Behavioural Activation for Depression in Long Term Conditions: Developing a Behavioural Activation Guided Self-Help Intervention for Depression in Dementia

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I certify that all material in this dissertation which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

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Abstract

Depression is common in people with long term conditions (LTCs) and is associated with worse quality of life, higher degrees of functional disability and increased risk of mortality. Treating comorbid depression in people with LTCs is therefore important. Meta-analyses have shown improvements in depression in people with LTCs associated with psychological therapies. However, treatment effect sizes have generally been small to moderate suggesting the need for continued development in psychological therapy for people with LTCs. Behavioural activation (BA) techniques have been recommended for the treatment of mild to moderate depression in people with LTCs, and with the simplicity of BA making it suitable for a broad range of populations it is an approach for further consideration. Informed by the revised MRC framework (2008) for developing and evaluating complex interventions, the overall aim of this dissertation was to develop a BA intervention for depression in people with a LTC.

First, a systematic review (Study One) examining BA for the treatment of depression in people with LTCs was conducted to identify the evidence base, examine effectiveness across LTCs and identify adaptations made to BA to accommodate LTCs. In total 18 studies were included in the review with effectiveness reviewed from eight randomised controlled trials. Studies reported improvements in depression and significant findings were reported compared to control in studies involving participants with dementia, stroke and nursing home residents. Across the studies common adaptations to the interventions included the involvement of others in the delivery or support of the BA intervention, additional treatment components and ensuring psychoeducation, materials and inventories were appropriate for the LTC. With the majority of significant findings reported for neurological disorders, and informed by current policy priorities, the decision was made to develop a BA intervention for depression in dementia.

Next, a BA guided self-help intervention (involving a workbook, practitioner support and carer involvement) was developed, with development informed by the findings from Study One, literature, contact with experts and guidance co-produced by people with dementia. Interviews with people with dementia and carers (n=12) were then conducted to discuss the suitability of the intervention and (if necessary) to inform modifications to the workbook.

Comments suggested the design and layout of the workbook may be acceptable, but potential difficulties with reading the workbook and completing worksheets were also identified. Based on comments from participants, example worksheets were included in the workbook and additional diaries were created.

Finally, a preliminary feasibility case series was conducted. This study investigated key uncertainties to inform further development of the intervention and future research. Difficulties were experienced recruiting dyads to receive the intervention alongside challenges delivering the intervention as currently developed, such as difficulties keeping sessions to time and a lack of engagement with the workbook. Some positive comments were however made about the therapist, workbook and telephone support, but participants still experienced difficulties understanding and completing the workbook. The findings from the case series were used to inform potential intervention modifications, including simplification, a separate carer workbook and flexible delivery.

Overall, more development is needed to make the intervention more acceptable and feasible, and more research is needed to investigate the suitability of BA guided self-help for depression in dementia.

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List of Abbreviations

AccEPT	Accessing Evidence-Based Psychological Therapies
ACE-III	Addenbrooke’s Cognitive Examination-III
AD	Alzheimer’s disease
AMED	Allied and Complementary Medicine Database
APA	American Psychiatric Association
BA	Behavioural activation
BAT-C	Behavioural Activation Treatment for Cancer
BATD	Brief Behavioural Activation Treatment for Depression
BDI	Beck Depression Inventory
BE-ACTIV	Behavioural Activities intervention
BEAMD	Behavioural Activation for Mood in Dementia
CASP	Critical Appraisal Skills Programme
CBT	Cognitive behavioural therapy
CD	Chris Dickens
CDR	Clinical Dementia Rating scale
CES-D	Centre for Epidemiological Studies Depression Scale
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CONSORT	Consolidated Standards of Reporting Trials
COREQ	Consolidated Criteria for Reporting Qualitative Research
CRD	Centre for Reviews and Dissemination
CSDD	Cornell Scale for Depression in Dementia
CT	Cognitive therapy
DoH	Department of Health
DQoL	Dementia Quality of Life instrument
DSM	Diagnostic and Statistical Manual of Mental Disorders
EMBASE	Excerpta Medica DataBase
EROS	Environmental Reward Observation Scale
GDS	Geriatric Depression Scale
GP	General practice
HRSD	Hamilton Rating Scale for Depression
IAPT	Improving Access to Psychological Therapies
IPT	Interpersonal Psychotherapy
JL	Jeff Lambert

