a tractor, something which she enjoyed: 'I felt like I was doing my bit for the war.' Socially, the war years were a good time for her; soldiers were billeted in and around the locality of her village and she frequently attended the local dances, regularly put on for them:

'That's where I learnt dancing really, but there were local people as well, local farmers' sons and that. (...) But you could choose your partners more or less and, as I say, quite a lot of locals, boys and girls, but I had quite a good time, in the war.'

Her biographical narrative of her post-war life was minimal. Aspects which were mentioned were a love of knitting and gardening. She has a baby great-granddaughter who visits weekly and her son-in-law suggested these visits were the highlights of her week. However, in our interview, Eliza was unable to definitively recall having any grandchildren or great-grandchildren and in the time I spent with her at the LDC, they were never mentioned.

5.3 The Piano

The roots of Eliza's musical career began in childhood, when she started learning to play the piano. This was something she enjoyed and had an aptitude for. She touched upon her piano-playing during our interview, but elaborated on it in greater detail to the group during the LDC sessions. By the time she was in her teenage years, her piano proficiency was such that she was invited to play at the local dances, as she told the LDC group:

'Eliza: I used to play at what we used to call the 'sixpenny hop' nights... it was only locals you see and er... one or two of us that could strum on the piano used to play and the rest would dance.

ED: So what kind of music would you have played?

Eliza: What I could get out of my head usually [all laugh].

ED: So you didn't play from music?

Eliza: Yes, I did as a rule if there was music there, but sometimes they didn't have a copy of the pieces they wanted, and if I knew it I could play it off by heart, if I knew it.

ED: So would the music have been just the chords or would it have been written out notes?

Eliza: Written out notes (...) there was a chappy there that used to dance with me quite a bit (...) and any local people would get up and play a tune or something they knew, and he would say 'come on, you know more about playing the tunes that we like', course it was very localised you see, people just knew what they liked to hear and there was just 2 or 3 of us would play those tunes.

ED: And you knew what they liked to hear.

Eliza: I knew what they liked. So it was many a Saturday night I used to be at the memorial hall strumming away.'

Additionally, although it was not clear which period of her life this was, Eliza reported being called upon to play at various community events; she was, in effect, the 'go-to' pianist in the village. She continued to play the piano throughout her life and suggested in her interview that her piano-playing continues to retain some regularity: 'most days, if I get the time, I'll go in and have a bit of a bang bang, you know.' This was contradicted by her daughter, who reported that Eliza's piano-playing had significantly reduced in the last three or four years. Her ability to read music was largely intact, but on the occasions when she did play now, she was less inclined to play solo; preferring to duet with her daughter, who suggested in our interview that Eliza 'really likes me to be involved in whatever she's doing'.

In addition to her piano-playing, Eliza's current dominant musical experience occurs during her regular visits to church, where she participates in congregational singing.

5.4 Eliza's Music in Everyday Life – The Context of Church and Its Significance in Terms of Personhood and the Self

Eliza has been a lifelong and regular church-goer. The church she now attends has deep roots in her family history, as it is the same one she attended as a child and where her father was a bell ringer. Moreover, she now has a particular standing within the church and village, as she is one of the oldest members, if not the oldest, of both her congregation and the village. Eliza spoke in her interview and frequently at other times of how much she enjoyed going to church, primarily because of the singing, she explained. Eliza's congregational singing is now the most dominant musical aspect of her everyday life and I would like to begin by discussing the church-going aspect, as a means of giving context to her singing, which will subsequently be addressed.

One of the recurrent themes which Eliza expressed as forming part of her attraction to church-going was being with and socialising with her community: 'Cos [we] meet the various people, we know each other see, well I suppose I know most people in the village... we come out and have a good old gossip, exchange family views.' Eliza frequently outlined the opportunity church afforded her to connect with people in her community. Her positive view of church attendance is firmly linked to socialisation. Over and over, her narratives centred around the socialisation aspect of church and it is possible to comprehend socialisation as forming part of a validation of self. In terms of identity and self, Ellis (2009) simplifies the various selves, as per Sabat and Harré (1992), with Self 1 being 'I exist', Self 2 being 'This is what I am like' and Self 3 as 'These are my different roles in life'. It is apparent that both Self 1 and Self 2 are supported by her going to church. For example, Eliza's discourse demonstrates that going to church allows her to maintain her 'What I am like' Selves ('I am a long-term participant, I am a church goer'), in addition to her Self 3 terms and roles of 'villager, singer, daughter, mother and grandmother'. She has, as already mentioned, lived in the same village most of her life, but is no longer quite so able to go into the village at will for whatever purpose and spontaneously connect with her community, since she

no longer drives and the walk is too far. Her regular church appearances are now weighted with greater significance than in her younger years, as it is the time when she knows she can rely on being able to reaffirm and ground her place in the community, thus helping her to maintain, in collaboration with others, both her personhood and sense of Self.

The value of social networks is characterised by Berkman et al. (2000: 849), who argue that:

‘social networks define and reinforce meaningful social roles (...) which in turn provides a sense of value, belonging and attachment. Those roles that provide each individual with a coherent and consistent sense of identity are only possible because of the network context which provides the theatre in which role performance takes place.’

Not only was the opportunity of ‘meeting people that I know go regularly’ an important aspect of church-going for Eliza, but also ‘mixing with people that enjoy the same things I enjoy’. This prospect of being with people who enjoy the same things not only refers to going to church, but also to the singing aspect, which is impossible to extract from the church context. Her dialogues demonstrate that the two are really just components of the one meaningful entity; aspects of one injecting joy or meaning into aspects of the other. The act of going to church fuses her to her community and family in that collective activity, but it also takes place through the collective act of singing together, as demonstrated by the following quote, taken from a conversation at the LDC:

‘I like going to church because I like to sing... I do, I do. (...) Well you can join in and do what other people do, you know, you crowd together. (...) I mean if we go to a dance, everybody dances. If you go to a church everybody sings, that’s my outlook. (...) I’m mixing with people that enjoy the same things I enjoy, that’s the only way I can explain it...Yes, I love going to church and singing and raising my..., I think my son does as well.’

Returning to Sabat (2002: 35) and his argument that if a person with dementia is stifled in performing any of their Selves 3, then they are restricted and likely to be conceived of by others more dominantly as a result of negative attributes. The very opposite is true of Eliza and her church-going, which enables her to present the attributes she values about herself (family member, village member, congregation member, singer and musician), in which case, it strengthens or maintains her sense

of self and identity. What is also highlighted time and again is the necessity for others to be complicit in her self-maintenance, whether these others comprise family members or fellow members of the congregation.

Building on the requirement for others to be involved in maintaining the self brings us to personhood, as previously discussed on p. 70. Kitwood (1997a), recommends that with regard to dementia, personhood should be understood in terms of 'emotions, feelings and relational capacity' and furthermore, it should be defined as a 'strong recognition of the interdependence of human life, the fact that no one can flourish in isolation; the well-being of each one is linked to the well-being of all' (Kitwood, 1997b: 223). This is what happens in the church scenario with Eliza and her co-congregants; Eliza relates to them as people, as singers and worshippers and as co-villagers, each with some shared history of experience. Moreover, not only do they (the rest of the congregation) contribute to maintaining Eliza's sense of Self and personhood, but she likewise contributes to theirs.

Referencing Buber's work (1937/1970), Kitwood (1997b) strongly equates personhood with Buber's 'I-Thou' mode of relating, in that the latter results in 'making contact with the pure being of another'. Additionally, Kitwood complains here that the relational, 'being with', 'I-Thou' mode is marginalised in dementia care by Buber's other mode, the 'I-It'. The 'I-It' concept is still relational, but requires less engagement or commitment. Relating 'I' to 'it' is, Kitwood implies, about 'information getting, objectivity (and) instrumentality' (Kitwood, 1997b: 4).

The above passage, where Eliza speaks about 'crowding together/mixing with people that enjoy the same things' demonstrates that going to church supports both 'relational capacity' and the 'interdependence of human life'. Moreover, it supports a personhood which involves a commitment to engage. Eliza's personhood is therefore sustained through being with her son and meeting, mixing and joining in the same activity with her fellow villagers through singing and attending church. The validation of joining like-minded people and performing the same activity re-affirms her sense of Self and personhood. The social aspect of singing is significant and in effect, exercises her relational capacity in a musicalised form.

5.5 Positioning

We have seen that what works to support personhood and a sense of Self relies on the collaboration of others and interwoven within this social collaboration for Eliza is also the opportunity to be positively positioned - the importance of which is discussed in section 2.4. By engaging with her community and having her community engage with her, Eliza has the means to become an active agent, involved in reciprocal forms of social action, both giving and receiving. In turn, her community facilitate this positive positioning by cooperating in corroborating the 'repertoire of personae' she inhabits; personae which she outlines as including church-goer, hymn singer and dancer, but which are also likely to include being a long-standing member of the community, musician, mother, grandmother and great-grandmother. Being positively positioned, as I believe Eliza is when at church, empowers her to enact her personal repertoire of personae. Moreover, if negative self-stereotyping, brought about by negative positioning, affects both memory performance and memory self-efficacy, as Levy found (Levy, 1996; Levy et al., 2002; Levy, 2003), this would suggest that the impact of positive positioning is not only that it validates a sense of self, but that it has a favourable impact on memory.

The significance of Eliza's family having an interest in church and church-singing, which aligns with her own interests, with regard to personhood, Self and positive positioning, was expressed by Eliza during a conversation at the LDC.

'I'm very glad they are [church-goers] because we can sort of associate our pleasures in a way;' 'I love going to church and singing and raising my... I think [my son] does as well. (...) I think he does, he usually does go on a Sunday. Anyway it's very often his suggestion, so I think well you must enjoy it, otherwise you wouldn't suggest it. (...) and he does sing up as if he is enjoying it.'

Here, she is outlining how she and her family not only share a common purpose and delight through church-going, which she is included in, but any differences between them in that instance also get eliminated (the 'crowding together', therefore, not only applies to numbers, a grouping, but to closeness as a family in terms of both proximity and inter-subjectivity). Moreover, as the matriarch of her family, this church is her territory and her family are there because of her. Additionally, it is a musically configured territory she occupies and where she remains in control and is competent.

Her family's church attendance reassures her that her family is as she is. They are a part of her church identity and as such, they can unite through their common desire to go to church and share singing. It could also be argued that whilst grounding or being rooted have static connotations and notions of bridges to the past, there is something of a projection into the future that this church-going, with all its pleasurable aspects, will continue. There is the reassurance of the familiar: the building, people, hymns, rituals and routines, but also the positive rewards from group singing, allied to a familiar yet evolving group of people, forming a bridge to the past. All this contributes to making her visits to church meaningful.

Each of these different layers of the social aspect builds up to complete the whole picture of the church-going experience for Eliza, illuminating how church attendance articulates and sustains networks, including through the singing. The social network within which the singing occurs, including the networking which occurs just prior to and just after the service, is not only a draw in itself, but encourages a confidence in Eliza, supporting her in her positive positioning. This in turn impacts positively on both her personhood and validation of self.

5.6 Freedom of Expression

In addition to the effect church has on Eliza's positioning, self and personhood, it also serves as a vehicle for freedom of expression. A quick online search of 'freedom of expression' will reveal that definitions incline mainly towards a human rights agenda, focusing on freedom of speech or opinion. Juslin (2003: 276) defines expression in music as 'a set of perceptual qualities that reflect psychophysical relationships between 'objective' properties of the music, and 'subjective' (or, rather, objective but partly person-dependent) impressions of the listener'. However, without addressing the lay musicker or the lay performer, this is only partially applicable; for example, what are the subjective or objective qualities being expressed? Self-expression gets closer to clarification within the current context, but crucially omits the 'freedom' aspect. My own definition, therefore, includes an intention to express something, perhaps tangible – an emotion, style or feeling - or perhaps something intangible; something which cannot be described through language. 'Freedom' is suggestive of extending beyond oneself, being unbound, unrestricted and inhabiting, if only

temporarily, the external sphere in more overt ways. Freedom of expression, in this instance, represents an opportunity for expanded participation and creative ability/facility.

A characteristic Eliza outlined from the outset with regard to singing in church was having the opportunity to raise her voice (see quote below). Drawing from the literature previously discussed (Kreutz et al., 2004; Bailey & Davidson, 2005; Clift & Hancox, 2010), it is likely that an initial aspect underlying the pleasure she derives from singing may be the physical act of singing itself. However, while at the LDC, Eliza additionally suggested that it was the opportunity church supplied for freedom of expression via the hymn-singing that was a primary motivator for her attendance:

'I love my church, well because I think... well my mother used to say the same, I look forward to church because I can sing. She said if we went through the village singing they'd think we were all drunk or mad or something, but we can go in the church and raise our voices with the services, you know.'

On another occasion, Eliza reiterated this point:

'I thoroughly enjoy going to the church. I like to sing [laughs]. I mean, somebody said to me one day, what do you go to church for? I said to sing. Well what do you want to sing for? Well I said, would you want to sing walking up through the village, of course you wouldn't. It's the only chance you get being able to raise yourself and enjoy yourself.'

We can see that church has become a liberating experience for Eliza, in that it is an arena which permits vocal freedom of expression in ways that Eliza (influenced by her mother) does not deem to be socially acceptable at other times or in other places during the week. Significantly, in both these quotations uttered on different days, she uses the same word 'raise', as in 'raise our voices' and 'raise yourself'. This shows that the singing enables her to experience liberation in upward as well as outward terms. I interpret the raising outward as the situation emancipating her to boisterously vocalise; it is the releasing of an inhibition. She is good at singing and music has always had significance in her life. She is a confident musician and church allows her to express this. In a sense, the singing enables her to inhabit and embody these realities. Moreover, in the light of her regular enjoyment of singing in church, I would suggest that part of the 'raising up' she refers to occurs through mood enhancement and engaging in an activity she perceives as joyful. I would then venture that music offers a different experience from what is common in day-to-day life and this is

another aspect of the 'raising' she is referring to. The singing and the music are transporting her to another dimension, to a greater or lesser degree.

The religious aspect could be assumed to influence her experience of being lifted, yet Eliza's conversations heavily suggested that religion was not an important determinant in either her church-going or enjoyment. Indeed, on one occasion, the four women at the LDC were having a discussion, instigated by Poppy, around the voting which had taken place in the Church of England the previous day and how this had gone against the ordination of women bishops. The conversation broadened to include general aspects of church-going, at which point I decided to pursue the religious aspect of Eliza's church-going. Despite repeatedly prompting her to clarify the place of religion within her church-going experience on several occasions, no direct response to this particular question was ever received. Instead, Eliza resorted to reiterating what it was she enjoyed about church, i.e. the singing and socialising.

Other aspects of the church-going experience will now be discussed, in relation to their contribution to its significance for Eliza's musicking. The purpose of this is to further emphasise the importance context plays and the potential effect of music and musicking on people with dementia, although in this case, it solely relates to Eliza.

It is not possible to dissociate aspects of ritual and taste from the congregational singing of a hymnal repertoire. Rituals are described by Collins (2004: 25) as a subtle 'pressure toward conformity' and the church could be regarded as an institution particularly demanding of conformity. Notions of yielding are certainly expressed by Eliza; for example, 'Sunday, you've got to go to church'. However, herein lies the contradiction, for it is within the strictures of church that Eliza feels able to express herself freely. Nevertheless, Eliza's involvement with the hymnal repertoire is ultimately passive in the sense that she does not select any of it, although by attending church, one could argue she is selecting the hymnal canon to some degree, as church is where she will undoubtedly locate it. Despite this, knowing she will encounter the hymn genre, more specific choice is not afforded her and the hymns are entirely externally determined and imposed upon the worshipper.

Although discussions of favourite hymns were held within the LDC group from time to time, Eliza never spoke with any affection about the specific repertoire itself. In effect, it was the actual singing, i.e. the participation and the social aspect of the live music activity which were more central to her enjoyment than necessarily the particular song or style. Indeed, the two dominant features she consistently referred to were the social act ('you can join in and do what other people do, you know, you crowd together (...) I mean if we go to a dance, everybody dances. If you go to a church everybody sings, that's my outlook') and the physical act of singing, as described on numerous occasions during my observations of her at the LDC ('I like going to church because I like to sing;' 'I love to go in there on a Sunday morning for a good old shout'). Eliza frequently spoke of church at the LDC and was always enthusiastic about the singing aspect; yet the word, 'hymn' was entirely absent from her discourse, denoting a greater affinity for the act than the artefact. For her, it was about being in concert with others, but more so through the activity than the song.

Illustrating this was one occasion when I observed Eliza in church. This was a family service aimed predominantly at the more youthful section of the congregation. The hymns, presumably chosen with the younger worshippers in mind, were all modern and jazzy in style, i.e. their melodies were more closely modelled on pop songs and included more syncopation than is typically found in traditional hymns. I stood with Eliza in church and the hymns were unfamiliar to us both, significantly affecting Eliza's ability to have a 'good old shout'. On leaving church, a member of the congregation, familiar to Eliza, approached her and enquired, 'How did you get on with those jazzy hymns?' To this, Eliza's (paraphrased) reply was 'I've got all my family with me, so what more could I want, everything's good'. This corroborates the idea that taste, if not ritual, is somewhat incidental to Eliza's enjoyment of the congregational experience. Moreover, music cannot 'be isolated from the activity; it is what arises with it, through it' (Hennion, 2004: 8).

On a subsequent occasion when I accompanied Eliza to church, the service and hymns followed more typical and traditional lines and Eliza proceeded to sing with great gusto throughout all of the hymns; a further indication, as Hennion suggests (2010) that taste cannot be isolated from the activity; performance is central to taste. For Eliza, the corporeality (physicality of singing and being in church) meshed with

the collective (social) and place (church and village) to reinforce the strength of her attachment to that particular world.

5.7 Comparability

To recap the Eliza/church music nexus thus far and break it down into its component parts, we can see that for her, music is tightly interwoven with being social; it is part of maintaining an existing social network and part of a re-affirmation or validation of the Self; it is a vehicle for continuity in terms of actions and repertoire; it provides an opportunity for freedom of expression and gives her joy. We know this because Eliza expresses it herself, although maybe not in these exact terms. However, her knowledge and understanding of what music gives her appears quite clear and acute.

Two points to reiterate here are firstly that Eliza's short-term memory capacity is limited. There were many examples of this, but two will suffice here. During our interview, she was unable to recall having any grand- or great-grandchildren (she has several whom she sees weekly) and her daughter described in our interview, how, when looking at photos of a family party from the previous evening, Eliza had no recollection of the event or being there. However, despite this impaired memory, the detail with which she could explain the meaning she found in musicking was retained and this was repeated frequently across the duration of my fieldwork. This is partly because it was not necessary, in the course of the discussion, to recall a specific event, such as 'I went to church last Sunday with my son'. What is relevant is that she recalled an amalgamation of memories and felt experiences which coalesced to form a whole body of knowledge, memory and understanding.

Eliza's patterns of musicking are, in fact, similar to those found amongst people who do not suffer from dementia. This is apparent from the research on everyday musicking (DeNora, 2003; Bull, 2003; Bull, 2005). By applying the theories of sociologists and music sociologists (who have no dementia-specific frame of reference), we are able to gain a much clearer understanding of what processes are at work in this case. To explain: Eliza is actively engaged in the music-actor-network. She is not a passive bystander waiting to be affected; she and the music (and the

church scenario) are the 'event' and such an event co-produces a desired 'outcome'; an outcome achieved on the basis of a lifetime of work. Gomart and Hennion's work offers perspectives from which to view passions or attachments which are not passively acquired, but realised over time and through 'active work'. On this basis, the above authors further posit that attachment can be a motivating force, considering the experience of living and feeling the attachment. We can begin to see how and why musicking comes to work for Eliza. Her attachment to and passion for church-singing within the context of church attendance has been practiced throughout her life. Eliza knows, as she frequently reiterates, how church-singing makes her feel and so she continues to seek it out. This is a clear manifestation of her lay expertise. Eliza's uses her insight into the meaning of her own musicking for her own ends.

Consequently, there is very little, if any, difference between the Eliza person-with-dementia/music nexus and a person-without-dementia/music nexus. Eliza's musicking is just part of the complexity of everyday life, involving meaning-making and retaining a secure sense of Self, just like anyone else. It is, however, loaded with greater significance, given her cognitive frailty. The 'thinning out' that Schillmeier describes (see section 2.20), or the lack of reliable mediators which can occur in dementia means that her ontological security is under threat and as a result, musical mediation is one avenue through which stability (as well as meaning) can be achieved. This is an idea which I revisit throughout the thesis.

5.8 Eliza, Musicking at the LDC

Eliza's music-making, both now and in the past, is firmly compartmentalised. It was observed that Eliza constricts her freedom of expression to times and places where more explicit active music-making is available for participation. To demonstrate: Eliza does not listen to music; by this I mean, she has never engaged in listening to music at home, as explained by her daughter; nor is music something she 'has on' as an accompaniment to other activities. It was observed that correspondingly, she did not engage in singing along to the background music at any time while at the LDC, irrespective of the music genre. However, out of all the LDC clients, Eliza was the most accomplished and experienced musician. Background and recorded music

were therefore not her conduit for freedom of expression, whereas the piano and or keyboard were materials she did engage with, either by playing or singing.