JW	Joanne Woodford
LT	Leanne Trick
LTC	Long term condition
MeSH	Medical subject headings
MMSE	Mini-Mental State Examination
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health
NPT	Normalisation Process Theory
PCDP	Primary Care Dementia Practitioner
PF	Paul Farrand
PHQ-9	Patient Health Questionnaire 9 item
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International Prospective Resister of Systematic Reviews
PwD	Person with dementia
PWP	Psychological Wellbeing Practitioner
RCT	Randomised controlled trial
SD	Standard deviation
SH	Sarah Harris
SMD	Standardised mean difference
SOC	Selection, Optimisation and Compensation Model
SW	Stacey Windeatt
UK	United Kingdom

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Dedicated to my Dad

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Chapter One: General Introduction

1.1 Background

1.1.1 Long Term Conditions (LTCs)

A long term condition (LTC) is defined as “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies” (Department of Health [DoH], 2012a, p. 3). This includes conditions such as diabetes, coronary heart disease, stroke, cancer and dementia (DoH, 2012a). Mental health conditions, such as schizophrenia, bipolar disorder, depression and anxiety, are also classified as LTCs (DoH, 2012a), however the term ‘LTC’ can sometimes be used to refer only to physical health conditions (Naylor et al., 2012). LTCs are prevalent in England, with the Department of Health (DoH) estimating that there are around 15 million people living with one or more LTC (DoH, 2012a), with this projected to increase to around 18 million by 2025 (House of Commons Health Committee, 2014). The number of people with multiple LTCs is expected to increase from 1.9 million in 2008 to an estimated 2.9 million in 2018 (DoH, 2012a).

People with LTCs account for a large proportion of service use, including 55% of general practice (GP) appointments and 68% of accident and emergency and outpatient appointments (House of Commons Health Committee, 2014). The average health and social care cost for an individual with a LTC is £3,000 per year, rising to nearly £6,000 for an individual with two LTCs (DoH, 2012a). It is estimated that the care of people with LTCs accounts for 70% of the total health and care spend in England (DoH, 2012a; House of Commons Health Committee, 2014).

1.1.2 LTCs and Comorbid Depression

Mental health problems, such as depression and anxiety, are common in people with LTCs (Naylor et al., 2012), and it is estimated that 12 to 18 per cent of all LTC expenditure in the National Health Service (NHS) is linked to poor mental health and wellbeing (Naylor et al., 2012). The prevalence of depression in people with LTCs of between 7.9 to 23% (Egede, 2007; Moussavi et al., 2007) is significantly higher than in people without LTCs (Moussavi et al., 2007). For people with multiple LTCs, depression is more common, with the 12 month prevalence and odds of major depression reported to increase as the number of LTCs increase (Egede, 2007).

Interactions between mental health disorders and health conditions are complex and widespread (Prince et al., 2007). Mental health disorders can be a risk factor for health conditions, as well as a consequence of them, and the prognosis or outcome of health conditions can be affected by mental health (Prince et al., 2007). Having depression comorbid with a LTC can impact negatively on the individual. For instance, comorbid depression in LTCs is associated with a decrement in health, with mean health scores significantly lower ($p<0.01$) in people with a LTC and comorbid depression than in those with only a LTC (Moussavi et al., 2007). Comorbid depression can also impact negatively on quality of life (Goldney, Phillips, Fisher, & Wilson, 2004; Yohannes, Willgoss, Baldwin, & Connolly, 2010). For example, research has demonstrated quality of life scores to be significantly lower ($p=0.05$) in people with comorbid depression and diabetes compared to those with diabetes only (Goldney et al., 2004).

Comorbid depression in LTCs is also associated with poorer outcomes, self-care and prognosis (Naylor et al., 2012). These include higher degrees of functional disability (Egede, 2007), greater odds of noncompliance with medical treatment recommendations (Dimatteo, Lepper, & Croghan, 2000) and an increased risk of mortality (Barth, Schumacher, & Herrmann-Lingen, 2004; Satin, Linden, & Phillips, 2009). With these associations it may be unsurprising that comorbid depression in LTCs is also related to increased service use and cost (Naylor et al., 2012). For example, people with diabetes and depression have more ambulatory care visits (12 vs. 7, $p=0.0001$), more filled prescriptions (43 vs. 21, $p<0.0001$) and significantly higher total healthcare expenditures than people experiencing diabetes without depression (Egede, Zheng, & Simpson, 2002). Additionally, a meta-analysis has found depression in LTCs to be associated with an increase of 49% in the odds of urgent healthcare utilisation ($p<0.0005$) (Dickens et al., 2012). However, the effects are smaller (and non-significant) in studies that control for other covariates (Dickens et al., 2012).

With these negative impacts being experienced both by patients and services, targeting and treating depression in people with LTCs has become of increasing importance. For example, with the Improving Access to Psychological Therapies (IAPT) programme extended to support the psychological needs of people with LTCs in England (DoH, 2011), there has been increased efforts to ensure the treatment of depression in people with

LTCs. Furthermore, there are also plans to integrate psychological therapies with physical health care services by 2020/21 (NHS England, 2016). However, barriers to depression care, such as the normalisation of depression in LTCs (Coventry et al., 2011) and limited acceptability of treatments when they are not adapted to meet the needs of specific LTC populations (Hind et al., 2010), may serve to prevent people from receiving appropriate treatment for mood disorders.

1.1.3 Psychological Treatments for Depression in LTCs

1.1.3.1 Recommendations. Psychological treatments for depression in adults with a LTC are recommended by the National Institute for Health and Care Excellence (NICE, 2009). For adults with mild to moderate depression (comorbid with a LTC), low intensity psychosocial interventions are recommended. These include individual guided self-help based on the principles of cognitive behavioural therapy (CBT) (which includes problem-solving and behavioural activation (BA) techniques), computerised CBT and group based peer support (NICE, 2009). High intensity psychological therapies (individual or group CBT, or behavioural couples therapy) are recommended for those with mild to moderate depression who have not benefitted from a low intensity intervention, and for those presenting initially with moderate depression (NICE, 2009). For individuals presenting with severe depression and a LTC, a combination of individual CBT and antidepressant medication is recommended (NICE, 2009).

1.1.3.2 Effectiveness of psychological therapies for depression in LTCs. The effectiveness of psychological therapies for depression in people with LTCs has been examined in a number of meta-analyses. Several meta-analyses have included a number of different LTCs (Farrand & Woodford, 2015; Rizzo, Creed, Goldberg, Meader, & Pilling, 2011; van Straten, Geraedts, Verdonck-de Leeuw, Andersson, & Cuijpers, 2010) whilst others have focussed on a single LTC (Dickens et al., 2013; Whalley, Thompson, & Taylor, 2014; Xing et al., 2016). Overall the reported effect sizes for psychological therapies have, generally, been small to moderate (Dickens et al., 2013; Farrand & Woodford, 2015; Rizzo et al., 2011; van Straten et al., 2010; Whalley et al., 2014; Xing et al., 2016). With regards to specific intervention components, small effects have been reported for problem solving (standardised mean difference (SMD) = 0.34) and skills training (SMD = 0.25) (Dickens et al., 2013). For CBT, a small effect for guided self-help (SMD = −0.40) and a moderate effect for individual-based CBT (SMD = −0.55) has been reported (Rizzo et al., 2011). Other meta-analyses have also reported small effect sizes for CBT (Dickens et al., 2013; Farrand & Woodford, 2015).

With the effects of psychological interventions for depression in LTCs often only small to moderate, it is clear there is a need for continued development in psychological therapy for people with LTCs. One potential candidate approach is that of behavioural activation (BA). In recent years there has been a resurgence of interest in BA as a treatment for depression (Dimidjian, Barrera, Martell, Muñoz, & Lewinsohn, 2011). With the increase in BA research there has been an expansion to novel populations, including people with psychiatric and medical comorbidity (Dimidjian et al., 2011). The following section provides an overview of BA before providing the rationale for a focus on BA for the treatment of depression in LTCs.