On a number of occasions, I took along some sheet music to play on the piano, situated in Poppy's living room. The repertoire comprised a mixture of traditional songs (e.g. 'Londonderry Air', 'Cockles and Mussels' and 'My Bonnie Lies Over the Ocean'), as well as hymns and popular songs from the 1930s and 1940s. On the first occasion I played, the first song was, 'If You Were the Only Boy in the World'. Just a few bars had passed when Eliza came and stood right by my side and sang at full volume for the entire song, even though the register of the song did not match her own, as it was considerably too high for her. After the end of the song, she did sit down, but continued to audibly sing along to most of the songs I subsequently played. Her singing put me in mind of her earlier quote on having 'a good old shout' and this was exactly what she was doing. It was as if the context of live piano-playing was ideal for eliciting her participation, not only mirroring her singing in the church experience, but also her own piano-playing experience.

In Sound File 1, Eliza sings along as I play the piano. Again, it is quite above her comfortable singing range, but this does not deter her and she sings for most of the song with strength and intensity. However, singing in this manner was not something she did when recorded music was on. She only did this if there was live music. As far as her own piano-playing was concerned, Eliza told me she would still play at home 'most days', although her daughter suggested this was inaccurate, as mentioned earlier. Her daughter added that Eliza's playing had reduced in recent years, becoming infrequent. She further added that Eliza was disinclined to play solo piano, preferring to play duets with her. Therefore, some discrepancy emerged between mother and daughter surrounding her current active piano-playing frequency. Nevertheless, Eliza regularly spoke of her piano-playing in the past, specifically her youth/teenage years when she played for dances.

If musicking includes talk as well as action, it is irrelevant that Eliza's playing is in inverse proportion to the amount she talks about how often she played in the past. She is well aware that she no longer plays for dances and her conversation supports this (demonstrated by her use of the past tense). However, believing that she still

goes in for a 'bang bang' most days (more regularly than possibly she actually does) is the way she is able to link her past and present and maintain her pianistic identity. It is her youthful, formative and social pianistic experiences in particular to which she is most closely attached and her narratives about these help retain their potency in her everyday life. Notwithstanding this, Eliza does in fact still play the piano and on one occasion in my presence, she was observed in action, as demonstrated by the following vignette.

5.9 The Piano Vignette

Poppy's house has a grand piano in the living room and an electric piano/keyboard in the dining room. On one occasion, after lunch, the four female LDC clients in attendance at this particular session were preparing to make their way back to the living room as usual. Just as they were doing so, with the keyboard lid already up, Poppy began joking around with some of the more comical pre-set demo. pieces on the keyboard. As there was some music already on the keyboard stand, I began to sight-read a little of it and Poppy proceeded to manipulate both the sounds and drum beat for further humorous effect while I continued to play. One of the women leant against the wall by the keyboard, obviously enjoying the jocularly, while another had already returned to the living room. Eliza and the other attendee remained seated at the dining table, continuing their conversation about dogs.

After around five minutes, Poppy returned to the kitchen to clear up after lunch and I ceased playing, although the demo. was left playing. The three women remaining in the dining room were now all standing together, admiring the view from the dining room window: a beautiful rural scene over rolling hills. Shortly after, I turned off the keyboard demo., as it was beginning to irritate me, with sounds that seemed to impinge that moment of admiring the view. The appreciation of this view continued a short while longer, before two out of the three women began to amble back into the sitting room to join their fellow-group members. At this point, Eliza moved toward the keyboard with the obvious intention of playing. I quickly turned the power back on and Poppy, becoming aware of what was happening, simultaneously rushed in from the other room to return one of the dining chairs, which she had just moved away from the piano, so that Eliza could sit down. Initially, Eliza played something from

memory, quite possibly the same piece she had briefly played the previous week on the grand piano in the living room. As before, however, she was unable to continue for long without her memory failing her. The music, namely a book of show tunes from which I had sight-read just a few minutes previously remained in place; it was open at the song 'Luck Be a Lady Tonight' and Eliza began to sight-read this. Both Poppy and I exclaimed, 'Oh, this is Luck Be a Lady!'. Eliza disclosed that the tune was unfamiliar to her and yet she continued to sight-read. The sight-reading was not flawless, but nonetheless, the piece was recognisable. After finishing this song, I picked up an album of 'The Sound of Music', which lay behind the book of show tunes and asked Eliza if she would play some tunes from it. She agreed and I picked out 'Edelweiss'. It was in the key of G major, but for a while, Eliza persisted in playing in B flat, all the while making comments such as, 'Oh, that's got one sharp' and 'I keep forgetting the F sharp'. Eventually, however, she did settle into the key of G, without the B flats.

For a while, I continued choosing different songs from the same song book and requesting that Eliza play them. After a while, there was a sense that Eliza was tiring or becoming reluctant and I apologised for being quite so dictatorial. Eliza turned and smiled, grabbing my legs and saying 'I am enjoying it, I'm just not very good'. She proceeded to suggest her perceived lack of ability was due to a lack of recent practice. She continued to play further, but complained that her hands were stiff. I complimented her ability to reach an octave, especially in the light of having hurt her wrist around a month earlier and only that week having had the sling removed. She agreed, stated that her wrist remained bruised and additionally pointed to the arthritis in her fingers. She remarked that she needed more practice, to which I light-heartedly responded that this was something we all needed. She then stood up and made her way back to the living room to join the other women.

5.10 What Can Be Drawn from This Event?

As mentioned previously, Eliza's daughter reported that her mother's piano-playing had reduced significantly in the past three to four years and on the infrequent occasions she did play, she preferred to duet with her daughter than to play solo. It is unclear why her playing had reduced, especially in view of the above demonstration

of both her playing and reading capability. With respect to her reduced playing, the incongruity lay in what motivated her to spontaneously play at Poppy's, whether on this occasion or others. Hitherto, both the piano and keyboard always remained in the same place at Poppy's and particularly in the case of the keyboard, in a highly accessible position. What were the conditions which supported her feeling drawn to play solo, which is no longer the circumstance at home?

Firstly, it is unlikely to be coincidental that this event occurred just after lunch, when energy levels were probably boosted. Secondly, confidence is the key consideration here and with further analysis of the two situations (home and the LDC), some clarity may be achieved as to the disparity between the two in terms of her confidence about piano-playing. At home, the day stretches out with the rooms; occupations; meanings; memories; biography, history, and daily toing and froing of the three other family members with whom she lives. Eliza's home, the domain where she has lived for so long and where she was once the dominant matriarch, is now the place of a subtle revolution involving the gradual re-alignment of roles and responsibilities being distributed among the other family members. Since the onset of her memory incapacities, she has accumulated a general loss of confidence around the home. This may have been further exacerbated by the building going on there, including moving walls downstairs to make the house more habitable for her daughter and son-in-law, since their move there a year or so earlier. Eliza's loss of confidence at home was referenced by Eliza's daughter, who mentioned in our interview that when at home, she (Eliza) 'really likes me to be involved in whatever she's doing'. In contrast, at Poppy's, the events generally occur in two rooms: the sitting room and dining room. The LDC situation presents less opportunity for disorientation, as the variation of occupations and scenarios is greatly reduced, Poppy's is an unchanging place and space and her time there supports a greater momentary stability, plus the opportunity for empowerment which bolsters her motivation to play the piano. Additionally, viewing the trajectory of Eliza's piano-playing in terms of her biography, her playing has involved a strong social component in the past. That need or desire to be musical in company has patently retained its significance in the present and is able to be mobilised at Poppy's.

The autonomy Eliza displays here is not absolute, as the music was not specifically her choice. However, the piano vignette consists of a demonstration of her substantiating herself or augmenting herself as a social agent and demonstrating a desire to re-connect with and keep alive the 'Eliza as pianist' identity facet. The motivation for her to present her pianist persona links with the literature on coping strategies mentioned in section 2.08, which identifies how people with dementia seek to maintain past Selves as a coping mechanism, often in collaboration with others (Pearce et al., 2002; Dijkhuizen et al., 2006). This is in contrast to other literature, e.g. Sorensen et al. (2008), in that she is not seeking to change her activities, attitudes or values to maintain 'personal value and dignity' but to continue with existing ones. Her identity was not recalled/re-created through the music itself, but through the practice/embodiment of playing; moreover, playing in a social environment.

I would argue that the above event was more dominantly a presentation of the Self to herself, rather than a 'presentation of self to others' (DeNora, 2000). Potentially, the confidence the scenario engendered encouraged her to test herself; to reassure herself that she could still play in front of a group of others, as she had done with such frequency in her youth. In her current daily life, the physicality of playing and hearing the piano had become an infrequent occurrence. Her playing, as in this vignette, not only augmented her social agency, but augmented the sentient experience of that moment/day. Playing and/or hearing the piano remained outside the normal realm of her daily sensations and perhaps this vignette, with the conditions being ripe, not only represents her enacting a yearning for a fresh sensation, but having the confidence to follow through 'embodied awareness' and 'an extension of the living in the here and now' (DeNora, 2000).

Eliza's piano-playing is now not nearly as central to her life as it once was and in effect, what the above vignette demonstrates is a thread running throughout this thesis, which is essentially an examination of the significance of the occasional. Eliza's piano-playing, once quite central to her identity and social being, now make up just a small slither of aestheticised aspects of the whole of her life; it is a secondary form of music-making for her. Nevertheless, this does not diminish its importance when it arises.

Eliza's need or desire to be musical in company has patently retained its significance in the present and is able to be mobilised at Poppy's. Returning more specifically to attachments, her talk and action (as outlined above) around her piano-playing leans heavily towards the social aspect. There was also the matter of her playing at dances, as she explained at the LDC: 'it was many a Saturday night I used to be at the memorial hall strumming away.' It was clearly important to her to be with people and to play with people. The vignette supports that this desire still lingers and so with the right conditions, it may be facilitated. These recalled past events have clear resonance with Hennion's 'cherished events'; they are a canon of occasions to which Eliza returns with great fondness and pride. Reliving her ensemble playing also linked her to the collective past experience and additionally, to a memory of her own facility within a network of others. Similarly, with her hymn singing, although this is something she expressly enjoys, the music and/or repertoire are never discussed. It is rather the structures surrounding the music, the social aspects and the association of pleasures, which dominate.

5.11 Petula

For Petula, as with Eliza, I will discuss her music-making both outside and within the LDC context, outlining parallels and divergence between the two, where appropriate. First of all, however, I will begin, as before with some historical context to Petula's life.

Petula's narrative conversation focused predominantly on her childhood and the teenage years prior to her marriage. She did, however, give more detail than Eliza with regard to aspects of motherhood. A great deal of the focus of her narrative, however, was dedicated to her love of dancing.

In the year of my coming into contact with her, Petula was 78. As was the case with Eliza, my initial meeting with her first occurred when I visited Poppy's house as part of the LDC. Petula was subsequently interviewed in her own home, which she currently shares with one of her daughters and this daughter's family. Prior to the

meeting, I had interviewed another of her daughters, who cares for her during the day, when the co-resident daughter is at work.

Petula had been diagnosed with dementia of a non-specific type around six years previously; her family had started to become concerned about her memory around three years before that. This was highlighted by an instance when she and other female members of her family were making bridesmaids' dresses for a family wedding. Petula, the most experienced dressmaker among them was unable to recall how to sew and ultimately, it was this event which highlighted the extent of her failing memory.

Petula grew up in a suburb of London and was the fifth child of seven. Living close to London meant that much of her education between the ages of six and 12 was disrupted by the Second World War. During our interview she explained: 'I was at school during the war so that was a bit of fun, you know. Not going to school sometimes (...) and then going in people's houses and playing with the children, you know.'

After leaving school, Petula worked at a company as a secretary. This required her to do some training in central London, where the company was based. It was a very happy period for Petula and one she frequently reminisced about.

'I used to go up on the train every day. I was a secretary up there. I had to go over the iron bridge to get to the office where I was working, yeah I loved it. Absolutely loved it. (...) When I was a teenager I jumped on the train where I lived and up to London to work. Every day I would cross that long bridge there, get some lunch, go back again to work.'

Petula was a keen dancer. The company she worked for had its own dance hall and band and she would regularly attend these dances. The dances were a few miles away from where she lived and she rode her bike to get to them, often through a wooded area: 'I used to be mad on dancing. I was always out dancing I was. My mother always used to know where she could find me. (...) I was dance mad I was.'

She came from a relatively musical household; her father was a violinist and her mother had a great love of music, so there was music played in the home. As a girl,

Petula learned and enjoyed playing the piano and it is with some pride that she recalled how amongst her siblings, she was 'the only musician in the family'.

Petula met her husband through her place of work and got married at the age of 19. The day after their wedding, she moved from London to the South-west of England. The couple went on to have five children. 15 or so years into the marriage, however, her husband left her, leaving her to support and care for the children with minimal income.

Petula grew vegetables to feed the family, although it is not clear whether this was preceded by her husband's absence. In addition, as was typical of the time, she made all the children's clothes herself. Although sewing was a necessity, it was also something which gave her great pleasure. She became proficient at general household maintenance, with her daughter suggesting that Petula 'could put her hand to anything'. Details of her life after her children left home were vague, although she briefly mentioned working as a cleaner for a local department store.

5.12 Petula's Musical History

Petula learnt and enjoyed playing the piano in her youth and, as outlined above, loved to dance. When describing frequenting her local dances, she expressed feeling 'ecstatic'. During her childhood in London, music had been a presence in the home; her father, whom she reportedly idolised, was a keen violinist and her mother frequently sang around the house.

After marriage and the five children who followed, she professed to no longer having the time or resources to play the piano and although she expressed a desire to play again, she did not 'think her memory would be much use'. She still had her father's violin in her loft and often expressed dismay that within her large family, there was absolutely no interest in learning to play it. Her daughter explained:

'She's always wanted one of us to play some sort of musical instrument, but we haven't. She was saying 'oh I don't know what went wrong, nobody plays anything. I thought this one would have played that and that would have played this, but no.' (...) She thought I'd be a piano player, because I've got long fingers. And one of my granddaughters, she's got ever so long fingers,

and I said 'oh there you go mother, what're you going to say about her?' 'Oh yes, that's the piano player if ever I seen one. Ooh might get one in the family yet.'

During a discussion surrounding general musicality in the family, taking place between Petula and two of her daughters, the importance she placed on instrumental ability became apparent, as she commented that no one in her existing family was musical. With some irritation, one daughter responded:

'Daughter: They all are [musical]. Don't be silly mum, all my four girls are.

Petula: Are they?

Daughter: Lesley and Laura are. All on karaokes.

Petula: Ahh.

Daughter: No they don't play, but they're all on karaokes.

Petula: They don't play, they don't play music.

Daughter: No, they sing. They sing. They're always, you know... doing music... but none of them actually play anything, but they still like music.

Petula: No, that's a shame isn't it. Nobody did...'

Currently, Petula's dominant musical preoccupation is her attachment to the popular violinist, Andre Rieu. He is a relatively recent addition to her life; the catalyst was a chance sighting around three years ago of a television advertisement promoting one of his CDs, in which the music of Johann Strauss was the prominent musical feature. The members of her family who also saw the advertisement were all fully cognisant of her longstanding affection for the music of Strauss and proceeded to buy her a Rieu CD/DVD. This event sparked Petula's intense connection to Rieu, to the extent that she watches his DVDs most days, if not every day. Petula's Rieu attachment coincided with a sharp deterioration in her memory, such that her family considered her incapable of living alone.

5.13 Petula and the Andre Rieu Connection

The first mention of Rieu in Petula's life was unprompted and occurred during an interview with one of her daughters. At the time of our interview, Petula was living with one daughter, but was cared for by another daughter at a different location during the day, while the other daughter was at work. The daughter who did not live with her relayed the nature of her and her mother's breakfast time conversations, using as an example a day on which Petula goes to Poppy's:

'Daughter: I'll be saying 'oh I think you've got some new ladies coming today' [to Poppy's] and things like that. [Mimics her mother] 'oh have I?' and I say 'Ooh, do you want to take your Andre Rieu?' which I forgot to give it back to her, because I've had her here for the last couple of days.'

ED: So what's that, a CD, er DVD of Andre Rieu?

Daughter: Yes. Oh she loves him. She's got every one of them. So I thought oh thank goodness she's got others at home. That's the latest one, I left here, I thought oh blimey, I'm in trouble now.

ED: So she watches that a lot, when she's at your sister's?

Daughter: Yeah, when she gets the chance. To her it's like watching it the first time. She'll say 'Ooh, I haven't seen this one before'. I'll put one on she's seen 50 million times, [mimics] 'Ooh, I haven't seen this one before, is this a new one?' 'No mum, you've seen it before'. 'Oh have I?' 'Yeah, 50 million times.' [Mimics earnestly] 'I haven't?' 'You have, never mind, it's nice anyway'. 'Oh well I'm listening to it then'. I say 'Go on then'.

ED: So is that every day she listens to that?

Daughter: She did when she was in her own house, yeah, every day.

ED: That she'd listen to him, or just music in general?

Daughter: Only him.

ED: Only him?

Daughter: Oh yes, she's not bothered about anything else. Just him. Her boyfriend.

A picture is forming here of the regularity with which Petula listens/watches Rieu, both at home and elsewhere, as she prepares for a listening/watching opportunity that may arise from the home, by taking a DVD with her to the LDC. The strength of her connection to Rieu is given further credence when the daughter intimates that her mother may be angry with her for moving a Rieu DVD from where Petula would be able to easily locate it. Another indicator of the Petula/Rieu attachment was given by the daughter as she described some troubling incidents which led to the family concluding that Petula should no longer live alone:

'Daughter: [It was] towards the end of the year. Cos I'd come home, and God one day I thought, what the hell has she been doing? Because I'd come in from work, cos I only worked part time. 'God has someone been cooking?' 'Oh I ain't cooked nothing'. She'd only put it in the microwave, turns it on and had forgotten about it cos she can't remember how to work it. So she just turned the button on and there could be like 20 hours on it and then she'll go in the sitting room, watch old Andrew Rieu, and ooh, that's gone out their head. And that's out there gaily burning away cos it's been in too long. You know the dish was melted to the flippin' bottom of the... and I thought ooh lucky it didn't catch fire. Or maybe it did in there, I don't know.

Petula was not oblivious to how her Rieu listening was generally viewed within her family unit, as is clear in the following dialogue between Petula, her two daughters and myself:

ED: Do you enjoy listening to music?

Petula: Oh yes.

ED: Anything in particular?

[General laughter between the 2 assembled daughters]

ED: Do you want to tell me more?

Daughter 1: We'll be here all day!

Petula: I'm an Andre, Andre. What's his name?...

ED: Rieu?

Petula: Andrew Rieu fan. And I drive them pots with his music.

Daughter 2: She's got all the DVDs.

ED: And what is it you particularly enjoy about Andre Rieu?

Petula: Well, it's not him it's the music, yeah.

Daughter 1: Don't lie. You fancy him! [all laugh]... you say he's dishy, as long as he cuts his hair.

Petula: Well I wouldn't say I fancy him but he is a bit dishy.

Now living with one of her daughters, the consensus was that Petula would listen to Rieu as often as she could; most commonly watching his DVDs on the television in the communal living room. However, Petula did say, 'I might go up in my bedroom, if I'm fed up or something and put him on'.

Andre Rieu is a Dutch violinist and self-styled 'King of the waltz'. He formed the Johann Strauss Orchestra, with whom he tours globally, performing a repertoire of light classical music with a heavy waltz/Johann Strauss bias in large venues, more commonly associated with rock and pop music. His stage shows, as depicted on the DVDs, are flamboyant in both costume and stage management. For example, the male members of the orchestra all wear tuxedos, with the women in ball gowns. His formula is hugely successful and in 2012, Classic FM stated that his tour that year was the second most popular in the world, falling behind Barbara Streisand, but outselling both Jennifer Lopez and Justin Bieber (Classic FM, 2012).

5.14 So, Why Rieu?

What is it about his particular kind of music that so appeals to Petula? An initial review of her biography elicits some clues. Firstly, dance music is a feature of his repertoire and Petula frequently reminisces about her love of dancing in her youth,

thus pointing to an obvious link. From an aesthetic perspective, it is clear that at surface level, she is moved by the acoustic properties of Rieu's music, however her taste has arrived at this point. During conversations at the LDC, Petula said: 'They're all my favourites [the pieces] (...) it's the only music I like to listen to, nothing else (...) it's just the sound... it's just the music (...) It's just lovely music.' She would also describe a preference for orchestral music, focusing particular attention on the violin within that set-up: 'I just like the orchestra. *I like orchestral; I do like the violin, not particularly on its own, but I like the violin around somewhere.*'

However, lying beneath the acoustic aspects of Rieu's music, Petula also expressed her affection for Rieu in terms of how he is visually represented in his DVDs. Rieu successfully fashions himself as a R/romantic virtuoso maestro fantasy figure and a persistent theme running through Petula's music conversation mirrors this. Rieu's Paganini-esque demeanour derives from images and conceptions of virtuosity, which are well embedded within Western culture. Indeed, Kawabata (2004: 89), in her discussion on virtuoso codes of violin performance, posits that 'in the peculiar performance culture of the decades following the French Revolution, it was not uncommon to invest violinists with qualities of heroism, power, and virility'. Kawabata further argues that these qualities were symbolised through a 'military aura', not only via the medium of the performance spectacle, but also through the distinguishing features or repertoire. The virtuoso violinist, in particular, therefore comes to reflect 'gendered conceptions of power in society' (Kawabata, 2004: 92). Despite the intervening 200 plus years since the French Revolution, pronounced resonances nevertheless remain and in this instance, are successfully exploited by Rieu. Moreover, Kramer (2012: 231) asserts that the virtuoso unites a trio of 'expressive power and sensitivity with celebrity', facilitating a 'licensed intoxication of ecstatic fandom'.

During the months I spent with Petula, she frequently employed romantic terminology in reference to Rieu. For example, if there was a request for a background music suggestion, as commonly occurred at the LDC, a common refrain from Petula was: 'Can we have my boyfriend on?' Apart from suggesting that Rieu is 'a bit dishy', when I asked her to describe her experience of listening to Rieu during an LDC session discussion on him, she responded, 'Well I'm just listening to the music and thinking

about all sorts of other things... mind you, give me a chance and I'd hop into bed with him'.

Another of the visual aspects which has impacted upon Petula was the size of Rieu's orchestra. She commented to the group at the LDC that she felt he was unique in the present day, asking: 'Where have all the musicians gone these days?' and 'He's the only one that's got an orchestra, isn't he? I don't know any other orchestras like that. I've never seen any other orchestras, have you? I like the orchestra, it's a big orchestra he's got.' Rieu was perceived by Petula as something of a handsome maestro, but also as a champion for the orchestral music cause, which Petula believes to be substantially diminished these days. During further discussion at the LDC, she expressed wonder at how popular Rieu was:

'Have you seen the crowds that go up to him? He's brought er... a lot to the music world he really has, I mean the youngsters that follow him, it's unbelievable. He is [hugely popular]. I couldn't believe it when I saw all the crowds, I just couldn't believe it (...) I think he's a wonderful man to get all those people like that.'

The manner in which Petula spoke about Rieu aligns with the manner in which Eliza spoke of her church-going; specifically the aspect of 'associating our pleasures/crowding together'. In a sense, Petula is associating her pleasures with those of the crowds she sees on the DVDs and the large number of these conspicuous Rieu devotees validates her own devotion. She is associating her pleasures with them, and also vicariously crowding together with them.

5.15 The Self, Taste and Symbolism

We saw that musicking for Eliza hinged upon the validation of the Self because, as Kitwood writes, 'people with dementia, like the rest of us, are historical beings, whose identity is inextricably linked to their personal 'narrative' (1997b: 11), as well as relational aspects of personhood. For Petula, however, Rieu is more central to her sense of Self than to personhood. Much of what is significant about Rieu is the continuity he represents with regard to various aspects of her life. When she listens to him now, it is not so much about engaging with others, but more about linking her to her own foundations. To return a moment to Selves 1, 2 and 3, as previously discussed (see sections 1.4 and 5.4), the impact of Rieu on, for example, Petula's

Self 1 in reference to these is that his music represents a continuity of viewpoint, which can be conceived in terms of the development of taste over time and in locations. The 'I exist' version of Self 1 (Ellis, 2009). Rieu's equation with Self 2 supports Petula's presentation of repertoire of personae, i.e. that she is a dancer; comes from a family of musicians, including a violinist; that she loves music, and that she likes 'classical' music'. Rieu's music encapsulates each of these for her.

Hennion (2010) points out we are composites of our pasts in sediment and such sedimented experiences are central to the formation of our identity. The kernel for Petula's taste for Rieu was clearly outlined during an LDC session as having begun in her youth and within the home environment. She explained: 'I learned to listen to [music] whilst I was with my mother and father.' The associations she draws with Rieu and both her parents as individuals not only lie in the specific musical genre, but also in their individual forms of musicking, namely her father's violin-playing, and her mother's singing. On one occasion, whilst listening to Rieu at the LDC, Petula commented, 'I hope and pray that my mother's listening up there... she used to love this music... she used to like to sing... she wasn't a singer but she was always singing at home'. Indeed, the exposure to this genre of music with her parents at home contributed to her learning the piano: 'Actually, I learnt my music by tinkling on the piano and listening to this [Rieu] (...) my mum was always singing around the house.' On another occasion, she asserted: 'I was brought up with his music, it's always been there.'

Petula recognises the role that social determinism has played in her taste acquisition, this deriving from early on in her biography, to the extent that she expressed at the LDC how she feels the music has 'always been there', it's 'just in there'. Hennion posits that taste cannot be solely accounted for in terms of obscured social sources, but is acquired through a dynamic process - through 'activity' (Hennion, 2007) and training. Acquired over the long term in this manner and aware of the significance this particular aspect of taste has in her life now, Petula works to maintain her taste through activity, via her repeated listenings. In doing so, she is reaffirming an aspect of her identity formed in her youth and as such, is demonstrating her taste (Hennion, 2007).

The evolution of taste is tightly interwoven with aspects of ritual, or the enactment of subtle or not so subtle rules and meanings (Collins, 2004). The regular repetition of rituals over time, therefore, is a contributing factor in taste formation. In his work on rituals, Collins argues that the power of symbols is hugely significant for rituals and it could be argued that Rieu, as a package, is loaded with resonant symbols for Petula. At its most explicit, Rieu's music, whereby both his and his orchestra's personae are included, is loaded with Romantic symbolism: the repertoire, the aristocratic costumes, the orchestration, or the 'dashing' virtuosic-type maestro. Rieu's clear intention is to transmit, both aurally and visually, an unequivocally Romantic impression. However, in tandem with the intended symbols, as far as Petula is concerned, his music contains other semiotic forces. For example, the genre of Rieu's music is allied to her own taste, which is in turn representative of her parents, her youth and her own previous musicking experiences, including dancing. In turn, each of these is further symbolised by the violin. Frith (1996: 121) suggests music 'stands for, symbolizes *and* offers the immediate experience of collective identity'. I would argue that for Petula, Rieu's music intertwines the symbolic with both a collective and personal identity.

Additionally, aspects of taste contribute to the indication of self-boundaries: an 'it's me' or 'it's not me' compartmentalisation (Kleine & Baker 2004: 8), deriving from the past or extending into the future, but also existing firmly in the present. This is illustrated by Petula's repeated stance at the LDC, of: 'I can't stand this crap they call music these days. I can't stand it. I like music. Real music.' With this statement, she is clearly distancing herself from contemporary music, allying herself to Rieu's version of classical music and to her own past. She reiterates this compartmentalisation of taste on another occasion at the LDC, whilst also including associating with 'others' of the same opinion:

'I think lots of the people that like it [Rieu's music]... have got so fed up with the bang bang and drums. It's all just you know, racket that the kids were playing; it wasn't music, it was just a racket. And I tried to steer clear my kids off of it. I didn't do a very good job of it I don't think, but I tried.'

5.16 Positioning

For Eliza, we saw that her particular form of musicking supported positive positioning. This was particularly evident with her church-singing, in which her community facilitated her positive positioning through their cooperation in corroborating the 'repertoire of personae' she inhabits. Moreover, at church, she was an equally valid participant in the activity, just like any other member of the congregation; neither her age nor memory incapacity formed any barrier to participation or singing capacity/enjoyment. Moreover, she was able to engage in singing with others, just as she had always done throughout her life. Her 'position' when singing in church is a non-marginalised one; it is one that includes valued knowledge and experience and therefore, it affords her a degree of power.

In the instance of Petula listening to Rieu, it is possible to see how others, her family and Poppy, collaborated with her to use Rieu in support of her positive positioning. This was apparent from how they would comply with Petula's requests to have his music played. Moreover, in the case of her family, they always ensured she had a Rieu DVD to hand, either when moving between different daughters' houses or when at the LDC. Rieu's music helped re-mind Petula of past identities and Selves during vital (in both senses of the word) periods in her life. This validation through music therefore helps to re-situate Petula in a positive position.

Additionally, however, the positioning concept can further be expanded to include the intrapersonal domain and what Tan and Moghaddam (1995) describe as 'reflexive positioning', or the 'process by which persons position themselves privately in internal discourse' (Tan & Moghaddam, 1995: 387). In Petula's case, I would argue that her Rieu narratives and discourses (not so private or internal) demonstrate that she reflexively used his music to help position herself positively. This chimes with the writings on identity and dementia by Steeman et al. (2013), who found that for this population, 'being valued for who you are becomes more important than being valued for what you do'. Rieu represents much of who Petula is, linking back to her biography and the personae she wants to present, i.e. those of a music and dance lover.

Stepping back, we can see that in the present day, each of the facets illuminated above combine to fashion a package for Petula, which she can cling to at times when her ontological security is threatened, as in the face of her impaired memory.

Ontological security refers to:

‘the need to experience oneself as a whole, continuous person in time (...) in order to realize a sense of agency. (...) When an actor has no idea what to expect, she cannot systematically relate ends to means, and it becomes unclear how to pursue her ends. Since ends are constitutive of identity, in turn, deep uncertainty renders the identity insecure.’ (Mitzen, 2006: 342)

From Petula’s perspective then, her ontological security is likely to be threatened by her memory impairment, which affects her sense of Self within a continuum of time and the trajectory of her personal history. This is a personal history which incorporates the ‘repertoire of personae’. These personae embrace her musical taste and dancing, both of which are influenced by her childhood/early adulthood experiences, associations and attachments.

For Eliza too, it can be understood that her ontological security is positively affected by her type of musicking. The continuity of the act (singing in church) over time and in one place serves to ground her as a ‘whole, continuous person in time’. Her congregational singing legitimises her sense of Self, helping her to maintain a secure sense of place in the world.

This package of Petula’s youth and parents; the united aspects bound up in Rieu’s music, such as the violin; the repertoire; the ensemble; the dancing connotations (waltz), and the parental connotations, all represent and connect the furnishings or accoutrements of her past/youth. They offer a sense of continuity; in addition, defining/maintaining identity. In a sense, Rieu, as a package, brings a sense of order to Petula’s self-concept, uniting some of her personae in one place. Furthermore, the DVDs and CDs are ideal vehicles through which she is able to express her self-concept, whether by talking about him or singing along.

Indeed, not only is Petula fully aware of how the attachment is derived (this is made plain through her regular expositions on the subject), but she is able to clearly describe how it makes her feel and consequently justify why Rieu has become such a

significant presence in her life. She reflexively notes the effect he has on her family: 'I'm in ecstasy, ecstasy. I just love that man, well not the man himself, but the music. I just love it.' This is something she stated during a conversation at the LDC and she further qualified that it is the music she is drawn to, and not the man; as if that would demean or sully her attachment to him. However, she herself subsequently admitted at the LDC that it was about 'the man' to a certain degree and her children tease her over this:

'I've always wanted a piano, but I never did get one (post-marriage). Couldn't afford one with 5 children. So it comes sort of dearer to me now, you know, while I've got the time to listen to it, which I didn't, not bringing up 5 children. (...) I'd have this on all day if I could. My kids, I think they just shut their ears to it, oh not this again when they come in, oh not this again. No I think it's beautiful to have that in the background and just go phwwwop. (...) I'd love to have it on all day, it sort of keeps you company, you know, you're not... you can talk away to yourself and think nothing of it, you know, but if there was no music there, you'd probably feel a fool.'

The fact that Petula's Rieu fascination coincided with her memory deterioration demonstrates that Rieu and the associated memories and attachments offer a haven for Petula. In a sense, Rieu has become a compensatory 'home' for her and his metaphorical presence assuages her. Hennion argues that through the active nature of acquiring attachments and by virtue of being our 'past in sediment', attachments make up 'that of which we are a part'. Petula's regular repeated listenings only serve to strengthen the attachment. In this way, Rieu's music offers Petula a haven which is not dissimilar to Bull's (2000) descriptions of personal stereo use, outlined in the Literature Review, whereby participants describe how personalised music assists them in having something portable from 'home' outside the home, which, in turn, supports feelings of security and well-being.

5.17 Places and Possessions

Building on the idea of Rieu offering a compensatory home, Bender and Chesterton (1997) argue that reminiscence for people with memory incapacities allows them to 'inhabit a lost kingdom'. Petula's narratives certainly indicate the significance of her past in her present. Alternative attachment concepts in other academic fields have been developed – in this case, most relevantly that of place attachment, which is classified as 'the emotional bond formed by an individual to a physical site due to the

meaning given to the site through interactional processes' (Kleine & Baker, 2004: n.p.). Although it is not entirely accurate to describe the past as a 'physical site', in terms of a 'lost kingdom', it might be considered a place and moreover, the past as a place has been ascribed meaning throughout a lifetime of interactional processes. The authors continue that place attachment represents 'a kind of self-extension; its formation requires personal history between self and place (...) it is multi-faceted (cognitive, emotive and behavioural) emotionally complex, and dynamic' (Kleine & Baker, 2004).

The self-extension concept has been hypothesised by Allport (1937) as the means by which identity and self-esteem are gained. It is a process involving 'a continuously expanding set of things regarded as one's own' (Kleine & Baker, 2004: 141). Continuing the relationship between possession and self-extension, Belk (1988) further clarifies this by explaining that self-extension occurs through the control, mastery, creation and knowledge of an object, adding that self-extension functions at both individual and collective levels.

To further concentrate on the past as an allegory of place, I would suggest that for Petula, not only is the past a place, but in relation to Rieu, it is a specific location, namely her home. During the conversation she and I had about Rieu, whilst simultaneously watching a Rieu DVD at the LDC, home was consistently alluded to; 'I hope and pray that my mother's listening up there... she used to love this music... she used to like to sing... she wasn't a singer but she was always singing at home'. In our interview, Petula's daughter illustrated this point further:

'her mother loved music. Cos she [Petula] said 'Ooh, I can see my mum now, waltzing round the living room, you know, dancing and doing the waltz to the music, or whatever,' cos funny enough he did play the violin her dad, but he never danced or anything like that so her mum had to just dance on her own. But yeah she [Petula] loves it, cos he [Rieu] plays Strauss and all that.'

Indeed, Petula's parents were important influences on her young musical life: 'I learned to listen to [music] whilst I was with my mother and father.' Moreover, not only did she learn to listen to music, but the exposure she had to this genre of music, with her parents at home, contributed to her learning the piano: 'Actually, I learnt my music by tinkling on the piano and listening to this.' The associations she draws with

Rieu and both of her parents as individuals not only lie in the specific musical genre, but also their individual forms of musicking – from her father’s perspective, because he was a violinist. This was a fact she was prone to mention, almost without fail, whenever Rieu was playing in our joint company, although she also referred to her mother’s singing and dancing.

The intensity of Petula’s memories from her youth appeared to be increasing. This is illustrated by communication I had with Poppy following the end of the fieldwork concerning Petula. She informed me that Petula, in a conversation about Rieu, had explained to her how she had recently begun to increasingly think of her mother and her mother’s dancing to Strauss, in connection with Rieu. Petula elucidated that these memories were particularly clear in her mind, as if they were ‘from yesterday’. The notion of elderly people recalling memories from 50, 60 or 70 years earlier, as if they were ‘fresh’ memories has much anecdotal support and it is proposed in the current research that for Petula, returning to the past may occur because it is a place of solace and comfort, or a secure place she can visit when unable to make complete sense of the present. The search for solace takes shape in relation to different materials, but for Petula, Rieu remains the key material.

Rieu is present in Petula’s life both in non-physical (i.e. aurally) and physical terms, via the material audio-object. The importance of the aural has already been discussed; however, the material is also of significance. The Rieu CDs and DVDs have become Petula’s cherished possessions, in a sense representing a souvenir of home; a souvenir of the past. They are *the* tangible and material objects, not only verifying Rieu’s existence but her own past and identity. To highlight this, on numerous occasions at Poppy’s, if a Rieu CD was playing, Petula would erroneously suggest it was hers, expressing frustration at lending out what she perceived to be her CDs and not having them returned. Poppy suggested that at present, Petula ‘is in a bubble about’ the CDs and so if anyone else has a Rieu CD, she regards it as hers, suggesting that Petula is becoming increasingly suspicious that others are stealing what she perceives as her cherished possessions. Kleine and Baker (2004) suggest that as self-extensions, material possession attachments are formed over time, through person-object interaction. These are interactions where the object becomes ‘psychologically appropriated, decommmodified and singularised’, in conjunction with

the gradual evolution of the meaning of the Self. There is clear resonance here with the Petula-Rieu phenomenon, in that the Rieu package has evidently been decommodified and personalised by Petula and she has psychologically appropriated and singularised his music. Indeed, if as Kleine and Baker (2004) surmise, possessions are viewed as 'part of the self' and also as instrumental in the development of the Self, it becomes clearer as to why the physical Rieu object in the form of a CD is so significant to Petula.

Outlined in the Literature Review were some of the challenges an individual with dementia may face, influenced by organic brain changes and/or environmental factors. Whatever underlies Petula's poorer cognition, i.e. organic neurological decay and/or any relevant environmental factors, she is faced with the demanding task of living with cognitive impairment. The above section demonstrates the great resourcefulness she employs to minimise the challenges she faces. By what would appear to be serendipity, she and her family happened upon an Andre Rieu television commercial and once the family had subsequently bought Petula a Rieu DVD, she became aware that this music was, in effect, something of a life raft, which could play a significant part in facilitating her management of day-to-day life. Rieu therefore became the apparatus she required. This was *her* knowledge and *her* know-how (or tacit practical knowledge) and she consequently implemented it by seeking Rieu out wherever and whenever possible. She was clearly able to describe what his music does and how it makes her feel.

Overall, Rieu's music offers a positive form of detachment from cognitive knowledge practices, e.g. declarative types of knowledge. Furthermore, the relationship that Rieu's music has with her identity (in the here and now, but relative to the past) means that his music is in some ways an instrument of power or control; it gives her power over aspects of her cognition (aspects of knowledge, memory or identity become more coherent) and power or control over her surroundings, while helping her to add her personalised 'stamp' (and identity) to an environment, whether in her own home or at the LDC.

To expand upon the 'know-how' concept, DeNora (2013: 1) depicts music as a potential place of refuge or respite and uses the term 'asylum' to portray 'a place and

time in which it is possible to flourish' and 'feel as if one is in the flow of things, to be able to feel creative and to engage in creative play, to enjoy a sense of validation or connection to others, to feel pleasure'. I would argue here that this is exactly what Petula derives from Rieu's music. Through the connections to her past, Rieu contributes to her meaningful world and one in which she can recover aspects of her identity; demonstrably leading to a pleasurable experience. Additionally, the process works to stabilise her ontological security and creates an environment in which her life world becomes more comprehensible.

Although Petula requires assistance in locating her DVDs and CDs and working the appropriate machinery, she is nevertheless the driver behind the action and as such, this is proof that for people with dementia, 'care' is not something that is passively received, but actively engaged in by both the 'carer' and 'cared for'. In some cases, such as this one, the 'care' is driven by the person with dementia, but this is not always the case. Nevertheless, care is most definitely a collaborative process, with the care 'baton' being passed in both directions.

5.18 Embodiment and Tacit Knowledge

For both Eliza and Petula, the context in which musicking occurs is significant, both in terms of where it currently takes place and its context relative to the past. This is with regard to agency, positioning, ontological security, personhood and Selves.

Returning to Kontos' work on embodiment (e.g. 2003; 2006; 2014), it becomes clear that tacit 'body knowledge' is part of the appeal and significance of music for both the women studied here. In each case, their personal musicking involves a feeling, as Eliza said about singing in church: 'It's the only chance you get being able to raise yourself and enjoy yourself.' She is describing how she feels here; the physical sensation of singing, but also the feeling of pleasure derived from it. Likewise, Petula explains, 'I'd love to have it (Rieu) on all day, it sort of keeps you company'. Like Eliza's singing, albeit less conspicuous, having music on to keep herself company is a felt experience, giving Petula the impression she is not alone.

Kontos' (2003) notion of the body being central to the 'continuity of our being' is apposite in both the above cases. Firstly, Eliza's lifetime of engaging with the

physical act of church-singing has obvious continuity into the present. However, Petula's statement, 'Actually I learnt my music by tinkling on the piano and listening to this (Rieu)' also demonstrates that her attachment to this style of music began with playing the piano, a physical act. The body continuity in relation to Rieu is perhaps not as consistent over time as it is with Eliza. There is, however, consistency over time in relation to the music engendering feeling and sensation. It is therefore linked, as per Kontos (2003) to the continuity of her being. For both women, their particular feeling in relation to music does not occur in isolation, but within the context of the present, as well as within physical/corporeal aspects of their pasts.

Eliza and Petula's discourses reveal that the two women demonstrate considerable tacit knowledge and lay expertise with regard to identifying the effect of musicking by way of feeling, as well as recognising that it is something they know they need. In Petula's case, she proves this by constantly asking for Rieu to be played, while Eliza regularly iterates that she enjoys singing in church. Their musicking has a clear goal and that is to make them feel good, to put it simply. This embodied knowledge, in terms of well-being, is crucial. What is also apparent in both these cases is that care is not something either of women solely receives passively.

5.19 Common Ground

There are therefore clear parallels between Eliza and Petula's musical lives. What became increasingly apparent throughout the process of analysis, however, were the similarities between the needs of people with dementia to the needs of people without it. Returning to Eliza, it is possible to observe how none of the significant aspects of her musicking are dementia-specific. For example and to recapitulate, music affords her an opportunity for self-expression; reciprocity of social interaction; communing with her local community, continuing to perform activities she has always done and is good at/enjoys; being with and undertaking an activity with her family, and implementing embodied knowledge. Listening to Rieu supports Petula's affirmation of taste; place of private asylum; link to past identities, and also offers a feeling of security. Each of these is an aspect which is not exclusive to cognitive impairment. The aspect of security has already been discussed in relation to work on mobile musicking carried out by Bull (2000) and Skånland (2011) (see pp. 80-81).

Skånland (2011) describes how the MP3 is utilised as a means of coping with stressors in an urban environment. Although Petula does not listen to music outside a home environment, the parallels are clear. Her music use is highly deliberate and mirrors Skånland's (2011) description of the ways in which people use MP3s to create personal solitude - or as DeNora describes it, a place of asylum (DeNora, 2013). Moreover, Skånland's respondents viewed their mobile music practices as facilitating a positive modification in the usually stressful daily commute. Music use on the part of Skånland's informants and Petula thus mirrors how music is actively used as a successful technology for stress management.