1.1.4 Behavioural Activation (BA) for Depression

1.1.4.1 What is BA? BA is a structured psychotherapeutic approach with a “reliance on the principles of a behavioral model [sic] and an exclusive focus on behavior change [sic]” (Dimidjian et al., 2011, p. 15). Although there are different BA treatments with variations in their protocols (for example Jacobson, Martell, & Dimidjian, 2001; Lejuez, Hopko, Acierno, Daughters, & Pagoto, 2011; Lewinsohn, Biglan, & Zeiss, 1976; Richards, 2010), all BA treatments are based on a behavioural model of depression and use behavioural strategies to change behaviour (Dimidjian et al., 2011).

The key behavioural models that form the conceptual foundation of BA as a psychotherapeutic approach are those by Lewinsohn (1974) and Ferster (1973). The behavioural model by Lewinsohn (1974) proposes depression to be a result of a lack, or low rate, of response-contingent positive reinforcement. Research shows depressed individuals engage in fewer pleasant activities and a significant positive relationship between mood and number of pleasant activities exists (Lewinsohn & Graf, 1973). Recent research is also supportive of Lewinsohn’s behavioural model and the relationship between depressive symptoms and a lack of rewarding experiences (Hopko, Armento, Cantu, Chambers, & Lejuez, 2003). Following this behavioural model of depression, BA interventions use operant conditioning principles (through scheduling) to increase access to positive environmental reinforcement (Ekers et al., 2014).

BA interventions may also draw on the behavioural theory by Ferster (1973). This theory is about the importance of a functional analysis of depression and highlights the role escape and avoidance behaviours play in depression (Ferster, 1973). Depressed individuals have a passive repertoire of behaviour and engage in a high frequency of escape and avoidance from aversive stimuli (Ferster, 1973). The BA treatment developed by Martell, Jacobson and colleagues (Jacobson et al., 2001; Martell, Addis, & Jacobson, 2001) draws on the principles of Ferster's model, with functional analysis and avoidance modification key components of their BA intervention. This BA intervention uses functional analysis to understand avoidance behaviours and to select alternative behaviours using the acronyms TRAP (Trigger, Response, Avoidance Pattern) and TRAC (Trigger, Response, Alternative Coping) (Jacobson et al., 2001; Martell et al., 2001).

In addition to the work of Lewinsohn (1974) and Ferster (1973), the BA intervention by Martell et al. (2001) also builds on the foundation of work by Rehm (1977) (Martell, Dimidjian, & Herman-Dunn, 2010), who proposed a behavioural self-control model of depression. Although some aspects of the self-control model are considered more cognitive (such as selectively attending to negative events), the model does emphasise the role of reinforcement in depression. The model postulates a feedback loop of self-monitoring, self-evaluation and self-reinforcement (Rehm, 1977). The self-reinforcement phase is of particular importance when accounting for depression, with depression characterised by relatively low rates of self-administered self-reward, and high rates of self-punishment (Rehm, 1977). Martell et al. (2010, p. 10) state the work by Rehm "has been influential in extending the understanding of the nature of reinforcement and the need to look at the client's predilection to benefit from short-term (versus long-term) rewards".

As highlighted above, there are different BA treatments with variations in their protocols and the strategies that may be used in the intervention. However, self-monitoring (of activity and mood) and activity scheduling are essential elements and components of BA interventions (Ekers et al., 2014). Some interventions may also use behavioural strategies such as activity structuring, problem solving, construction of a hierarchy, shaping, reward, social skills training (Dimidjian et al., 2011) and functional analysis (Jacobson et al., 2001). With different BA interventions attempts have been made to classify the interventions. A meta-analysis by Mazzucchelli et al. (2009) classified different variants of the BA approach by the different researchers or protocols they cited: pleasant activities interventions (crediting Lewinsohn); self-control interventions (crediting Rehm); contextual interventions (crediting Jacobson et al. (2001), Martell et al. (2001) or the BA intervention from Jacobson et al. (1996)); and behavioural activation treatment for depression (crediting Lejuez, Hopko, and Hopko (2001)). A more recent taxonomy has classified BA by components (Ekers et al., 2014), with simple BA being predominately self-monitoring and scheduling, and complex BA including additional behavioural components such as functional analysis and/or values focussed components (Ekers et al., 2014).