In DeNora's (1999) research investigating the everyday musicking of women aged between 18 and 78 (none of whom were identified as having any cognitive impairment) there are many similarities. DeNora highlights how for her respondents, musicking, when employed reflexively, was used as a means of social agency, 'to constitute and reconstitute themselves as specific types of agents (...) as a resource for the conduct of emotional 'work', and for heightening or changing energy levels' (DeNora, 1999: 31). Her respondents 'also turn to music as a device for on-going identity work and for spinning a biographical thread of self-remembrance. Music provides respondents with scaffolding for self-constitution and again, all this applies to Eliza and Petula, who can be seen appropriating music (and their knowledge of it, whether bodily or otherwise) as what DeNora (1999) describes as a 'technology of the self', or a means of self-care. There are therefore no differences between how people with or without dementia use music.

Therefore, what are the implications of this discovery in terms of the current research project? In broader terms, what are its implications in the music and dementia field? Returning to my critique of the snap-shot approach, which is so prevalent in much of the music and dementia research (see section 2.19), I would argue that what Eliza and Petula's musicking makes more plain is that using a medical model as a template for research in this area means that much of what is truly relevant about the 'effects' of music on people with dementia is missed. Most of the music and dementia research discussed in the Literature Review reports music supporting positive change, e.g. Goddaer and Abraham (1994), Hicks-Moore (2005), Ziv et al. (2007), and

Sung et al. (2010), it is not being suggested here that such research is entirely invalid. However, the 'before and after' approaches already critiqued in this thesis can only ever offer a superficial level of understanding as to why or how music may 'work' for this population, because they fail to engage with or explore a wealth of relative aspects. These aspects would better inform, not only of why music may work at any particular moment for any particular individual, but also of how to best employ music in the longer term, as a means of supporting well-being. In addition, the snapshot/before and after procedures incline towards 'othering' people with dementia.

'Othering is a process that is undertaken by individuals to identify those people who are classified as different in a negative way or categorically both distinct from and of lesser significance than oneself and accepted social norms' (Doyle & Rubinstein, 2014). Theories on othering have been established with regard to race (Said, 1978; Luke, 1994; Jensen, 2011), gender (de Beauvoir, 1949/1997; James, 1998; Bleijenbergh et al., 2012), disability (Wendell, 1997; Boréus, 2006), and age (Twigg, 2004; Riach, 2007; Higgs & Gilleard, 2014). Wendell (1997: 271), for example, writes 'When we make people 'other,' we group them together as the objects of *our* experience instead of regarding them as fellow *subjects* of experience with whom we might identify' (emphasis in the original). People with dementia will differ in some ways from those who are conducting the research on or with them; most obviously in age and memory capacity. However, if the field of music and dementia research paid more attention to their participants as 'humans', or as per Kitwood (1997), PERSONS-with-dementia, as opposed to persons-with-DEMENTIA, a greater, more nuanced and more helpful understanding could be achieved.

In seeking to gain an enhanced comprehension of the 'What, why and how?' of everyday musicking phenomena, I have presented the musicking of two individuals in this chapter, for this very purpose. Moreover, focussing on their musicking, both within the context of the LDC and beyond that environment allowed me to demonstrate the way in which what occurs on the outside can affect a micro-environment on the 'inside', i.e. the LDC. In doing so, I began to build a picture which contrasts and compares musicking in both of these cases. Eliza's music-making 'outside' was driven by a desire to express herself freely and to do this socially with others, whether family or community, in order to have her position with both her

family and community recognised and maintained. Church-singing for Eliza is a practice of continuation, upon which she reportedly places great value.

For Petula, Andre Rieu is less representative of an on-going continuation in that his music is a relatively new addition to her life. Nevertheless, the genre he harnesses is a key conduit to her past and as a result, to a place of security. Petula's desire for Rieu's music seems less about fulfilling a need for freedom of expression, but more about acquiring a feeling or a sensation, which can be internalised and exploited to maintain a sense of stability. Eliza is similarly driven to acquire feeling and sensation, but in a manner which can be externalised and shared.

Transported to the 'inside' at the LDC, Eliza, without tending to sing along to background music, demonstrated an occasional need, whenever she felt it was appropriate, to externalise her musicality by playing the piano or singing along with gusto when I played the piano. Conversely, Petula continued on the inside just as she did on the outside; requesting Rieu whenever the opportunity arose.

Although there is some divergence between the women with regard to how they engaged with music, there were clear similarities between them in terms of the ultimate consequences of this music engagement, whether within or outside the LDC. For example, in each case, their particular musicking worked to positively position them, validating their identities and/or Selves. Music engagement was also implemental in supporting aspects of their personhood. Furthermore, for both, musicking supported a demonstration of combined tacit knowledge and lay expertise. This tacit knowledge included musical preference; melody; pitch; phrasing; lyrics, and rhythm. The lay expertise which both deftly employed to their own ends was twofold. Firstly, they knew what impact their particular form of musicking had on them, but secondly, they also knew musicking was something they needed. They consequently set about, within the limits of their lives, to access it wherever possible. In this case, they can be seen to be actively engaged in the care of the Self, in a manner not dissimilar to Batt-Rawden et al.'s (2005) 'self-applied music therapy' concept. This kind of lay expertise echoes DeNora's (2003) perception of music having the potential to be a 'technology of the self', or a device through which one has the means to care for or 'treat' the Self.

CHAPTER SIX

6.0 Foregrounding the Background

The previous chapter focussed on two case studies and their musicking in everyday life, including at the LDC. This chapter similarly has at its core, the impact of everyday musicking. However, its overarching aim is to counter, with numerous examples, the supposition that background music is a triviality (North et al., 2004). It will in fact demonstrate the ways in which background music supports or is actively harnessed by people with dementia.

The majority of this chapter focuses on one individual named Joe, who attended the LDC service. With regard to Joe, as outlined on p. 122, I did not succeed in securing an interview with him. Therefore, knowledge of his biography is limited here. However, as I observed during the fieldwork, it became apparent he was very engaged with the background music, in subtle yet meaningful ways. What follows below therefore details this music engagement as firmly situated within the LDC context and demonstrates the significance of everyday musicking for an individual with dementia. Owing to the limited knowledge I acquired about Joe, it should also be highlighted that he cannot be conceived of as a case study in the traditional sense. Nevertheless, I found his engagement to be highly significant and of a type that has not thus far appeared in any music and dementia literature, thereby warranting his inclusion here. The section on Joe foregrounds the vital importance of context when working to comprehend the impact of music for people with dementia. However, more than this, I drew upon observations which evidence how a person with dementia (in this case, Joe) can use music as a vehicle to care for others.

There follows additional, accompanying detail on a single homeward car journey from the LDC (see Appendix G for consent). This section on the car journey should be regarded as a supporting sub-section, adding further weight to my propositions, namely the fundamental consequence of context in relation to music and dementia, the collaborative care which occurred between group members in this example and the often overlooked significance and impact of background music. Necessarily, both sections in this chapter relate to and support areas which have already been

discussed in the previous chapter on Eliza and Petula. Where relevant, I have highlighted the commonalities.

6.1 Joe

The scale is small, but that is where we live. (Stern, 2010: 6)

When I first encountered Joe, he was one of the individuals making up the Tuesday group at the LDC. Poppy had suggested I meet him, as she felt he could be a potential interviewee, owing to his having begun to demonstrate a connection to music on his visits, as observed by his regular singing contributions during the session.

At that point, Joe had been diagnosed with dementia of a non-specific type and while I was in his company at Poppy's, I acquired minimal facts pertaining to his personal biography. At no time did he volunteer any personal details. When I joined Joe's group, he had been attending weekly LDC sessions for around three months and by this stage, appeared to be well-integrated and comfortable within the group, although this had not always been the case, as Poppy explained in our interview:

'He was very reluctant to come, it took a bit of persuading for the family to get him to agree to come out on a Tuesday but when he first started to come, he sat...his body language was not negative but it was quite sort of er... controlled if you like, so he had his hands firmly on his lap and I'd try and tease a question or two out of him and he'd give me a polite, but one syllable answer. So it was quite hard work.'

However, after about a month, he began to settle into the group. The group sessions were generally jovial in atmosphere and his tendency was not to engage in conversation or partake in the weekly crossword or word quizzes. He did, however, enjoy making quips and involved himself in the group by punctuating the proceedings with a pun or humorous comment.

I will now focus specifically on Joe's musicking within these LDC sessions. By incorporating excerpts from the audio-recordings, the manner in which his singing materialised will be demonstrated and its significance unpacked.

Music is important to Poppy on a personal level and as has already been discussed, it is something she felt was an effective communicative conduit within the LDC scenario. Poppy explained that when she acquires a new client, a high priority for her is to ascertain their music preferences; occasionally, some detail of this will be in the referral notes, but such information is rarely formally recorded. She has two main strategies which she uses to assist her in uncovering people's taste in music. In the first instance, this comprises explicit questioning of clients and their families, with whom she comes into contact at pick-up and drop-off times. In conjunction with this is a secondary experimental approach, where she trials various songs/pieces/genres with clients during the session to gauge their reactions. By exploiting her own extensive and broad-ranging music collection and by being attentive to individuals' responses, whether verbally, musically or physically, Poppy is thus able to detect what music appears to be preferred and accordingly, adds it to the sessions' repertoire canon.

Moreover, Poppy takes care to ensure that all individual tastes are catered for during each session and what is more, continues to assess her clients' unfolding dispositions, tempering the music accordingly; musically curating the scene in a quasi-club DJ manner. Once an idea of musical taste is established, Poppy then has the means to reach out and across to individuals, thereby easing their integration into the group and the session, as was the case in this instance. Largely ignorant of Joe's musical taste, it was the second approach which Poppy successfully employed. Consequently, he began to sing along to the background music, which by now was an almost constant presence, gradually settling into the group as he did so.

From my first encounter with Joe, the degree to which he sang was immediately apparent. He would often sing along for prolonged periods and to most of the songs played, as demonstrated in Sound File 2. He was not unique in singing along with the background music, as others also did from time to time, but the extent to which he did so was substantially more than that of his fellow-group members. In Sound File 2, we can hear the beginning of an LDC session. All are seated in the living room, waiting for their tea and biscuits; meanwhile, Poppy's husband brings in a portable gas heater. There is some banging and crashing whilst he manoeuvres the heater into position and is heard to be offered assistance. There is an exchange about an

unidentified book: 'Whose is this? Is this yours?' 'No, I might have brought it last week.' However, as soon as the vocal line of the music on the stereo begins, Joe starts singing, the surrounding scenario seeming to be of little relevance to him in the presence of music. Dissecting Joe's singing purely from a musical perspective, he demonstrably employed phrasing which was both lyrical and relaxed in manner, revealing a voice which was in tune, broad in range and rich in tone. Consistent with much of the music and dementia literature, he did not display any obvious difficulty recalling song melodies or lyrics.

The range of music played during the LDC sessions encompassed classical (Mozart), light classical (Johann Strauss, Gilbert and Sullivan), hymns, and popular songs from around the 1920s to the late 1960s. Joe's knowledge of songs and music was wide-ranging and he did not restrict his singing to any particular genre or era. Occasionally, he would sing a song in its entirety, but more frequently, he would choose to dip in and out of songs. Songs pitched beyond his own range did not deter him from singing and he also varied the power of his delivery, constraining the volume at times, particularly in the presence of concurrent conversations. At other times, he would express himself with more abandon and with increased volume.

6.2 A Background to the Everyday

Sloboda states that:

'everyday uses of music tend to be characterized by a much stronger role for the context or the accompanying activity. If you use music while engaging in some activity (...) you are not, thereby, elevating the music above the non-musical activity. The non-musical task still 'drives' the situation, in that the non-musical goals remain to be achieved'. (Sloboda 2010: 500)

However, I believe this to be too simplistic an interpretation of what constitutes an activity, because an activity is rarely a single, elevated stand-alone unit. For example, going for a walk is an activity, but the whole package of going for a walk will be enhanced or detracted from by any number of things, including where one walks, who one walks with, the weather, how fit one is feeling, what one is wearing, etc. Which of these can be elevated above the other? Just as going for a walk is an amalgamation of aspects allied to and including the placing of one foot in front of the

other, music can also can form part of a package of entities coalescing, in this case, to form the 'whole', i.e. being at the LDC.

To conceive of levels of elevation, with regard to where music may or may not sit in any given scenario, resonates with a perception of music limited to purely artistic terms, which I find restricting. In Joe's case, the overall activity is being at the LDC and at times, the music is certainly subordinate to the overall context for him. Conversely, at other times, as will be illustrated, the context is definitely subordinate to the music for him and so music takes on a much stronger role than the accompanying activity. For example, in Joe's case, the overall activity is being at the LDC; however, as illustrated in the following sections, Joe clearly proves that the presence and purpose of background music is significantly more nuanced than just an aesthetic modification to the environment.

Joe's interaction with music at the LDC evidences that background music can be a starting point for a variety of actions and processes, the music effectively working as a kind of concealed enabler. For example, as described above, the background music's initial impact was to enable Joe to gradually become acclimatised to the group, by constituting a familiar element in an unfamiliar environment. Although knowledge of Joe's musical preference was not elicited from him in person via an interview, it was possible for me to observe some of his preferences on account of his almost continual singing along to whatever happened to be playing. This idea of familiar music assisting in acclimatisation is supported in the literature (see, for example, Sung et al., 2006; 2010).

As Joe adapted to the LDC group, he chose two participatory paths: one was quipping, the other singing. There are parallels to be drawn between the liminality of Joe's singing and his habit of subtle quipping; both outputs are marginal and discreet, yet in a manner which works for him. In one sense, quipping more closely allies him to the group dynamic in the moment, whereas his singing denotes a separation away from the group in that he is not 'with' them, but away from them 'with' the music. Given his initial insecurity, Joe started on the edge, at the fringes of the LDC group, but was gradually drawn in via Poppy and the music and became comfortable within the environment he found himself in. The literature concerned with the relationship

between joint and communal music and its impact on health and well-being frequently draws associations with the social aspect of music-making (Clift et al., 2007; Elliot & Silverman, 2012; Dingle et al., 2013).

Joe presents an anomaly here, because although his music-making in this instance is situated within a group, more often than not, he is not participating in making music with others. His is a quasi-private musicking, yet in a shared space. In a sense, the group's involvement in the music is immaterial to him for much of the time, in that he is not affected by whether those present engage or not. Yes, singing is a communicative act, but at times he does not appear to require any reciprocity, or seek any communicative musical exchange with the others in the room. An example of Joe's quasi-private musicking in a shared space, demonstrating the group's immateriality to his music-making, can be heard in Sound File 3. The group members are doing the crossword together, which eventually leads to a debate over the subject of dinner ladies. The concurrent background music playing is 'Somewhere over the Rainbow'. Joe takes no part in the conversation and can be heard to be very quietly humming at the beginning of the clip. He then drops out as the debate's intensity increases. However, as the song reaches the climax of the prelude to the chorus, he can be heard to enter in with singing, at first *sotto voce*, but soon after, with increased volume. The fact a conversation was still going on may have initially been a barrier to his singing, in that he ceased humming as the dinner lady chat ensued. However, he eventually lost his inhibitions and the concurrent conversation does not serve as an impediment to his music-making, as demonstrated by his re-entry prior to the chorus.

6.3 Freedom of Expression

A less concealed element that background music permits is freedom of expression. As Joe became more comfortable, his confidence within the group grew and he felt supported in expressing himself freely – rather similar to Eliza in church. I propose that clear parallels can be drawn with the uninhibited manner of Joe's singing and the explanation Eliza gave for her love of singing in church ('I look forward to church because I can sing. (...) if we went through the village singing they'd think we were all drunk or mad or something, but we can go in the church and raise our voices with the

services, you know'). For Joe, the LDC has similarities to the musical significance of church for Eliza, in that the respective scenarios encourage and stimulate a greater range and more nuanced forms of expression, than would be the case in everyday conversation, to which Joe is not a frequent contributor in this case. Both church and the LDC are environments which facilitate a freedom of creative expression and they are also 'safe' contexts, in which vigorous expression is permitted. Eliza admitted she did not think it appropriate to sing on her own, while 'walking down the street', but explained how appropriateness rendered loud vocal expressions in church, not only possible, but also socially acceptable. Similarly, Sound File 4 highlights Joe's spontaneous vitality. He only needed to hear the first line of the song to recognise it, in order to come in with strength and vitality, all the while maintaining the musicality of his phrasing. For both Joe and Eliza, their respective musical environments support them in vocally contributing to the context with subtlety and conviction.

Although Joe's music-making at the LDC could not frequently be classified as joint or communal, as would be the case in congregational singing, the very fact of being situated within a group setting and existing, if not participating, in the general chit-chat, as well as the background music, liberated him (and similarly, Eliza) to confidently, clearly and creatively express himself. For both Joe and Eliza, their creativity and expression are masked by the group; more so for Eliza, owing to the larger group within which her musicking occurs. This masking enables each to be expressive; being almost ignored or subsumed by their respective groups actually gives them the confidence to burst forth vocally, as they are not left exposed. Although for Joe, the group's musical engagement is not required to support his musical agency, since he will sing anyway, irrespective of whether he is joined by others or not, I propose that the group dynamic is nevertheless an oxygenating presence, vital for producing a supportive environment in which Joe has the freedom and confidence to indulge his singing with complete autonomy.

Furthermore, on occasions when Joe was 'locked' into the music, he remained with it, even during some physical exertion, as is illustrated by Sound File 5, where he begins singing, comments on the song title and then decides to leave the room. His mobility is somewhat restricted owing to arthritis and he has some trouble getting up from the sofa, which he jokes about. However, in the process of getting up, he

continues to sing, as if unable to let go of the music. Even as he is leaving the room, moving away from the music, he can be heard singing. His attachment to the music and his singing is such that he appears reluctant to let it go.

The music Joe sings along to is familiar to him and this supports the stabilisation of his ontological security. These more (musical) personalised ecological elements at the LDC provide a sense of continuity derived from his past, but more than that, they allow him to reflexively demonstrate his own musical ability (and enjoyment). Through embodied performance, he is therefore able to inhabit a positive, possibility-laden view of his own Self.

6.4 Capital Exchanges

The next, albeit less discernible, aspect which is evidenced as being supported by background music, as demonstrated by Joe, relates to music as a form of social capital. This has been highlighted elsewhere with specific reference to music therapy (Proctor, 2004, 2011). Since the publication of Putnam's *Bowling Alone: America's Declining Social Capital* (1995), social capital has 'become a key concept in academic theories and research, and influential as a framework for guiding policy-making that seeks to shape everyday practices in relation to building social integration' (Franklin et al., 2009: 1). Additionally, Putnam perceives the social norms constituent of social networks as facilitating both risk and reciprocation, also making them safe (Proctor, 2011). Proctor discerns a parallel here with music, arguing that 'musical culture' also supports and contributes to an environment in which risk and reciprocation are made possible, drawing individuals into 'a sense of being with others' (Proctor, 2011: 252). This in turn facilitates access to the opportunity 'to feel meaningfully *part of society*' (emphasis in the original) (Proctor, 2011: 257).

In the case of Joe, the risk-reciprocation argument is clear, demonstrated by his initial reluctance to attend the LDC and his subsequent constrained social engagement. This gradually became loosened through Poppy's use of music, as she explained in our interview:

'Joe was very affected and frustrated by his memory problems and physical deterioration. Music gave him confidence and huge enjoyment and his

participation in the group became huge. It was only when we started to, you know, put different pieces of music on that he actually began to relax and then over the weeks he was then, almost like putty in my hands really.’ (Poppy)

His increased relaxation in this instance can be attributed in part to the familiarity of the music helping to assuage his apprehension. Although Joe’s dementia was not advanced and he was not observed to exhibit the agitated behaviours often associated with the later stages of dementia - in other words, the sort which has garnered the attention of much of the music and dementia research (Ragneskog et al., 2001; Remington, 2002; Hicks-Moore, 2005; Sung et al., 2006; Goddaer & Abraham, 1994; Ho et al., 2011) - parallels are apparent within the root causes. His being situated at the LDC, in an unfamiliar environment with unfamiliar people and potentially without fully comprehending why, was unsettling and confusing and the familiar music served as an ‘environmental modifier’ (Sung, 2006), assisting his gradual assimilation into the group.

Similar to Petula’s case, Michael Bull’s work on mobile musicking (2000) is relevant here. We saw earlier (see p. 164 how Petula transported or requested the presence of her specific familiar music (Rieu) to the different locations she inhabited, i.e. the LDC and either of her daughters’ houses (see section 5.10). In each of these situations, Rieu’s music added a recognisable entity, which, fortuitously, was also easily portable. For Joe, the familiar music in this context, although not necessarily requested, also allowed him to have something of ‘home’ with him. The consequence of this was that his world, as with Petula, became ‘intimate, known and possessed’ (Bull, 2005: 350). Music, therefore, became Joe’s social Sherpa (as opposed to Bull’s ‘cognitive Sherpa’), consequently easing his safe passage within the group, while also facilitating his acquisition of enough confidence to take risks (by quipping and singing) within the social norms of the context. This, in turn and as outlined by Putnam, led to increased trust, which grew from week to week.

In the sense that capital, social or otherwise, is something which, in simple terms, is accumulated and distributed, the musical capital which Poppy shared with Joe was then reflected back, or back out, into the group, as she explained in our interview: ‘Whatever I put on he loved, so it was almost impossible not to put music on once Joe started coming even if I’d wanted not to put it on, because I saw how happy it

made him and how it enabled him to flourish.’ As a result of this, there was a gradual shift in the group’s collective focus to a greater musical bias: ‘music was the thing that linked him and me and linked him with others in the group.’

Pavlicevic and Ansdell’s (2004) perception of the ripple effect is apposite: ‘music naturally radiates, like dropping a pebble in a pond and seeing the waves of energy spread out in concentric circles’ (Pavlicevic & Ansdell, 2004: 16). The ripples are clearly defined with Joe’s musicking. First, it prompted Poppy to put on music at the LDC with more vigour, or perhaps more devoted attention than previously. There was then a consequent shift in the group’s course towards a stronger musical bias. Owing to Joe’s singing, Poppy’s relationship with him also shifted and vice versa. Not only did it strengthen a link between the two, as outlined in the quote from Poppy in the previous paragraph, but working to put on music that would please him engendered reciprocity: ‘he knew that he made me laugh too, the way he did his really deep ones.’ Here, Poppy is referring to the jocular way in which Joe would sometimes playfully exaggerate the low notes of a song for comic effect.

An additional ripple effect was that Joe transported his singing out of the house into the car on the journeys home, which is detailed later. The following quote from my interview with Poppy demonstrates how the group came to be re-configured as a result of Joe’s singing:

‘Once he and I discovered music together then it unlocked everything and made him to me the centrepiece of the whole Tuesday because he was so funny as well. And the way he just carried on singing... and... not that he ever showed off, because he wasn’t a show man, but he knew that he made me laugh too, the way he did his really deep ones (...) so it gave him a role that was lacking in his life.’

Through the shared importance of music for both Joe and Poppy, Joe’s standing in the group rose, and he became Poppy’s central figure. In their description of what makes music therapy effective, Pavlicevic and Ansdell (2004) could just as well be describing Joe at the LDC: ‘music therapy can work ‘outwards’ for an isolated person towards community and it can also bring the community in, and can create community within a building.’

6.5 Symbiosis

In this section, I build upon Proctor's arguments relative to Social Capital, as described above, i.e. how music engagement enables people to 'feel meaningfully part of society' and experience a sense of cohesion with others. Furthermore, using Joe as an example, I demonstrate the distribution of a musicalised Social Capital, thus further highlighting the significance of background music in this case.

It was only when we started to, you know, put different pieces of music on that he actually began to relax and then over the weeks he was then, almost like putty in my hands really and we had this wonderful banter and humour and the way he used... you know, how he used to put his head up, because it was very stooped and arthritic, and he'd put it up... he'd raise his head and look at me and sort of smile and it was the most wonderful thing, I mean how it makes you feel so warm inside when you get that off somebody, it's wonderful. (Poppy)

Having covered the first sentiment in the above quote, i.e. the relaxing aspect of the familiar background music supporting Joe's integration into the group, I will now turn to the second part of the quote, which alludes to what Joe provides for Poppy, but also includes what he contributes to the group dynamic as a whole. I will first focus on the group in the section below. The impact Joe has on Poppy is considered in the subsequent section.

In the Sound File 6 clip of 'Downtown' (see also the index below), Joe begins to sing, as is customary, within the opening few bars of the song, concurrent with some general chit-chat. His first musical entry (two octaves below the recorded vocal line) is humorous, playing with and subtly exaggerating the word 'downtown', swooping up to hit the first note for comic effect. Poppy and I sing in unison with Joe at this first entry and Poppy is prompted to laugh afterwards, owing to the simultaneous spontaneity, but also to Joe's playfulness here. He joins in the subsequent iteration of 'Downtown' (pre-empting slightly) at the same octave and with the same portamento ornamentation as previously, but this time with a softer dynamic and in doing so, conforms to the terraced dynamics often employed with repeated phrases in conventions of performance from Western classical music. He is absent from the third and fourth 'Downtown' iterations, although he makes a quip about drinking tea: 'the more you drink the more you wish you hadn't.' He reappears on the fifth repetition, but singing out of a comfortable range; straining and tightening to reach

the octave, one below the line of the vocalist. He drops out of the next verse, only to re-enter at the end of the bridge section. However, this time he self-corrects by relaxing his throat, not straining and projects an improved rendition. Perhaps this is why he came in at the end of the bridge, to give himself a ‘run up’ to the chorus and improve on his previous effort.

Joe finally works subtly, yet with some persistence, to lead everyone to join in: ‘your turn then... it was your turn then.’ The other members of the group duly oblige and are rewarded with a unified moment of jocular spontaneity; a performance of group silliness and a joyous moment apparent in the vociferous laughter to be heard following this final ‘Downtown’ instance. The moment is brief, but as Aasgaard emphasises, the word ‘moment’ derives from the ‘Latin word *momentum* that can also mean “moving power”’ (Aasgaard, 2002: 205). I would suggest that the final ‘downtown’ moment did indeed contain some forceful momentum.

Table 3 The Downtown Index

SONG LYRICS (bold black = Joe singing)	Samples of parallel general chat (bold black = Joe’s comments)	Comment on the actions
<p>INTRO</p> <p>When you’re alone And life is making you lonely,</p> <p>You can always go DOWNTOWN (mf¹)</p> <p>When you’ve got worries, All the noise and the hurry Seems to help, I know, DOWNTOWN (p²)</p>	<p>‘Can I have a top up please while you’re standing?... erm... of course.’</p> <p>‘That’s Petula Clarke isn’t it/Can I have another cup of tea?/I thought we were having Andy Williams/Yes of course, I’ll do it for you.’</p>	<p>ED and Poppy sing. Joe also sings, humorously.</p> <p>Joe sings with humorous delivery, slightly quieter than last time, slightly pre-empting the vocalist.</p>

¹ Mezzo-forte = moderately loudly

² Piano = softly

<p>Just listen to the music of the traffic in the city Linger on the sidewalk where the neon signs are pretty How can you lose?</p> <p>The lights are much brighter there You can forget all your troubles, forget all your cares and go Downtown, things'll be great when you're Downtown, no finer place for sure</p> <p>DOWNTOWN (mp³, 8va⁴), everything's waiting for you (Downtown)</p> <p>Don't hang around And let your problems surround you There are movie shows Downtown</p> <p>Maybe you know Some little places to go to Where they never close Downtown</p> <p>Just listen to the rhythm of a gentle bossanova You'll be dancing with 'em too before the night is over Happy again</p> <p>The lights are much brighter there You can forget all your troubles,</p> <p>FORGET ALL YOUR CARES AND GO DOWNTOWN (mp) where all the lights are bright</p> <p>DOWNTOWN, (pp⁵) waiting for you tonight, Downtown, you're gonna be alright now (Downtown, downtown)</p>	<p>'Do you want more tea?/Yes please/... There we are/I've paid up/...It's such a great song this, don't you think it's a good song?/ I've paid up/Yes you have, no probs. Anybody else? You OK? How are you doing?' 'The more you drink the more you wish you hadn't.' 'Are you OK?...Good.'</p> <p>'Now what about Dusty Springfield? Yes, now you're talking/Andy Williams/I am trying, but I'm just not being very successful/You're very trying/Andy Williams was a favourite one/ What was that, lovely?/Andy Williams/ is there any particular song of his that you really like?/ Ooh God no, I can't remember them anyway, there probably was but I can't remember (...)'</p> <p>[more chatter]</p> <p>'Let's see, Andy Williams'</p> <p>'Where's he hiding then? 'What is that woman saying?'</p> <p>'OOH' 'Downtown/Downtown what, what else?/I</p>	<p>Poppy hums.</p> <p>Poppy sings.</p> <p>Mobile phone alert goes off.</p>
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³ Mezzo-piano = moderately softly

⁴ 8va = sung up an octave than immediately previously

⁵ Pianissimo = very softly

a peak during the 'Downtown' example, when such co-operation was taken a step further to include 'singing leader' and more subtly in this case, 'humour leader'. It was not necessarily obvious to the group in real time that they were being led toward the comical 'downtown' unison, even though this was a deliberate act by Joe. Without the co-operation or collaboration of Poppy and the fellow LDC attendees, these two positions would not have been possible. Therefore, In terms of personhood, the other LDC members conferred the status of 'singer-in-residence' and furthermore, this is a complicit construction of Joe's Self 1 and Self 2.

I return to the flip side of the notion that negative positioning can negatively impact upon memory (Levy, 1996; Levy et al., 2002; Levy, 2003) and argue that positive positioning will potentially have the opposite effect. In Joe's case, a quote written in a communication to a local Age UK services manager regarding Joe's time at the LDC neatly demonstrates this:

'His daughter says he remembers very little of his day but he always comes back happy and very often singing which she thinks is great!'

Joe's memory is still impaired following his attendance at the LDC, but his memory of the act and most likely, some of the repertoire of songs is retained. It could be argued that, for Joe, the singing is the most significant positioning/personhood/ Selves dimension of the environment and so those memories are more intact.

On p. 176 I describe Petula's listening to or viewing Rieu in order to reach a place of asylum. Asylum, in the musical context depicted by DeNora (2013: 1), is 'a place and time in which it is possible to flourish' and 'feel as if one is in the flow of things, to be able to feel creative and to engage in creative play, to enjoy a sense of validation or connection to others, to feel pleasure'. I propose that parallels can be drawn with Joe. The background music does provide him with a creative space and what's more, his creativity is not confined to musicking, but also includes his sense of humour. The 'Downtown' example is but one which highlights his connection to others, supporting his sense of Selves and validation of Self. Additionally, time and time again, his singing was representative of his pleasure in the music, with this singing, as can be heard in the sound files, uniting creativity, connection and validation.

What is also evidenced by the 'Downtown' example is that 'care' is rarely unidirectional. The official and designated carer in this instance is Poppy; yet below this, care can be seen to be operating at many subtle levels, not just from the top down. Using 'Downtown' (Sound File 6) as an example, the first stratum of care begins with Poppy putting on the song. However, the scenario is already more complex than would appear to be the case, because immediately prior to putting on the song, Poppy, who had been searching through her music collection, happened upon a Petula Clark album, exclaiming, 'Petula Clark, oh Petula, I love Petula Clark'. A moment or two later, she read 'Downtown' from the back of the CD cover, commenting, 'Everyone remember that?' and then hums the opening riff to remind them. Joe can then be heard to follow her lead by singing 'Downtown', almost in the manner of an orchestral musician warming up. In these moments, it is possible to observe that Joe has been primed by Poppy; she having already stated she is a fan of Petula Clark.

Joe's first entry is then immediately lightly humorous, which supports Poppy's earlier quote: 'He knew that he made me laugh.' Here, Joe sings, possibly to please himself, but by playing around with the delivery on this first 'Downtown', he is demonstrating care for Poppy. This is not care in a therapeutic sense, or a 'caring for' sense, but in a humanistic sense; he exhibits he is 'caring about' her by trying to make her laugh and he is successful, as she does laugh. Similarly, cajoling the group to join in his playfulness is further evidence of his 'caring about' them. He is offering the group an opportunity for fun in real time and in a split second, the group accedes, with little time for contemplation. Thus, there exists a stratum of 'caring about' which emanates from the rest of the group to Joe.

Minimal attention is paid in the music and dementia literature to the positive elements generated by people with dementia in the flow between actors. This is in part due to the heavy influence of the medical model and a bias towards interventionist approaches to research (Gerdner & Sawnsen, 1993; Sung et al., 2006; Sung et al., 2010; Ziv et al., 2007; Ragneskog, 2001). As mentioned earlier, (section 2.18), all too often, particularly in the literature concerned with background music and dementia 'care', there is a presumption of acquiescent response. What the above example clearly demonstrates is that this is not the case and we can see considerable agency

on the part of Joe. On the other hand, it would not have been possible to have captured this, if my research model had been 'snap-shot' and interventionist. An exception to this can be found in the work of Götell et al. (2002), who found that during and after singing familiar songs to patients with late stage dementia, nursing staff experienced enhanced bonding with their patients.

The aforementioned general proclivity of music and dementia research to focus on the effect of music on non-music behaviour limits what can be revealed. To concentrate with greater intensity on the effect of *musical* behaviours, or what occurs within the music between people, supports the uncovering of additional tiers of action. Moreover, a longitudinal approach gives the space required to understand more comprehensively what and who flourishes in such contexts and how musical exposure supports this.

Joe's singing should not be perceived as secondary to the group dynamic, but primary, for it is through his singing that he gives life to the music. He becomes in a sense, the group's 'musical oxygenator'. Additionally, and as in the 'Downtown' example, he contributes musically-framed jocularly to the context. Humour is one of Joe's 'stock-in-trade' resources and one he regularly calls upon. Music is an additional arena which allows him to incorporate this humour, offering the opportunity to play and be playful on an alternative layer and in an alternative dimension. In the 'Downtown' example, therefore, Joe donates, whether consciously or subconsciously, both his musicality and his humour to the group dynamic, meaning that in that moment, particularly in the case of the final 'Downtown' iteration in the clip, he becomes the key enabler of a moment of joy. This clip reveals that there is much to be found 'between the cracks' when one shines a light on inadvertent or subterranean musicking; music-making which ebbs and flows between other goals and other activities. Observing this form of musicking evidences a richer and more vibrant micro-ecology than would be suggested by research which focuses on broader themes of music in dementia care, such as behaviour and agitation.

6.6 Additional Transformations, Musically Supported

Most, if not all the research highlighted previously, focused on background music and dementia care, specifically concentrates on the effect of music on *non-musical* domains; for example, agitation (e.g. Ziv et al., 2007). The idea that background music affects behaviour has considerable support, but I propose that an aspect of behaviour which has not yet been substantially addressed by the music and dementia literature is the effect music has on people's *musical* behaviour. Ultimately it was the effect of music on Joe's musical behaviour (i.e. his singing) which drew attention to him, via observation and the audio-recordings. Moreover it was Joe's musical behaviour which defined who he was and how he was perceived in the LDC group, namely as the singer-in-residence. This led to a general transformation of the group, in that it became generally more musically biased. Moreover, it was Joe who instigated the singing in the car during the LDC journeys back and forth; a legacy which continues (detailed below). Additionally, it was Joe's musical behaviour (his singing) which was noted by his family when he returned from an LDC session (outlined in section 5.26). Essentially, therefore, it was specifically Joe's *musical* behaviour indicated the point where he began to take some active ownership of the background music and so his singing became transformative, both for him and for the group.

So, why did Joe sing? I believe there were two crucial elements working in conjunction to make it possible. Firstly, the constancy of background music at the LDC slowly acclimatised him, whilst simultaneously and subtly priming him to realise that singing was a possibility, or something he could recover. Simultaneously, working together with this in subtle ways and unbeknownst to either the group or Joe, was the context, i.e. Poppy and Joe's fellow LDC members were also gently acclimatising him and making him feel comfortable enough to sing. Therefore, Joe's musical behaviour was in the first instance supported equally by, a) music (the background music) and, b) context (the rest of the group).

A secondary outcome of Joe's singing occurred in relation to his speech. This was not something he had demonstrated any particular difficulty with; nevertheless his spoken sentences were frequently short in comparison to his sung sentences, which

were greatly extended. Music facilitated ease of vocal production and access to an increased vocabulary, such that the bulk of Joe's vocal interjections in the group were sung. This suggests he was more comfortable singing than speaking. Furthermore, the singing gave him access to enhanced vocal fluidity and a greater expressive range; an expressive range falling outside the realms of language. The more comfortable Joe felt, the more he sang and the further he cemented his place within the group, as 'the singer'. The background music allowed him to evolve and grow as an individual.

Sound File 7, which contains a rendition of the hymn, 'Eternal Father', demonstrates Joe's vocal (and musical) fluency, his vocabulary and increased expressive range.

[Recording begins] - Eternal father strong to save

Joe's singing begins, piano *takes breath*

Whose arm has bound the restless wave [vocal fluency]

(piano) *(accent)*

Who bidst the mighty ocean deep [In this line Joe builds intensity of emotion and volume. He employs vibrato on 'ocean'.]

(accent) *(diminuendo)*

Its own appointed limits keep

(piano) *(crescendo)*

Oh hear us when we cry to thee

(accent)

For those in peril on the sea [Ends phrase as per cultural norms with a diminuendo]

He drops out of the next verse, joining in at the end of the next chorus.

The extended musical phrases Joe almost constantly sings evidences him taking pleasure in his own musicality: the richness of his voice and the musicality of his phrasing through lengthened excerpts of lyricism. This is also demonstrated in Sound

File 8, where he begins singing at the line ‘the fundamental things apply’ and commenting on his depth of range, says: ‘It’s gold down there?’ He appears to revel not only in the sounds he creates, but how he employs them, through rubato (rhythmic fluctuations) or changes in dynamic, attack and timbre. The impression he gives is that he is primarily performing his musicality and creativity for himself; it often appears to be of ancillary importance whether others are listening to him or not, as he is the main beneficiary intended for his performance and he clearly enjoys making music. The singing therefore supports a freedom of creative musical expression allowing him to both liminally perform, while not expressly performing for the others.

6.7 Coming Together and Going Home

This final section continues to focus on the currency of background music, but moves away from Joe and beyond the LDC; instead, zooming in on one car journey home. Moreover, I also illustrate that even in the absence of background music, background music is nonetheless influential beyond its initial hearing. What follows builds upon what is discussed above, namely symbiosis, musical behaviours, freedom of expression and social capital.

In addition to having a classical music radio station on during the outward journey over the past year, singing during the return journey has become a staple. In the extract below, taken from my interview with Poppy, this is shown (those clients present in the car journey outlined below are referred to by anonymised initials):

‘It is a sort of ‘Pavlovian’ occurrence now (...) Petula now comes on a Thursday and whilst she says she absolutely can’t sing she was most definitely doing just that last Thursday. Most return journeys are entirely spent singing, typically the same familiar songs – Scottish shanties to war-time favourites, such as It’s a long way to Tipperary. Even ‘Bobby Shaftoe’ has had a rendering [H’s favourite], ‘Oranges and Lemons’ too. Singing on the return journey has now become compulsory! It really does make us all very happy indeed!’

It’s interesting to consider how this started and further unpack these events. By Poppy’s account, it does not seem like it was necessarily an overtly deliberate act on her part to ‘get everyone singing’ in the car. The main influence was in fact Joe, in that singing in the car became a continuation of Joe’s in-house singing. F, one of the fellow LDC attendees, is now the main singing instigator. Consequently, for the

others, simply being in the car is enough of a primer to prompt singing (even for Poppy), but only on the return journey. Furthermore, as with mealtimes, people work together for positive ends. This is suggestive of embodied cognition, as was highlighted earlier in the work of Kontos (e.g. 2003; 2004; 2006; 2012; 2014). It is also allied to Hughes' (2013) rationale (see p. 48), which conceives of understanding as an aesthetic act, including the interpretation of feelings, postures and gestures.

In the case of this car journey, we see that 'care' is not only top down, as previously demonstrated in the 'Downtown' example, but multi-directional. In addition to F leading the singing, therefore being a driving force behind the 'in-car care' on such occasions, Poppy illustrated how others in the car contributed to the co-constructed care. On a particular return journey, the car group was singing 'The Bonnie Banks 'O Loch Lomond', and at the end of each subsequent different song, F commenced singing 'Loch Lomond' again, forgetting that the song had already been sung. It was Poppy's estimation that 'Loch Lomond' was repeated some seven or eight times throughout the journey. This highlights two things: firstly that memory exists on multiple levels. Cognitively, F forgets that Loch Lomond has already been sung on a number of occasions, yet submerged below the cognitive remembrance is an internal memory, part of which is embodied.

As singing is a skilful act, the learned memory of the above skill is 'stored', as Dreyfus (2002: 367) argues, 'not as representations in the mind', but as bodily representations and 'as dispositions to respond to the solicitations of situations in the world' (Dreyfus, 2002: 367). Furthermore, in the light of F and the rest of the in-car group's expertise in singing, with their 'vast repertoire of situational discriminations', he/they are able to perceive 'what needs to be achieved [and] (...) how to achieve [t]his goal' (Dreyfus, 2002: 372). F's memory of 'Loch Lomond' is therefore 'felt'. It is an element of physical know-how and also forms part of a collective memory, because group singing is a familiar act for him. Nevertheless, his memory here is more than subterranean recall, for F knows/remembers that the implementation of this particular physical memory is pleasurable, hence his almost continual repetition. He also perceives that in singing the song, pleasure is being gained by his travelling companions, in which case it is the memory of the pleasure and elements of intersubjectivity which are complementary driving forces here.

Secondly, there is an implicit understanding of the other members of the group, who perceive it is unnecessary to cease the flow of the session by highlighting F's oversight in repeating the song quite so many times. Moreover, they perceive a general beneficence to be achieved by staying with F through his 'Loch Lomond' journey. Each member of the group is therefore contributing to F's care, which is not to say he does not also contribute to theirs, including Poppy's: 'it really does make us all very happy indeed.'

Sound File 9 contains nine short excerpts from one return car journey home and it neatly evidences 'collaborative guardianship', whereby conspicuous cross-level care, mutually experienced, is heard to be operating at ground level within the whole group, including for Poppy. There is no one designated carer, as it were, within the group, but there is an active process of co-constructed guardianship, in which individuals demonstrate care for and about everyone in their party. As a process, it is democratically enacted; moreover, it is messy, improvised, disjointed and spontaneous, although highly effective. It should be highlighted that Joe was not present during this journey.

The car journey home begins and Poppy checks that all four of her passengers (F, D, H and Petula) are OK. In the next excerpt, some moments later, F asks D if she is OK. D is the oldest member of the group, aged 99 and physically frail. She frequently spends long periods at the LDC without speaking, just dozing for extended periods. She is unlikely to start a conversation, although from time to time, she will make a comment, or answer a question if asked. Once F is happy that D is comfortable, he then indulges in a little light flirting, at which point Poppy begins to prompt some singing: 'Is anyone in fine voice today? (...) What songs have you been practising?' To which H responds: 'There was something and I thought, oh we can sing that in the car, and of course in between times I forgot what it was.' Poppy reminds them they had enjoyed singing 'Daisy' last time, at which point F starts singing. 'What's that, F?' says H and then D wryly comments, 'I think I'd rather have 'Daisy'', at which some laughter is heard from those assembled.