1.1.4.2 The evidence for BA. Several meta-analyses have been conducted to evaluate the effectiveness of BA as a treatment for depression in adults. The most recent meta-analysis of BA interventions has reported a moderate-to-large effect size (SMD = -0.74) when compared to control conditions (waiting list, placebo and usual care) (Ekers et al., 2014), similar to effects reported in previous reviews (Cuijpers, van Straten, & Warmerdam, 2007; Ekers et al., 2008; Mazzucchelli et al., 2009) (0.87, -0.70 and 0.78 respectively). Although study quality was sub-optimal for all but six studies included in the Ekers et al. (2014) review, it is important to note that no significant relationship between study quality and effect size was found. An effect size of -0.67 was reported for BA compared to control in the high quality studies (Ekers et al., 2014). With regards to the different types and variants of BA discussed above, Ekers et al. (2014) found no association between level of complexity (simple and complex) and effect size. Similarly, in the Mazzucchelli et al. (2009) review, the effect sizes of the different variants of BA (pleasant activities, contextual and self-control) did not differ significantly from each other.

Comparisons between BA and CBT/cognitive therapy (CT) for depression in adults have also been made, with several meta-analyses finding BA to be equally as effective as CBT/CT (Cuijpers et al., 2007; Ekers et al., 2008; Mazzucchelli et al., 2009). Further evidence for this comparison comes from a recent high quality fully powered non-inferiority and cost-effectiveness study (Richards et al., 2016). This study is the largest BA trial to date, with 221 participants randomly allocated to BA, and 219 to CBT (Richards et al., 2016). In this trial a complex BA intervention (delivered by junior mental health workers) was compared to CBT (delivered by qualified CBT therapists). In terms of treatment effectiveness in reducing the main symptoms of depression, no evidence of inferiority for BA compared to CBT was found (Richards et al., 2016). Additionally, with junior mental health workers delivering the BA intervention, BA was found to more cost-effective than CBT, with a significant difference (–£262·29, p <0·0001) in mean intervention cost per participant (Richards et al., 2016). This trial also provides evidence for the longer term effectiveness of BA. Modified intention to treat analysis found 66% of the BA group met the criteria for recovery from depression (a score of 9 or less on the Patient Health Questionnaire (PHQ)-9) at 12 months (Richards et al., 2016).

Unlike the evidence for BA as a treatment for depression in adults, which has been reviewed in multiple meta-analyses (Cuijpers et al., 2007; Ekers et al., 2008; Ekers et al., 2014; Mazzucchelli et al., 2009), the evidence base for BA in people with LTCs has not yet been systematically reviewed. In 2011 an article on the origins and current status of BA for depression highlighted the expansion of BA research to people with medical and psychiatric comorbidity, with work in the early and exploratory stage (Dimidjian et al., 2011). With, at that time, a heavy reliance on case studies and case series in people with medical and psychiatric comorbidity (Dimidjian et al., 2011), this may explain why no randomised controlled trials (RCTs) delivering BA interventions were included in the meta-analyses of treatments for depression in people with LTCs (Rizzo et al., 2011; van Straten et al., 2010). The article by Dimidjian et al. (2011) did, however, discuss some studies of BA for depression in LTCs, highlighting promising outcomes for BA from a case study (Armento & Hopko, 2009), case series (Hopko, Bell, Armento, Hunt, & Lejuez, 2005) and RCT (Hopko, Armento, et al., 2011) involving depressed cancer patients.

1.1.4.3 Why BA for depression in LTCs? There are several reasons why the continued development of psychological therapy in LTCs should focus on BA for depression. Firstly, the “simplicity of BA interventions … makes them suitable for a broad range of populations” (Mazzucchelli et al., 2009, p.405). BA is a psychotherapeutic approach that is simpler than interventions such as CBT (Jacobson et al., 1996). The simplicity of BA may make it appropriate for people with LTCs, especially for those experiencing functional impairment. For example, with the BA rationale being simpler than the rationale for CBT (Rhodes et al., 2014), it may be easier for patients to understand and more suitable for people with LTCs experiencing cognitive impairment. Indeed, for stroke patients it is recommended that CBT becomes more behavioural with the worsening of cognitive and communication abilities, focussing on elements such as BA for depression (Kneebone, 2016). Secondly, a meta-analysis of treatments for depression in people with LTCs (not including BA) concluded that the efficacy of psychosocial interventions for depression in LTCs is comparable to their efficacy in people without LTCs (Rizzo et al., 2011). As discussed above, meta-analyses have reported moderate-to-large effect sizes for BA interventions in adults (Cuijpers et al., 2007; Ekers et al., 2014; Mazzucchelli et al., 2009), and this may, therefore, be comparable in people with LTCs. Finally, BA techniques are recommended by NICE for the treatment of mild to moderate depression in people with a LTC (NICE, 2009).

1.2 Overall Aim

With the need for the continued development in psychological therapy for people with LTCs, the overall aim of the programme of research reported in this dissertation is to develop a BA intervention for depression in people with a LTC. The development of the intervention is informed by the revised Medical Research Council (MRC) guidance for developing and evaluating complex interventions (Craig et al., 2008; MRC, 2008).

1.3 Dissertation Structure

Chapter One has presented an overview of LTCs, comorbid depression in people with LTCs and psychological interventions for the treatment of depression in LTCs. The rationale for developing a BA intervention for depression in people with a LTC has also been provided. This chapter has also reviewed the theory and evidence base for BA and presented the overall aim for this dissertation.

Chapter Two presents an overview of the methodological approaches utilised in this dissertation. The MRC framework (Craig et al., 2008; MRC, 2008) is discussed and details are provided on how the development of the intervention in this dissertation is informed by the MRC framework. Secondly, the methods used in this dissertation are discussed, including systematic reviews and qualitative research.

Chapter Three presents Study One, a systematic review of BA interventions for depression in people with LTCs, conducted as the first stage in intervention development following the MRC framework (Craig et al., 2008; MRC, 2008). The aims of Study One were to review the effectiveness of BA for depression in people with LTCs and to identify adaptations made to BA to accommodate LTCs. This review was conducted to identify the existing evidence base for BA in LTCs, to identify a LTC to target for intervention development and to inform development of the intervention in this dissertation. Based on the findings from this study, and informed by current policy priorities (DoH, 2009, 2012b, 2015), the decision was made to develop a BA intervention for depression in dementia.

Chapter Four presents the development of a low intensity BA guided self-help intervention for depression in people with dementia. The chapter starts with a background covering dementia, comorbid depression in dementia and the barriers to accessing depression care for people with dementia. The rationale for developing a low intensity intervention is also presented. Details are provided on how the development of the intervention was informed by the findings from Study One, literature, contact with experts and guidance co-produced by people with dementia. A detailed description of the intervention is also presented. This chapter also presents Study Two, a qualitative study involving interviews with people with dementia and informal carers. These interviews were conducted as part of the development of the intervention, to refine the intervention workbook and to inform delivery.

Chapter Five presents a preliminary feasibility case series (Study Three) conducted to help develop the intervention and to inform future research. This case series investigated key uncertainties following phase II of the MRC framework (Craig et al., 2008; MRC, 2008) including uncertainties regarding recruitment, feasibility and acceptability of the intervention.

Finally, Chapter Six provides an overall summary of this dissertation and considers the strengths and limitations of this programme of research. Implications arising from the research findings and recommendations for future research are also discussed.

Chapter Two: Methodological Overview

2.1 Introduction

This chapter provides an overview of the methodology and methods used in this dissertation.

- This chapter initially reviews the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Craig et al., 2008; MRC, 2008) and highlights how this programme of research follows this guidance.
- Secondly, this chapter discusses the features of systematic reviews.
- Finally, there is a discussion regarding the qualitative methods used in this dissertation; the quality of qualitative approaches and strategies for strengthening the trustworthiness of qualitative research. The justification for conducting a preliminary feasibility case series is also presented.

2.2 The MRC Framework

The MRC framework for the development and evaluation of complex interventions (MRC, 2000) was developed to provide investigators with guidance on recognising the challenges in evaluating interventions, and to provide strategies for addressing the challenges (MRC, 2000). The framework was updated in 2008 (Craig et al., 2008; MRC, 2008), extending the guidance by encouraging a phased and, if needed, iterative approach to developing and evaluating interventions (Craig & Petticrew, 2013). The framework consists of several phases and elements (see Figure 2.1) around the development, feasibility and piloting, evaluation and implementation of complex interventions (Craig et al., 2008; MRC, 2008). Careful development of interventions is important, and the new guidance highlights the need to consider implementation questions throughout the phases of developing and evaluating interventions (Craig & Petticrew, 2013). Interventions should be developed systematically, based on theory and evidence, followed by an investigation of the key uncertainties in the design, before an exploratory and subsequent definitive evaluation (Craig et al., 2008; MRC, 2008).