Poppy perseveres with trying to galvanise some singing: 'Anyone in a singing voice today?' she asks. F responds with some further flirtation that he is waiting for the ladies to show him the way. Petula is reluctant and claims she cannot sing. Keen to sing, F says, 'Well, let's have a tune, name a tune'. To this, D responds 'Well you do it'. 'This is called passing the buck', says F. The rest of the car agrees. Petula takes up the bantering baton and points out to F that he is the only man in the car, implying it is his role to lead the singing. There is some more joking and Poppy commends F on how well he copes with being the only man at the LDC on these occasions. At this point, rather movingly, Petula says, 'Well, I for one would miss him if he didn't come one week'. With this compliment in mind, Poppy decides that the buck does stop with F and he should lead the singing. Eventually he starts humming and then breaks into song.

The car journey moves on, but later, F begins to sing 'Shenandoah'. This time, very shortly after, D joins in with him. F stops singing and says 'I can't get high enough', to which Poppy replies, 'What was that D? You knew that one'. F tries again and D joins him; singing for an extended period. F's voice dominates, but D can be heard to sing all the way through with him, quietly, but clearly. The support is three-way in this particular excerpt. F starts the singing, D joins in, F drops out and then D is encouraged to sing by Poppy, leading F to try again. D then supports him (and herself) by singing the whole song – an example of collaborative guardianship in action.

A while later, and perhaps on account of having noticed her singing to 'Shenandoah', Poppy encourages D to sing again; this time to a song she is aware he knows, as Poppy has sung it with her before. In this case, Poppy sings the song, 'My Mother Said' and both Poppy and D are rewarded, as D can be heard to sing along to the humorous song. This satisfies Poppy, since it was her intention. It is another example of collaborative guardianship; Poppy encourages D to sing, for D, and she obliges. Had D not wanted to sing, she would not have done so. However, aware that Poppy wants her to sing, she accommodates her, in which case, they are both caring for each other.

Subsequently, F starts singing, but in comes H. She falters as F is still singing, but persists and sings, 'Bobby Shaftoe', with Poppy joining in a little. F sings a full verse uninterrupted, with rhythmic determination. Afterwards, Poppy asks H: 'Is that the one you were thinking of?' to which H responds that it was – an example of situated memory. At the beginning of the car journey, H knew there was a song she wanted to sing, but could not recall which one. Some time and some songs later, she was able to remember, as the situation supported her memory and recall.

The final excerpt is a further example of collaborative guardianship. As part of her general move to encourage people to sing and extend the joy as long as possible, Poppy opens by commenting she would love to hear a Welsh male voice choir. Although this was a sincere sentiment, part of her reason for saying it was because it was one of the 'box of tricks' she used to encourage singing. While she riffed on the theme of Welsh male voice choirs, F began to sing the Welsh national anthem, as if trying to grant her wish. Before too long, Poppy joined him. The trajectory of this excerpt is Poppy working to support the group and F working to support Poppy, although in the end they both supported each other. What the car journey illuminates builds upon what was made apparent by the focus on Joe and his musicking. In the discussion that follows, I will draw comparisons between the two.

6.8 Discussion

As I stated at the outset of this chapter, the primary concern was to shine a light on the overlooked subtleties allied to background music exposure. The example of Joe indicated that such subtleties include an opportunity for freedom of expression, the generation of social capital and support for symbiotic relations. Background music can therefore legitimately be understood as a conduit for action. In the music psychology literature, the definition of 'everyday' in music terms is almost interchangeable with that of 'background music', which Sloboda and O'Neill (2001: 418) specify as being when music's presence is not the main focus of a particular event or occasion, but is incorporated within 'a complex situation of which music is only a part'. North et al. (2004: 75) perceive background music as 'sonic wallpaper', or 'a product (...) to be consumed during the achievement of other goals (...) not necessarily characterized by deep emotional investment'. However, I would argue

that Joe disproves the 'sonic wallpaper' logic, as well as the measure of emotional investment, as he experiences it during some sequences of background music.

The context in which Joe encounters the music certainly adheres to aspects of both the everyday (a regular occurrence) and background (an ambient enhancer). However, the example of Joe presents a contradiction to Sloboda (2010) and North et al. (2004) in that it illuminates how 'everyday' or 'background' music are not part of an inferred binary in which music is either mundane or special, in the case of a concert, for example. In any case, allying the everyday with the mundane is not applicable in this case, as the lines dividing the mundane, everyday, special and background are significantly more blurred than a dualist approach would suggest.

Even in the case of a concert, I would suggest that music remains integrated within 'a complex situation of which music is only a part'. We can refer back to the walking analogy: music may be the main reason an individual is situated where they are but there is a whole web of complementary aspects which contribute to the experience. Additionally and again in the case of a concert, if music is the main focus of that event, this does not guarantee it will remain so for the duration. Attention may wander periodically during a concert for a myriad of reasons, in which case even though music is the main event, it can at times become submerged as sonic wallpaper.

A review of the Petula/Rieu phenomenon within the LDC context also supports this 'blurred lines' perspective. Rieu's music is regularly played at the LDC; sometimes chosen by Poppy, or at other times when requested by Petula. The majority of occasions on which Rieu is played at the LDC, it would fall under the 'background music' banner. Concurrently, there may be other activities unfolding alongside the music, such as chatting, banter or doing the crossword, so the music is being 'consumed during the achievement of other goals'. Nevertheless, its presence is not trifling for Petula; hence her requests to have Rieu played. Furthermore, there is an aesthetic aspect in the music which both enhances her LDC experience and more significantly, reasserts her ontological security.

The car journey, described above, adds weight to the argument that it is inaccurate to perceive background music as sonic wallpaper, or as something to which little

emotional investment is attached. My research demonstrates that background music supports subtle agitations taking place. Without a longitudinal research approach located in more than one research site, this would have been missed. To explain this further, one needs to step outside the particular car journey previously detailed – from which Joe was absent, it should again be noted - back into the immediately preceding LDC session, where he was present (two cars were required to take LDC clients home and on this occasion, Joe was in the other car). The presence of background music in the preceding LDC session had been instigated by Poppy, but was then reinforced by Joe's almost constant singing along. Both these aspects can, in the light of the car journey, be viewed as having worked as a subtle primer in relation to the singing that later transpired in the car.

What the above car journey illuminates is that not only can background music be consequential in the moment it is heard - of which Joe is an example - but it also radiates beyond the moment to impact other people, at other moments and in other contexts, as was the case with the car journey. This corresponds with what has previously been described (see p. 189) by Pavlicevic and Ansdell (2004:16), namely that 'music naturally radiates, like dropping a pebble in a pond and seeing the waves of energy spread out in concentric circles'. The impact of background music, therefore, is both more significant and situated across a broader timeframe than Sloboda (2010) and North et al. (2004) understand it to be. This is evidenced by the two following quotes:

'everyday uses of music tend to be characterized by a much stronger role for the context or the accompanying activity. If you use music while engaging in some activity (...) you are not, thereby, elevating the music above the non-musical activity. The non-musical task still 'drives' the situation, in that the non-musical goals remain to be achieved'. Sloboda (2010: 500)

and the idea of music as 'sonic wallpaper (...) not necessarily characterized by deep emotional investment' (North et al., 2004: 75).

The above Sloboda quote describes how music is subordinate to the achievement of other goals. In the case of my research, the car journey demonstrates that this is not the case; the goal of musicking is engendered by the background music at the LDC (and is acted upon by some people at times), but the emotion, memory (embodied or

otherwise) collectively drives a musical goal to be subsequently realised in an altogether different context.

Furthermore, the car journey example dispels North et al.'s idea that background music generates minimal emotional investment. It may not be explicitly apparent in the LDC sessions that some people are emotionally engaged with the background music, but the car journey demonstrates that some were. This is evidenced by the car journey including songs which were part of the background 'sonic wallpaper' at the LDC. In the case of the LDC, the background music is shown to work on multiple levels and have an extended trajectory.

For example, the background music helped Joe to acclimatise, leading him to a positive and more dominant position. It strengthened the group dynamic and bolstered Joe's confidence, which enabled him to freely and musically express himself. Moreover, it allowed him to perform his humour. The cumulative effect was that some of these elements transferred to the car journey home. Elements such as a strong group dynamic and the confidence to freely express, although additionally, collaborative guardianship, or a symbiosis coalescing around music.

Simply put, background music leads to agency, both musically and socially, which in turn leads others in musical and social agency. Background music can be consequential in the moment it is heard, but it also, as per Pavlicevic and Ansdell (2004) radiates beyond the moment out to other moments and contexts. This is highlighted both by the car journey and the aforementioned quote from Joe's daughter that he remembers little of his day at the LDC, but always comes home happy and very often singing.

This research process has cultivated the realisation that a more accurate definition of background music would incorporate less rigidity. From Joe I learned about the degree of fluidity occurring during exposure to background music, even within the space of just one song – the music imperceptibly morphing from foreground to background, peripherally to centrally, significantly to insignificantly. Furthermore, the near/far focus of the music is not incidental, but the result of decisions made by Joe. It is he who foregrounds or backgrounds the music as, when and how he wishes.

Background music can in fact be seen here to be an activity, not just an ambient enhancer or environmental modifier, although at times it may be either of these. What is significant is Joe's choosing, or working, to decide when to actively engage musically via singing, humming or listening, or else none of these. This establishes, therefore, that background music has the potential to be considerably more than a mere commodity upon which little value can be placed. Engaging with background music for those with or without dementia is consequently more meaningful and loaded with emotional investment than has previously been comprehended in full.

CHAPTER SEVEN

7.0 Music in Everyday Life

An intention of this research was to discover what shape everyday musicking took for a small cohort of people, but it was also to gain enhanced insight into the ‘What, why and how?’ of such music practices. The presentation of the two case studies in Chapter 5 shows two different modes of personal musicking. Eliza’s was a physical and highly relational mode, whether relating to family, community or place (church). Petula’s musicking was less overtly animated and the social element was significantly less important for her. The manner in which the two women appropriated music differed and there were also disparities between some of the reasons why they appropriated music. For example, we see in section 5.4 that Eliza viewed musicking as an important vehicle for joining people and places. Moreover, the opportunity it provided for freedom of expression, both musically and physically manifested, was also meaningful to her. In the case of Petula, however, her more solitary form of musicking provided her with a place of asylum, as illustrated on p. 176. However, there were more similarities than disparities underscoring their various modes of musical engagement. For instance, their musicking afforded positive positioning; the validation of identity; a representation of the familiar, whether genre, repertoire or activity, as well as an arena for the presentation of Self/ves.

Few of the reasons for musical engagement highlighted in the above paragraph necessarily have any specific exclusivity to people who have dementia or cognitive impairment, as demonstrated by examples in the literature pertaining to music and people who do not have dementia; for example, music as asylum (DeNora, 2013), freedom of expression (Blacking, 1995), identity (Willis, 1978; Turino, 1999) and Selves (Campbell, 1998). It is this point which I believe gets at the core of what this project ultimately demonstrates and furthermore, it is something that a great deal of the music and dementia literature overlooks. That is to say, many of the reasons why people with dementia engage with music are the same as for those without dementia. What this cohort need and can be supported with musically is often similar for others. Additionally, as Eliza and Petula demonstrate, not only do people with dementia know what they need, musically speaking, they also know where and how to access

it. Their dementia or physical frailty only becomes relative to their musicking in that they now require more assistance to access it, i.e. Eliza needs to be taken to church, as she no longer drives, and Petula needs help using an audio- or audio-visual device. Therefore, returning to the literature critiqued in section 2.19, I argue that all this adds further weight to my proposition that employing snap-shot/medical model approaches to such research is unsatisfactory. For example, if an aim of music and dementia research is to improve the well-being of those under investigation and if, as I suggest, people with dementia know what they need, then it is logical to follow the lead of those very individuals whose lives or well-being is sought to be improved. These individuals, just like anyone else, know best what musicking 'does' for them and overlooking this fact means aligning with negative positioning, stigmatisation and othering.

In the case of dementia care and allied to the above argument, the two women also revealed that what occurs musically in one place can affect what occurs in another, i.e. in this case, outside and within the LDC context. Eliza's music-making 'outside' was driven by a desire to express herself freely and to do this socially with others, whether family or community. She also desired to have her position in both the family and community recognised and maintained. For Eliza, church-singing is a practice of continuation, upon which she reportedly places great value. For Petula, Andre Rieu is less representative of an on-going continuation, in that his music is a relatively new addition to her life. Nevertheless, the genre he harnesses is a key conduit to her past and therefore, to a place of security. Transported to the 'inside' at the LDC, Eliza, although she tends not to sing along with the background music, demonstrates a need to externalise her musicality from time to time, when it feels appropriate to her and she does this by playing the piano, or singing along with gusto when I played the piano.

Conversely, Petula continued on the inside as she did on the outside, requesting Rieu whenever the opportunity arose. Petula's desire for Rieu's music seems to be less about fulfilling a need for freedom of expression and more about acquiring a feeling or sensation, which can be internalised and exploited to maintain a sense of stability. Eliza is similarly driven to acquire feeling and sensation, but in a manner which can be externalised and shared. These are examples of tacit or embodied

knowledge, as discussed in section 2.5, or as per Kontos (2005): they are representative of 'bodily sources of agency'.

Having little knowledge of Joe's musicking outside the LDC makes it more difficult to see how the three might interweave. Nevertheless, the LDC emerges as a place where, like Eliza, he has an opportunity to freely express himself and once he felt secure, he maximised this. Within the LDC, music (grounded firmly within the context) transformed the reluctant attendee into a 'singer in residence', who subtly encouraged others to join him. Like Eliza, he emerged as an individual with a strong need to externalise his musical feelings and sensations; a further example of embodied knowledge. In the 'Downtown' example, what we also begin to see with Joe is the way he harnesses his own tacit and embodied knowledge of what music can do to unify a group. We recall his cajoling of the LDC group (see Table 3), with remarks like 'it's your turn', as he subtly encourages his LDC colleagues to join him. This is him enacting personal agency as there is a clear goal to his intention. Aware of the likely effect of a group recitation of 'Downtown', i.e. humorous, he works towards that end result. What is more, his intention, underscored by a tacit assumption, proves successful. I would venture this is also evidence of caring for others. Projecting ahead to the joint 'Downtown' iteration, Joe anticipates that the end result will be enjoyable; hence his encouragement.

This collaborative guardianship concept is further supported by Poppy's discourse surrounding Joe and music, in which she initially spoke of how 'it was almost impossible not to put music on once Joe started coming, even if I'd wanted not to put it on, because I saw how happy it made him and how it enabled him to flourish'. Later, she revealed that Joe would humorously play around with his singing and the songs for comic effect, expressly for her benefit: 'he knew that he made me laugh too, the way he did his really deep ones.'

This also leads back to the earlier discussion on p. 48, relating to Hughes (2013), who urges an aesthetic approach to understanding people with dementia, in view of its emphasis on 'perception, intuition and imagination'. What I think the example of Joe illuminates is that not only does Poppy have an aesthetic understanding of Joe, Joe possesses and demonstrates (as in the musical examples) an aesthetic

understanding of Poppy. Moving on to the car journey example, this is representative in some way of a variant of Joe's actions in the 'Downtown' example, whereby the in-car group also demonstrate an aesthetic understanding of each other; an understanding based on 'perception, intuition and imagination'.

Stern (2010: 3) writes that 'vitality (...) is a manifestation of life, of being alive. We are very alert to its feel in ourselves and its expression in others'. I believe that this hits at the core of what is both attractive and has impact in music for these individuals (both inside and outside the LDC): its contribution to and facilitation of personal vitality. Joe's sound files repeatedly illustrate his vitality and bodily experience of intensified living; at times quite internally focused, at others, as demonstrated in the 'Downtown' example, in association with others. During this particular example, his intention of wanting to experience the feeling of 'life manifestation' in others is evidenced by his urging the group to join him in singing, knowing what they will feel and what he will feel from them and with them by their doing so; he was right and was rewarded by the final group laugh.

Hearing Eliza sing in Sound File 1 is also to witness her embodying a form of vitality with vigour. The listener can hear her feeling and experiencing this through her singing. I would surmise that Eliza's love of church-singing not only relates to the vitality it engenders in her, but also to the vitality it engenders in others, with her being yoked to that combined vitality. Petula's demonstration of vitality differs from that of Joe and Eliza, in that she does not express it musically, i.e. via singing. Her expression exists through narrative; talking about how much she admires Rieu and what she likes about his music. Petula describes what she feels, rather than singing what she feels, as is the case with Eliza and Joe.

Stern (2010: 8) further describes vitality as a 'separate kind of experience'; a Gestalt emanating from 'the theoretically separate experiences of movement, force, time, space and intention' (Stern 2010: 5). There are many other activities which could be said to involve a combination of the aforementioned elements, but which are not unique to music. However, part of the potency of music, as experienced by the three case studies, is the very fact it offers an experience outside of, or augmenting everyday life.

Joe's response to background music is particularly noteworthy in that it is contrary to what is theorised by other scholars on the significance of background music. It is clear that the background music in this context works as a vitality regenerator. Additionally, it has the potential to override aspects of Joe's cognitive incapacity, affording him access to freedom of expression ('a separate kind of experience'). This in turn becomes part of the Gestalt incorporating 'manifestation of life' and 'movement, force, time, space and intention'. More than this, the music generates a subtle inter-subjectivity, initially between Poppy and Joe, but one which proceeds to radiate further out into the group. The manifestation of life is ultimately fed and maintained by the whole group. Vitality, however, cannot be measured or very easily described.

Common to all of the musicking already discussed is that each lies entirely outside the realm of the professional or expert musician or facilitator. The words and actions of the three case studies demonstrate that this lay musicking is an effective tool for the re-invigoration or maintenance of well-being. What is also illuminated in this research is that the individuals are not passive recipients of music, specified by time, place, duration or ensemble. These individuals, frequently with minimal assistance, inhabit the role of expert facilitator. In the literature, the 'tendency is to undervalue the musical skills of people lacking formal music training' (Göttel et al., 2002: 196) and Denis Dutton, in proposing the 'art instinct' (2009: 50), infers that the untrained may not necessarily lie at the bottom of the musical food chain. Indeed, he posits that art should be perceived in terms of 'a field of activities, objects and experiences that appears naturally in human life'. Shining a light on such naturally appearing musicking within the context of everyday/human life experiences highlights the significance and value to be found in lay musical expertise. This is demonstrated by the following excerpt from an email (already quoted earlier) sent by Joe's daughter to the local Age UK services manager, regarding Joe's time at the LDC:

'His daughter says he remembers very little of his day but he always comes back happy and very often singing which she thinks is great!'

That Joe does not remember what occurs following each LDC session is an indication of what cannot be recalled in the short term, not an indication of an

impaired knowledge of the event. Moreover, the above quote demonstrates musicking's affect, which remains with him long after the memory of other simultaneous experiences have faded. This, for Joe, is conducive to his wellbeing. To return to DeNora's (2013:1) quotation cited earlier, in which she refers to music as a potential place of asylum, the effect of Joe's musicking in the context is a 'sense of validation or connection to others, to feel pleasure, perhaps to note the absence, or temporary abatement, of pain'. In this case, musicking could also be conceived of as a positive form of detachment from cognitive knowledge practices.

However, the focus on knowledge here is a useful contrast to memory. Memory is the a priori dementia symptom, but memory loss and knowledge loss are not interchangeable. Broadly speaking, knowledge can be defined as what is known (practically or theoretically) and that which is transmissible, while memory is the 'faculty by which the mind stores and remembers information' ('Memory', def. 1). In this case, the impairment of the storage facility, as in dementia, does not necessarily signify an impairment of knowledge; merely the means to access it. Fortunately, Joe, like all of us, is comprised of more than cognitive memory. These other ways of knowing, or 'knowing(s) otherwise', implicitly understood, exist closer to the core of one's being than propositional or declarative knowledge. Declarative knowledge is 'formal, explicit, derived from research and scholarship and concerned with generalisability' (Rycroft-Malone et al., 2004). Or, as Yılmaz and Yalçın (2012: 50) write, it is 'the knowledge that we are aware of and we tell about'. Therefore, when the facility to access propositional or declarative knowledge is impaired, reliance on the implicit intensifies. This is supported by Bourdieu (1990: 73), who argues that 'what is 'learned by the body' is not something one has and can brandish, like knowledge, but 'something that one is'. The 'between the cracks' abstraction is a useful one in that it opens up a space where other knowledge and experiences exist. Such knowledge is tacit and implicit and, to borrow words from Toni Morrison (1984), has hitherto been 'discredited', or at least undervalued.

Adjacent to the concept of knowing otherwise is the extended mind thesis, which advocates an active externalism, based on the active role of the environment in driving cognitive processes (Clark & Chalmers, 1998). It argues in favour of the 'general tendency of human reasoners to lean heavily on environmental supports'

(Clark & Chalmers, 1998: 8), i.e. the use of pen and paper to perform long multiplication or the use of physical re-arrangements of letter tiles to prompt word recall in Scrabble. In Joe's case, it is not so much inanimate elements of the environment which support his memory here, but the animate ones, i.e. his fellow-attendees at the LDC. As Noë highlights, 'consciousness is not something the brain achieves on its own. Consciousness requires the joint operation of brain, body and world' (Noë, 2009: 10).

The data illuminated in this first section vindicates employing Ansdell and Pavlicevic's gentle empirical approach. Spending substantial time with the participants and the phenomena has led to rewards of enhanced insight and perception. The approach demonstrates that employing swift methodologies with rigid boundaries, temporally, musically or spatially, will not necessarily aid in comprehending how, what, when and if music works to maintain well-being in the daily lives of people with dementia.

7.1 BACK TO THE BEGINNING: DISCUSSION AND CONCLUSIONS

In the dementia and music literature, there tends to be an over-reliance on research situated in care homes, concerning those at an advanced stage of dementia, along with a bias toward 'snap-shot' approaches and a tendency for negative positioning. Moreover, there is a lack of attention to 'moral space'. In this study, data were drawn from interviews with the person with dementia and their family carers (with one exception). An ethnographic observation was then conducted over a period of five months. The empirical nature of the inquiry, with a focus on environments, capacities, knowledge and relationships, is central to this project.

In this chapter, I discuss the findings in relation to these key constituents. Reflections on the methodology, study limitations and the implications for policy and practice are also presented.

The two preceding data chapters engaged with three individuals' ways of musicking. The unifying link is that all the musicking was observed at various LDC sessions, attended by all and this environment formed the main context of the musicking. This was where it was situated, observed and analysed (although, uniquely, with Eliza, her

musicking was also observed outside the LDC scenario). In the sections which follow, the findings are distilled into four categories: environments, relationships, capacities, and knowledge. Here, I highlight the differences and similarities occurring between the three individuals.

7.2 Environments and Relationships

The Literature Review covered the contexts in which the main body of music and dementia research is situated. At present, the vast majority of music and dementia research is actually situated in long-term care environments. The consequence is that current understanding of music and dementia is limited. Therefore, one of the contributions of this project is that it broadens the contexts where research into music and dementia may be situated.

My concern is not only that the limited contexts in which the research is based, but, the fact the field gives too little attention to contextual features and their importance in musical engagement and its outcomes. All too often, music is applied in the manner of a pill; the environment in which it is situated often receiving no or scant description or consideration. Given that people with dementia are known to be highly sensitive to their surroundings, I argue that this does no justice to either the experience as a continuous ontology, with an associated sense of agency, nor to the line of inquiry.

As a result, a key contribution of this project is to show just how significant context or environment actually is. For example, I return to the concept of freedom of expression, as first demonstrated by Eliza within the church context. Eliza clearly exhibited enjoyment in her freedom of expression in church, but this was not achieved in isolation. Reaching this point was a culmination of a lifetime of attachments and practices, such as going to church, repetition of the singing act, repetition of repertoire, and family/familiar and community associations. For Eliza to be able to reach the state where she felt moved or confident enough to express herself required a complex interplay of each of these aspects. Therefore, context is key.

This points back to ANT and particularly to Gomart and Hennion's (1999) suggestion that amateurs become transformed by their attachment to a collective. Eliza's 'transformation' or motivation to agency is firmly rooted in the process, or 'active work' (Gomart & Hennion, 1999) of attachment. The presence of freedom of expression - her church-based musicking - is only made possible through an integrated actor-network, contextualised in church. The concept of actor networks, which is of clear significance, not only to what drives Eliza to musick, but also why she perceives it in such positive terms, is almost entirely overlooked in the music and dementia research field. An exception to this may be found in Hara (2011), who describes a music and dementia care world collectively, as an active agent.

Although Eliza's motivation for freedom of expression was mainly linked to church, there were a number of occasions within the LDC context when her need for musical freedom of expression was supported and satisfied, i.e. her singing along to my piano playing (see section 5.8) and her own piano-playing (see section 5.9). Both these modes of musicking mirror her musicking biography, in that she is a pianist and singer. In ANT terms, these are a realisation of a 'script', or things-in-use prescribing specific forms of action (Verbeek, 2005). The context of the LDC here facilitated her to enact a particular script; albeit a script formed many years previously and in other locations.

Joe was another subject engaging in freedom of expression, although the route he took to get there within the LDC environment differed from Eliza's. Poppy highlighted how Joe was initially a reluctant LDC attender, but gradually became acclimatised to the situation, partly through background music as a place of asylum. However, as his confidence grew, even though he continued on occasions to retreat to the background music sanctuary (see Sound File 3), background music also paradoxically facilitated a freedom of expression. This is evidenced by his almost continual singing along to whatever music is playing and demonstrating his pleasure in the embodied nature of musical representation. This may be perceived, as Kontos (2003) suggests, as embodied goal-oriented intention; a capacity which is separate from the cognitive. A further expansion of Joe's general singing pleasure was that the background music, facilitating his singing, led additionally to his acquiring positive positions or roles within the group: roles such as 'singer-in-residence', 'singing

leader', and 'humourist-in-residence' (both musically and non-musically defined). The context in facilitating all of these is clear and consequently, it provides a musically configured trajectory of action. Moreover, the boundary of the trajectory moves beyond the LDC context and into another, i.e. the car journey.

In order to understand the significance of this freedom of expression in context and in terms of having dementia, as a means of maintaining or achieving well-being, the 'Self' as a concept needs to be revisited. Davis (2004: 376), referencing Kitwood, describes the Self as being 'experienced as a continuous ontology, associated with a sense of agency and position in the world'. In the case of Eliza, her sense of Self is maintained by the musicking (this being a vehicle for agency and positioning), but more importantly, by the combination of the musicking situated within a context which is meaningful to her. The context in this case supports her agency and positive positioning, which is where the relationship part of this section comes in, because it is the other actors within the church scenario who collaborate (along) with her in the production or performance of her Self/ves. The church environment in particular provides Eliza with an 'environment that aids expression and production of self' (Davis, 2004: 376). In essence, this represents the opposite to Kitwood's theory of 'malignant social psychology', in which 'the dysfunctional aspects of the social world of the afflicted person (...) can have profound effects upon the afflicted, beyond those of neuropathology' (Sabat, 1994). The social and musical processes, ecologically situated, here work to strengthen Eliza's sense of self and ontological security, which helps explain why church-singing is so significant for her and how it contributes to her well-being.

Moreover, returning to Schillmeier (2008), as discussed on p. 78-79 of this thesis, it is possible to see here that music/king re-thickens Eliza's world, increasing mediators of coherence through the enactment of 'spatio-temporalities of minds, bodies and things constantly re-relat(ing) to each other' (Schillmeier 2008: 144). Her ontological security and therefore, her well-being can be said to be maintained through the meshing of environment, relationships and music/king.

Joe's sense of self within the context gradually became established during his time at the LDC. On his first few visits, he was reportedly insecure and used the background

music (which was familiar to him and therefore supported his ontological security) as a kind of quasi-life raft. However, over time, as his anxiety dissipated (through the presence of music, his use of music and the craft of Poppy), what had initially been a place of refuge or asylum (see the discussion on DeNora p. 174) morphed into a vehicle to present his Self/ves through his freedom of expression. Not having had the benefit of an interview, it is not possible to situate his freedom of expression within any biographical context, unlike the case of Eliza. However, what may be noted is that musicking supported him in advancing various personae, such as 'singer-in-residence'.

Furthermore, in terms of the Self (as was the case with Eliza), interaction with others was a vital component in validating Joe's sense of self. This supports what is proposed by Sabat and Harré (1992: 446), namely that the existence of Selves 2 (publicly displayed personae) 'hinge on the social cooperation or consent of others'. The musicking for both Joe and Eliza is meaningful and supportive here, owing equally to the context in which it is situated and the relational aspect of that context. Moreover, both their particular forms of musicking help positively position them further, re-emphasising a sense of self and agency. The environment and relationship aspects are crucial to music's impact on well-being. This further corroborates my frequently stated concern over the music and dementia literature, which adheres too closely to a medical model, largely ignoring relational and contextual characteristics.

The Petula/Rieu continuum allies with both the asylum-seeking of Joe and the freedom of expression musicking of Joe and Eliza (albeit in a less directly 'musical' manner). Regarding the former, much of Petula's narrative surrounding her listening to Rieu at home and within the LDC suggests that the context or environment in which she listens to Rieu is not so significant as actually hearing his music (*'I think it's beautiful to have that in the background and just go phwwwop. (...) I'd love to have it on all day, it sort of keeps you company'*). She is intimating that no matter where she is, as long as Rieu's music is around, she is content, even perhaps if she is not alone. In terms of DeNora's (2013) asylum argument, Rieu's music can be said to bring both a sense of validation and pleasure. Moreover, in a further development of this, Petula states: *'I might go up in my bedroom, if I'm fed up or something and put*

him on' and this chimes with Bull's hypothesis that listening to personal stereos allows individuals to have 'power of control over their experience of time and space (...) by managing their mood and orientation to space through the micro-management of personalised music' (Bull, 2005: 343). Petula listening to Rieu appears to be predominantly a private and personal experience, in which the relational plays little or no part.

However, along with Small's (1998:9), definition of musicking, which includes musically taking 'part in any capacity', I would suggest that Petula's Rieu talk (which was frequent) falls within the definition of musicking and moreover, it is also a form of (musically related) freedom of expression. Furthermore, this freedom of expression requires the cooperation of those in whose presence she expresses her pleasure over Rieu's music. Therefore, the relational is not irrelevant after all. The argument can be put forward that, as with Eliza and Joe, Petula's sense of self is validated and a positive position secured. These are both achieved through her different forms of musicking, her private listening and her ensemble recitations. In all three cases, what is consequential is that the musicking, whatever its form or configuration, significantly impacted upon the subjects' sense of/ or validation of Self. That the environment and relationships were essential components in this dynamic, aligns with the social constructionist view of dementia (e.g. Sabat & Harré, 1992; Bender & Cheston, 1997). The music/king, whether allied to asylum-seeking or freedom of expression, is a vehicle through which ontological security and positive positioning is achieved.

Musicking thus far, for these three individuals, has been shown to support agency, positive positioning, expression, a secure sense of self and ontology. Bound up with these is the meaning derived through musicking. Returning to the earlier discussion regarding attachments (see discussion in section 2.21), it is possible to comprehend that meaning is partially constructed from what is attached to music and musicking (taste, identity, passion, association, biography and familiarity), but it is also the process of attaching. This is a process which, for Petula and Eliza (the process is not known for Joe), has included church-going, congregational singing, playing the piano, dancing, listening to the post-war dance-music genre and complimentary family musical activities. Understanding the specific time-evolving attachment processes in these cases contributes to better understanding how both the women have sensitised

themselves to things, situations and moments (Hennion 2007). Moreover, it also contributes to a more rounded and grounded comprehension of the context of their musicking within contexts (LDC, church, home) and how musicking is meaningful for them. This thesis has demonstrated the significant part played by relationships, along with musicking, in the co-production of Selves and positive positioning.

The validated Self or positive position is an end result, but not *the* end result. As Willis (1978), Frith (1987; 1978), Hall (1980) and DeNora (2000) observe, music is 'an active ingredient of social formation' (DeNora, 2000: 7) contributing to the production of social life. This clearly resonates with Pavlicevic and Ansdell's (2004: 16) proposition that 'music naturally radiates, like dropping a pebble in a pond and seeing the waves of energy spread out in concentric circles'. Within the context of the LDC, it is Joe (with initial assistance from Poppy), who in a sense, manipulates the background music to the foreground, thus rendering the dynamic of the group and the day more musicalised. Moreover, the production of social life expands beyond the LDC context, with the distribution of energy continuing into the car journey home. The musicking subsequently incites social action to produce social life (DeNora, 2000). The home-bound car journey is in fact a clear representation of 'energy spreading' and the production of social life.

7.3 Capacities and Knowledge

A concern of this thesis has been to expand the comprehension of the place of music within dementia care, by exploring music's place in the lives of three individuals with dementia. Both environment and relationships have consequently been established as contributors to music's positive impact. Indeed, environments and relationships significantly contribute to a supportive framework: one which facilitates the musickers to appropriate music as is relevant to each individual. Moving to capacities and knowledge, the focus shifts to what is enabled by the accommodating environment/relationship framework. A primary component supported by this framework and from which other components feed, is that of self-esteem. The 'losses in the domains of control and competence affect(s) self-confidence (Clare, 2003: 1024) and consequently, when self-esteem is eroded, as in the case of dementia, a person will feel they are no longer valued (Steeman et al., 2007). Additionally, Sabat

et al. (1999: 17) argue that people with dementia frequently become excluded from 'activities that define local social worlds'; activities which will provide avenues through which the Self can be expressed. This in turn will lead to a loss of self-esteem.

I argue that musicking was instrumental in re-gaining or maintaining self-esteem for these three individuals. To support this, I refer to Sabat et al. (1999). They adopt the position, whereby if a 'person-with-dementia' is treated primarily in these terms, then the focus is on defects: 'The AD sufferer is 'managed' rather than 'interacted with', is seen as being a 'patient' first and foremost, is often assumed tacitly to be defective, uncomprehending (...) and is (...) dealt with, on the basis of such assumptions' (Sabat et al., 1999: 17). Continuing this line of thought and offering a summary of Sabat et al. (1999), Frazer et al. (2012) accordingly suggest that:

'the individual maintains a worthy public persona (Self 3) by reaffirming their life to others, by maintaining relationships with others, by referring back to aspects of his or her former personae in an earlier social world, thereby maintaining pride and integrity (Sabat et al 1999). Without another person to participate in the construction of Self 3, the person's attributes and beliefs about those attributes (i.e. Self 2) may become harder to sustain.' Frazer et al. (2012: 679)

It is clear that music and musicking, particularly in the case of Eliza and Petula (because more is known of their biographies), bolsters self-esteem. This is in light of the fact (outlined above) that their lives are re-affirmed to others (and themselves) via reference to former (and formative) personae in earlier social worlds. Pride and integrity are achieved and self-esteem supported.

When I mention above that self-esteem is a primary component on which other components feed, I mean that once secured (via the supportive framework), self-esteem - in this case musically engendered - fosters other capacities. Joe is a good example of this. The other capacities he demonstrates, once feeling more confident, are singing, quipping, musically quipping, and leading others in their singing (each of these relating to freedom of expression). He was also seen to engage in collaborative guardianship and perhaps unknowingly, musicalised the group. Once confident, he was able to be a more securely active agent, becoming empowered and flourishing as a result, evidenced by the previously included quote – 'his daughter says he remembers very little of his day but he always comes back happy and very often

singing'. This was achieved predominantly in the presence of background music and a co-operative ensemble.

In their work on young onset dementia, Clemersen et al. (2014) described how some of their participants felt their identity was threatened by the decline in both physical and intellectual capacity, resulting in a reduced sense of self-worth. However, the above authors observed that participants were able to recover a stable sense of Self 'by holding on to their existing self-concept', 'using techniques such as minimising past skills and placing greater importance on preserved skills' (Clemersen et al., 2014:459). In a sense, this is what is occurring with the musicking of the participants in this research. One of the techniques involved accessing preserved skills (musicking ability), as the opportunity arose, although not necessarily placing greater importance on those preserved skills. The consequence was that through their own musicking, individuals were able to recover a stable sense of Self.

In terms of quality of life, Kitwood and Bredin (1992) identified 12 indicators of well-being behind which they advanced 'four 'global states', 'grounded in the life of emotion and feeling', rather than in 'elaborate cognition' (Kitwood, 1993:66). These global states are self-esteem, agency, social confidence and hope. In essence, this summarises the 'What?' and 'How?' of musicking's potency, for music and musicking, as has been consistently highlighted throughout this thesis, contributes to greater agency, social confidence, self-esteem and, consequently, hope.

Feeding into these capacities is knowledge and a 'knowing otherwise', which is 'grounded in the life of emotion and feeling rather than of elaborate cognition'. I argue that this is a further capacity to be factored in when endeavouring to comprehend the influence of music. One type of knowledge referred to here corresponds with Kontos' notion of 'embodied selfhood', where she was influenced by the work of Merleau-Ponty and his proposition that 'the pre-reflective moving body is (...) intentional by virtue of being naturally invested with a certain perceptual significance, a bodily know-how or practical sense' (Kontos, 2005: 560). Kontos contends that to consider tacit knowledge with the concept of the Self as embodied, is to perceive 'the acted-upon nature of the body both of which are of paramount importance for understanding tacit knowledge'. Moreover, she argues that embodied selfhood is

'what makes tacit knowledge possible both in terms of providing its foundational structure and facilitating its manifestation' (Kontos & Naglie, 2009: 691). Elsewhere, Taylor writes:

'Our body is not just the executant of the goals we frame. (...) Our understanding is itself embodied. That is, our bodily know-how, and the way we act and move, can encode components of our understanding of self and world. (...) My sense of myself, of the footing I am on with others, is in large part also embodied'. (Taylor 1995: 170-1)

Musicking incorporates both embodied and tacit knowledge; the being addressed by Kontos in subsequent work (2014). She argues, again referencing Merleau-Ponty (1962), that there are forms of the 'primordial potentiality of the body' which bear no relation to intellectualist reflexive knowledge. 'Knowledge (...) is the capacity for acting the know how belonging to a subject whose primary relation to the environment is that of pre-reflective active, and practical involvement' (Kontos, 2014: 109). Moreover, she adopts the position that when people with dementia (although the examples she uses are far more advanced than the three studied here) engage with music or musicality, it is contingent on music having been incorporated into their 'bodily schema'. In support of the significance of environmental and cultural interplay in musicking, already discussed, Kontos further adds that the acquisition of sociocultural bodily dispositions, or musically-based embodied selfhood, includes cultural aspects, e.g. ritualised patterns of behaviour which are consistent with personal musical experience.

Musicking is a demonstration of tacit knowledge, partially by virtue of it being embodied. Allied to this and referring back to Kitwood's global states, 'grounded in the life of emotion and feeling rather than that of elaborate cognition', it forms a lay expertise which is overlooked in the music and dementia literature. Furthermore, what this research highlights, related to music, but not resulting from it, is that each of the individuals in this project demonstrated a clear understanding of their own tacit knowledge (and preserved skill). Moreover, this was something that required an outlet. In a sense, it can be seen to fall under the umbrella of self-care. In other words, I mean that when the environment provided the respective individuals with the opportunity to harness their implicit knowledge, they did so.

It consequently it became apparent that the individuals in this study clearly knew what they needed for self-care or well-being in given situations (LDC, church, home) and they also knew how to access it, providing the opportunity was there. In fact, they rarely missed the chance to engage with their implicit knowledge. Their expertise in this area was evidenced by, for example, Petula, who would generally ask for Andre Rieu when there was a call for music requests at the LDC. The women here spoke explicitly and in detail of their needs: 'I look forward to church because I can sing'; 'I'm in ecstasy, ecstasy. I just love that man, well not the man himself, but the music. I just love it. (...) I'd love to have it on all day.' Joe did not verbalise in such overt tones, but demonstrated by action what he wanted/needed. As if unthinking, Joe would engage in his liminal musicking, helping to 'furnish' the environment (DeNora, 2013) with musical materials that allowed him to take pleasure in and become more active with and through music.

7.4 The Limitations of the Study

In this research project, I used a multi-method approach, incorporating elements of Grounded Theory and ethnography. I adopted these approaches so that I could remain close to the phenomena, whilst simultaneously gaining a better understanding of the 'meanings of individuals' actions and explanations' (Savage, 2000). Such an approach permitted detailed exploration of the everyday musicking of a number of individuals. Given the nature of understanding I hoped to achieve, i.e. one which illuminated the potential significance of context and relationship pertaining to the affect of everyday musicking, a longitudinal non-experimental study design was deemed appropriate. The methodology I applied enabled me to observe individual similarities and differences, as well as acquiring a much more nuanced and detailed understanding of their capacities, tacit knowledge and lay expertise. However, my methodology is not something which has been widely used in relation to music and dementia, particularly with an early to moderate stage, community-based population. What the methodology I employed demonstrates is that unless researchers engage with participants over extended time periods, the outcome will be impoverished and the potential to capture subtle forms of agency, missed

This was a small study involving the everyday musicking of just three participants with dementia, residing in the community with family members. The small sample size means the study is limited in its generalisability to those with dementia in similar community settings. I am not attempting to argue that these three subjects are a representative sample of the wider dementia population. However, I do believe that what this study lacks in quantity, it makes up for in quality, i.e. detail and nuance. Such attention to detail would not have been possible with a considerably larger cohort, particularly given the time and personnel limitations of a PhD research project. I have consequently been able to add to and develop an existing theoretical understanding of how music 'works' and how musical engagement is linked to well-being for people with dementia.

A further limitation of this study is that I was unable to secure an interview with Joe, which impeded the general uniformity of this research. Additionally, although far from the snap-shot approaches I have critiqued, this research project nonetheless represents the musicking of these individuals in 'a moment in time', albeit a protracted moment. How would their musicking practices and preferences have changed over a longer time? Would, for example, Rieu's significance have remained with such intensity for Petula, or was his music just part of a trajectory?

7.5 What This Study Adds

This study focuses on the everyday musicking of people with dementia. To date, research on music and dementia has focused predominantly upon those living in long-term care environments, inhabiting the advanced stages of dementia. Hitherto, it is mainly the medical model of research which has been used as the methodological template, i.e. one in which music is 'administered' in the manner of a quasi-medicine; generally by a professional member of staff (academic or caring) and for short periods of time, e.g. 20 minutes a day over a period of four weeks. With this kind of research approach, music is something which is 'done to/on' individuals and one in which research participants have minimal autonomy or input. Furthermore, the examination of the subjective experience of music for people in earlier stages of dementia is sparse. The tendency is to approach the use of music solely as something that will modify or mollify a symptom (commonly, agitation). The

investigation of music as a means of improving more general areas of quality of life or well-being over time is extremely limited.

This study goes beyond monitoring the short-term effect music may have on people with dementia, by expanding the research scope and remit to an extent not achieved elsewhere. This is accomplished through the protracted duration of fieldwork, observation in more than one context, shifting the research paradigm away from addressing what is 'wrong', i.e. challenging symptomatic presentation, to what is 'right', i.e. what works, showing how often organic or spontaneous music, or musicking enhances well-being in everyday life. Along these lines, an additional aspect realised was to follow the lead of individuals with dementia; learning from their expertise, agency and knowledge, but also exploring the significance of relationships within the music and dementia nexus. These are all neglected foci in music and dementia research, particularly when concerned with community-based and the early to moderate stage of the disease.

The key findings of my research support the hypothesis that the medical model insufficiently represents a music and dementia dynamic, owing to the extremely limited nature of its usual duration and focus. Furthermore, I would argue that this research highlights the fallacy of acquiescing to the paternalism of the medical model, which holds that it is only the trained who possess a 'true' or 'valued' knowledge. The knowledge on which this thesis hinges was gained from the knowledge and practices of the participants and the LDC host, Poppy, none of whom would be considered 'trained' or 'expert' in academic terms'.

The aim of this research then has not only been to achieve a better understanding of what constitutes everyday musicking with a small cohort of people with dementia, but also to comprehend how musicking helps contribute to enhanced quality of life and well-being. Below, it is outlined what such knowledge adds to the music and dementia field. Some of the knowledge acquired supports understanding which already exists in music sociology and dementia-specific fields. A contribution of my work is to join the two spheres together in the context of music, everyday life and early to moderate dementia.

This research not only shows that background music has the potential for more significance than previously understood, but also shows how and why this is the case. Background music for people with dementia can be a place of asylum when the situation demands, as demonstrated by both Joe and Petula. It can also, however, in a short subsequent timeframe, become a conduit for agency; musical agency and in this case, humorous agency. Furthermore, this research demonstrates that background music heard in one scenario (the LDC) and predominantly harnessed by others (i.e. Joe) can have a positive impact on others in different scenarios (i.e. the car journey). This is in opposition to North et al. (2004: 75), who propose that background music is something 'rather taken for granted (and) not necessarily characterised by deep emotional investment'.

Ultimately, what this thesis contributes to understanding about why and how everyday musicking impacts upon quality of life and well-being for people with early to moderate dementia is as follows; music provides opportunities for enacting embodied knowledge; music is a conduit for presenting the Self to Self and others; music contributes to identity maintenance; music can be instrumental in reframing identities; music provides opportunities for social engagement with others; music supports positive positioning; music boosts confidence, thus leading to shifting 'roles', e.g. Joe, who was able to take on a more musicalised persona; music is a socially acceptable form of freedom of expression; music helps forge and strengthen relationships; music can help constitute collaborative guardianship; music, like care, is not uni-directional, but musicking is something people can contribute and donate to others, and musicking is agential.

Additionally, something which the music and dementia literature has not hitherto covered and which this thesis demonstrates is that people with dementia (at least the three in this study) know what they need and how to access it; they just need help doing so. For example, looking at the cases of Eliza and Petula, both were fully aware of what music 'did' for them, because they spoke of it many times. They were not oblivious to its impact. Moreover, in no uncertain terms, they both made it plain that going to church or listening to Rieu was important to them and something they wanted to do. The subtext of such expression is, 'I know how this makes me feel and it is what I need'. Similarly for Joe, his constant singing was not accidental or

subconscious, but a clear demonstration of 'I know how this makes me feel and it is what I need'.

Each of the above aspects is not only applicable to those with dementia, but any one of the elements outlined could equally be applied to people without dementia. However, given that the literature consistently shows that dementia brings insecurity in oneself and one's sense of identity (Sabat, 2002), there is a propensity to be negatively positioned (Harré & Van, Langenhove, 1999) and lose confidence (Clare, 2003). The significance of music in terms of each of the above is therefore that much greater.

7.6 Implications for Practice and Policy

The focus of this research has been on people with dementia living in the community and this group make up two thirds of the UK's dementia population (Alzheimer's Society, 2011a). It is estimated that there are 670,000 people acting as a primary carer for someone with dementia (Alzheimer's Society, 2011a). Moreover, 60% of family carers for a relative with dementia are spouses (Benbow & Lennon, 2000). Given that the disease primarily affects older people, the majority of carers will therefore be older people themselves. The question is, how the knowledge acquired in this project can be extrapolated more widely to help enhance well-being and quality of life for people with dementia, as well as those that care for them in the community? Moreover, what 'food for thought' might there be for those 'caring' in the community who may not fall into the 'friends and family' category? Furthermore, what implications are there for those at more advanced stages of the disease? My suggestions are presented below.

This research uncovered the 'What, why, how and where?' of everyday musicking for a small group of people and highlighted its respective impact. This musicking incorporated singing, playing, listening, watching and talking about music. Beneficial effects included music providing opportunities to enact embodied knowledge; music as a conduit for presenting the Self to Self and to others; music contributing to the maintenance of identity; music possibly being instrumental in reframing identities; music providing opportunities for social engagement with others; music supporting

positive positioning; music boosting confidence, leading to shifting 'roles'; music as a socially acceptable form of freedom of expression; music helping to forge and strengthen relationships, and music helping to constitute collaborative guardianship. My research has shown that the way music is used by people with dementia and moreover, what it 'does' for them, is not so different from what music means to the non-dementia population. However, and this is the crucial point, the need for people with dementia to have the elements outlined above supported is more intense than it is for others, which explains why music is so effective at enhancing well-being and quality of life for some.

For carers who know the musical taste and experience of those they are caring for, I would suggest value could be found in employing familiar and preferred background music. A trial and error approach would be needed to ascertain where, when, how and what. It may be that the music will be used as a place of asylum, i.e. as in DeNora's (2013) place of 'removal', or equally as a place that is created collectively; a shared building of an aesthetic ecology. Equally, it could be the case that if exposed to background music within a group setting, other agential and social aspects come into play. Nevertheless, I would argue that excessively experimenting with background music could lead to effective musical strategies being collaboratively devised for mutual advantage. Additionally, for individuals like Eliza, who may have a history of and continued motivation for practical musicking, opportunities to engage with it could valuably be procured and again, incorporated into a strategy to enhance and maintain quality of life for all parties concerned.

For those carers, who are most likely professionals, with a more limited knowledge of the individuals' biographies and musical history, the task involves a great deal of 'detective work' and sensitivity. One suggestion would be to follow the potentially very subtle musicking emitted by clients and act upon it. What is it they want to listen to or watch? Do they need an opportunity to engage in a musicalised freedom of expression? Can this be supported? Can others also engage in it? In essence, the agency (and therefore empowerment) that everyday musicking supports could be harnessed for mutual benefit. I acknowledge that professional carers are often employed to concentrate on aspects of personal care and have extremely limited time in which to fulfil their responsibilities. Additionally, they may not have a regular

client base, in which circumstances, the aforementioned suggestions would be unrealistic.

For those in the more advanced stages of dementia, I would argue that all the above points apply. However, in the case of professional carers, the 'detective work' required will be greater and a longer time will be needed to acquire the information which will permit working towards collaborative guardianship, enhanced well-being and quality of life.

This research addresses the community-based dementia population, adding to the existing research which demonstrates that music is effective for enhancing well-being amongst those with or without dementia. However, by virtue of its ethnographic and longitudinal nature, it offers a more detailed explanation of why this is so, with particular reference to people with dementia. Raising awareness of and the profile of the expertise and agency with which this population musick is in line with shifts in dementia practice, policy and research. These are shifts which are moving away from a focus on medical recipients and medical reliance, more in the direction of the situated-embodied-agent (Hughes, 2000).

Taking this into account, dementia support and advice organisations could usefully interweave music-based recommendations into care plans, wherever this would be appropriate, working towards ways which consider and utilise the lay expertise of both people with dementia and their carers. This has the potential to enhance confidence, a sense of Self, self-esteem and well-being for the person with dementia, but also to help ease the burden for the carer.

7.7 Future Research

Despite its limitations, the present study provides novel directions for future research; drawing together music sociology and dementia research, in order to better understand the relationships between, music/king, identity, selfhood and well-being.

Much more research needs to be carried out into the way people with dementia and their carers use music in their everyday lives. Given the cognitive impairment present

in dementia, it is important to understand how musicking may work to compensate for this, but also its role in sustaining identity, selfhood and well-being. Moreover, value is to be found in how such an understanding can ultimately be transformed into coping strategies to help maintain stasis.

Research along similar lines to those I have pursued here is needed to substantiate whether these findings apply across a wider and more diverse population.

Throughout this thesis, I have repeatedly advocated the necessity for music and dementia research to incline less toward snap-shot approaches and in light of my findings, I reiterate this point. This is particularly the case for those with advanced dementia, residing in long-term care environments. I suggest that future research should include exploring everyday musicking with those in the later stages of dementia, whether community-based, or in long-term care environments. It would also be productive to scrutinise how for people with dementia, the motivation for musicking might change over time at any stage of the disease, whether practically or in terms of genre.

The G8 Dementia Summit stated an ‘ambition to identify a cure or a disease-modifying therapy for dementia by 2025’ (G8 Communique, 2013). The trap this statement falls into is to infer that a singular entity, cure or therapy will ultimately be the answer. Law (2004: 6) crucially argues that:

‘events and processes are not simply complex in the sense that they are technically difficult to grasp (though this is certainly often the case). Rather, they are also complex because they necessarily exceed our capacity to know them. No doubt local structures can be identified, but (...) the world in general defies any attempt at overall orderly accounting.’

This is not to suggest accepting defeat, but to call for other ways of perceiving. Indeed, one might ponder whether the quest for evidence-based, scientifically-approved ‘treatments’ is a form of avoidance behaviour, supporting an unrealistic expectation that the answer will ultimately be a simple one. Currently, there are more pressing ethical concerns to be addressed which involve all of us and which are not simply a matter of a doctor, pill or patient, with the potential to affect change long before 2025.

A key finding and recommendation from my research is that a simple silver bullet approach, whether with drugs or music is insufficient and people with dementia would be better served by an ambition which is more akin to the bespoke and crafted method adopted in an LDC. Therefore, in order to enable people and environments to flourish, greater attention needs to be paid to 'the small' – small, as in the fine-grained texture of people's lives and loves - supports (e.g. playing Rieu on the stereo) and groups. The LDC group size rarely exceeded six in this study and the intimacy of this number gave the individuals the space and time to flourish at their own pace, in a way which was appropriate for them. This afforded them greater autonomy and agency. Significantly, new friendships were also formed, as the gradual process of collaborative guardianship evolved. Daley et al. (2013) argues that recovery in adult mental health contains elements of 'hope, acceptance, agency, peer support, valued social roles and connectedness', all of which the LDC clients were able to access. The LDC model is the polar opposite of the warehousing which so offended Kitwood in the 1990s, as it re-personalises rather than de-personalises.

The concept of 'bespoke' is not one that is generally associated with economy; yet what is being proposed here in the collaborative guardianship approach is comparable to social anarchy, in that it promotes integrative techniques. It is also located at the specific level of social relationships, localities and lived experiences. It is activated, maintained and sustained at ground level, not from the top down. Elemental to this are aspects of positive psychology and the 'distributed/extended mind' constructs, as accentuated in Langer's work in *Counterclockwise* (2009). In essence, this entails heeding and harnessing the importance of environments and materials, but tapping peoples' capacities, not treating their incapacities. In short, the solution to obtaining and maintaining well-being in dementia care is not simple, but rather complex and diffuse. On the other hand, it is highly achievable when supportive frameworks are in place.

APPENDIX A

Steps leading to Plan B via Plan A

- Observed individuals at day centre and LDC.
- Information leaflets supplied to individuals via service co-ordinator/LDC host.
- Consent to be interviewed obtained (for consent process see below).
- Interviews undertaken.
- Discounted the two women (Eliza and Petula) from LDC as regards further involvement on account of either living arrangements or perceived intrusion into a well-managed situation.
- Only Keith from day centre determined as a focus for part two (of Plan A).
- Began working with Keith and his wife towards engaging with a music intervention.
- Keith dies.
- Necessity to construct **Plan B**.
- Eliza from LDC revisited accordingly; she now becomes the focus of the research.
- On-going attendance at LDC for observation of Eliza, supplemented by attendance at her other music-related events, i.e. church.
- Emergence of relevance of Petula's musicking.
- Began attending Tuesday's LDC group to assess Joe's suitability for interview (as suggested by the LDC host) and to further observe Petula.
- Did not manage to secure an interview with Joe; continued attending Tuesday group for six weeks, for open-ended ethnographic observations.
- With consent from all concerned, began recording both the Tuesday and Wednesday group.
- Transcription of the recordings revealed Joe as almost constantly, yet subtly, musically engaged within the NDS context.
-

APPENDIX B

Acquiring consent from the interviewees

Below is the condensed consent procedure for interviewees, from both the day centre and LDC:

Informal meeting/observation in situ with potential interviewees



Information leaflets supplied to identified participants via the respective Age UK representative



Potential participants then approached the Age UK representative if they were happy to cooperate, or were prompted for a response by the Age UK representative after a period of time



Interviews arranged over the phone with spousal or family caregiver



All caregivers requested were interviewed; first at home and in the absence of their wife/husband/parent

APPENDIX C: INFORMATION SHEET 1



REQUEST FOR PEOPLE TO TAKE PART IN A RESEARCH PROJECT

Why this leaflet?

This leaflet is being given to a number of people who use the Age UK services. Its purpose is to tell you about a project which I hope you will want to be involved in.

What is the project all about?

Liz is a student researcher at the University of Exeter. She is interested in the positive things that make up a day for a person with memory difficulties.

Liz would like to talk with you about your hobbies and pastimes. She would also like to ask you about areas of your life in the past.

If you agree to talk to Liz, she will use a machine to record the conversations. This will save her time taking notes.

If you are interested in taking part, please tell Poppy, who will put you in touch with Liz.

How will the project work?

If you choose to take part, Liz will arrange with you and your wife/husband/partner/relative a good time to meet and talk to you. If you are happy to, Liz would like to talk to you alone.

What happens after the project has finished?

Liz will write a report and tell other people what she has learned from you. The report will not use anyone's names. Liz hopes later to publish work about the best parts in a day for people with memory problems. No one's names will be mentioned there either.

If you have any other questions please tell Liz about them.

Please remember:

It is entirely your decision to take part. If you don't want to, that's alright. You do not have to give a reason if you do not want to take part.

If you start, but then decide you want to stop, you are free to do so.

Whatever you decide will not affect the help you get here or anywhere else.

Thank you very much

APPENDIX D: PARTNER INFORMATION SHEET



REQUEST TO PARTICIPATE IN A RESEARCH PROJECT

I am looking for people to collaborate with me in a project based at the University of Exeter.

The aim of this project is to get a broad understanding of the daily lives of people who experience mild to medium memory problems and those with whom they live. I want to discover what the positive parts of their day are, and what routines constitute their daily life.

You have been given this leaflet because the project will focus on the views and experiences of some of the people who attend a variety of the services provided by Age UK in Exeter.

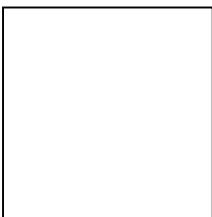
What does the project involve?

I would like to meet with couples to discuss their life histories, both as individuals and as a couple. I would also like to talk about the present, including hobbies, pastimes, passions and the routines that make up your daily life.

I would like to talk to you and your husband/wife separately, if you would be happy for me to do so.

To save me taking down notes and to be sure I represent your views accurately, I will audio-record the conversations we have.

Who will be the person doing the research?



This is Liz. She is a PhD student with a long-standing interest in older people and their everyday experiences. She has received a scholarship from the University of Exeter to carry out research in this area.

When will these discussions take place?

These discussions will take place at a time and on a day that suits you.

Where will these discussions take place?

This is entirely dependent on each participant. If you would prefer me to come to your home, I will. However, if you would rather meet at a different location, that would also be fine.

What will happen to the audio-recordings?

All information will be treated with strict confidentiality. All personal references and/or other identifying information will be removed.

What about consent to take part?

Since the project involves collaboration and input from both the person with memory problems and their spouse/relative, I will talk to both parties about what their participation in the project would involve and check that they are happy to take part. Anyone who does agree to take part is free to withdraw at any time.

I am available at any time to speak to anyone who wants to find out more.

What if my husband/wife/relative becomes upset?

If this does occur, I will offer comfort and adapt sensitively to the situation. If the person wants to stop that particular conversation I will comply; however, if the person wishes to continue, I will take my direction from them.

What safety checks have been carried out?

This project has received ethical approval from the University of Exeter and I have an Enhanced Disclosure CRB certificate.

Additional Information

This project is divided into two parts and all the information in this leaflet relates to Part One. For people who do agree to be interviewed in Part One, they may be asked at a later stage whether they are interested in being involved in Part Two. Participation in Part Two is also entirely voluntary and further details will be given at that time.

If you are interested in being involved in this project or have any questions, please do not hesitate to contact Liz, Libby at Age UK, or the project supervisor, Professor Tia DeNora.

Liz Dennis contact details:

Professor Tia DeNora, project supervisor, contact details:

Thank you very much

APPENDIX E: INTERVIEW SCHEDULE FOR PERSONS WITH DEMENTIA

SCRIPT: Thank you for agreeing to talk to me. The reason I'm here today is to learn more about the everyday experiences of older people. I'm interested in learning about your everyday life, routines, mundane activities, less mundane activities, etc.

All answers you give me will be treated as anonymous after today and with complete confidentiality. If it's OK, I'm going to record the interview and also take notes, in case the machine doesn't work! If you'd rather I didn't record, please say so. Also, if there are any questions you don't want to answer, please don't answer them. If you suddenly think of something you want to add or say at any point please feel free to interrupt me or to mention things I haven't asked about.

BACKGROUND

A-1 When and where were you born?

A-2 Can you tell me a little about your parents?

e.g. where were they born, what do/did they do for a living?

A-3 Can you tell me a little about your childhood?

A-4 Can you tell me anything in particular you enjoyed about your childhood? Was there anything in particular you enjoyed doing?

A-5 What did you do after you left school?

EXPERTISE

B-1 Can you tell me about any particular skills you may have which you haven't already told me about?

FAMILY

C-1 Have you been married?

C-2 Do you have any children/grandchildren? Where do they live? Do you get to see them regularly?

C-3 Where do you live?

C-4 Who else do you live with?

DAILY LIFE

D-1 Can you describe a typical day for me?

D-2 Are there any days when you have specific appointments?

D-3 Can you describe for me what you do there? (Elicit feelings surrounding such occasions)

D-4 Could you describe for me the best parts of your week?

PASTIMES

E-1 Do you have any particular hobbies/pastimes? How long have you been doing this? How did you get interested in this?

E-2 What is it that you particularly enjoy about this?

E-3 Could you describe for me how you feel when you are doing this/these thing(s)?

E-4 How do you like to relax?

E-5 Are there any other interests of yours which we've not yet covered?

CODA

Just a couple of questions to finish up...

G-1 I'm interested to know why you agreed to be interviewed

G-2 How have you found the experience?

G-3 Finally, could you finish this sentence for me 'I am never happier than when...'

APPENDIX F: OBSERVATION CONSENT FORM

Research Project Consent Form

I have spoken to Liz Dennis about the above project.

The conversation took place on.....

Tick One

	Yes	No
I have looked at the information leaflet		
I have had a chance to talk about the project and ask questions		
I know enough about the project now		
I understand that I will be part of a group that Liz is observing		
I understand that Liz will be recording the sessions		
I understand that it is my decision whether or not to take part		
I understand that if I do not want to take part, I do not have to give a reason		
I understand that if I do not want to take part, this will not affect any help I am getting now or get in the future		

I understand that if I take part, I can stop at any time		
I understand that if I stop taking part, this will not affect any help I am getting now or get in the future		

I agree to take part in the project.

Signed.....Date.....

Name (in block letters).....Date.....

APPENDIX G



Research Request

Why this leaflet?

This leaflet is being given to everyone who attends Poppy's Age UK Neighbourhood Day Service on a Tuesday or Wednesday.

What is this all about?

Liz is a student researcher at the University of Exeter. She is interested in the positive things that make up a day for people experiencing memory difficulties. She has been visiting Poppy's Wednesday sessions since June and has been visiting Poppy's Tuesday session since the end of August.

Liz has very much enjoyed joining the groups at Poppy's house and getting to know everyone. She has found the general chats, crosswords, singing and games of such interest that she would like to audio-record some of these sessions at Poppy's.

Is there anything else?

Liz understands the car journey to and from Poppy's can often be filled with laughter and she would like to record these journeys too.

What will happen to the recordings?

The majority of the recordings will be just for Liz to listen to, but there may be occasions when some small parts of the recording will be used to help her explain to other people what she has learned during her time with Poppy's groups.

What if I am happy to be recorded, but unsure about my name being identifiable in the recordings?

In the general chat that goes on at Poppy's, peoples' first names will occasionally be heard. If you would rather that your name was not heard, please tell Poppy, or sign here..... and it will be removed from the recordings.

If you would like to speak to Liz or ask her any questions about this, then please contact her on..... or.....

If you are happy to let Liz record some of Poppy's session, either sign this leaflet here

.....and return it to Poppy, or if you prefer, just tell Poppy.

Please remember

It is entirely your decision whether or not you want to let Liz record your time at Poppy's. If you don't want to, that's alright. You don't even have to give a reason if you don't want to. If you say 'Yes' and then change your mind, that's fine. Whatever you decide will not affect the help you get here or anywhere else.

Thank you very much

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