Adopting the MRC framework to inform the methodological approach increases the possibility of developing a successful intervention by ensuring interventions are feasible, and the design of the intervention and evaluation are appropriate (Faes, Reelick, Esselink, & Rikkert, 2010). This dissertation follows the development and feasibility phases of the MRC framework, which are explored in more detail below.

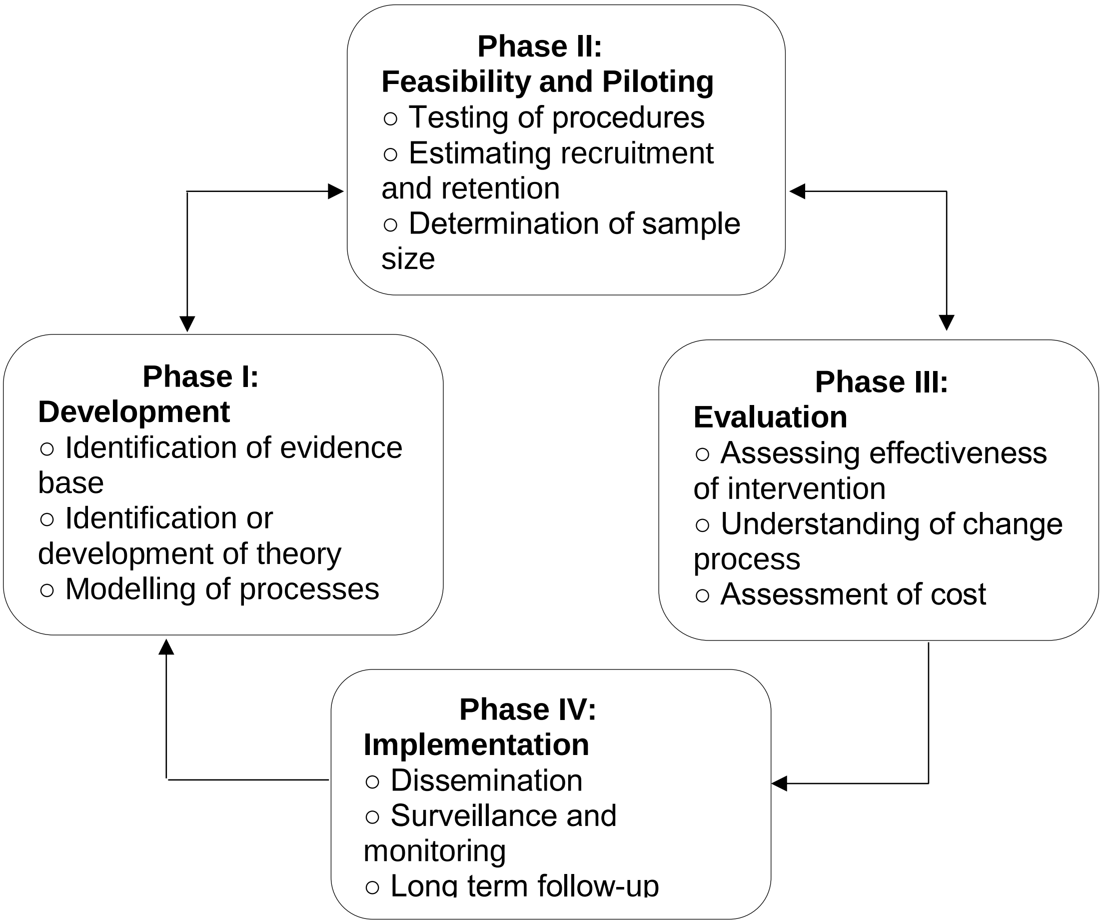


Figure 2.1 The phases and elements of developing and evaluating a complex intervention (adapted from Craig et al, 2008, p. 980)

2.2.1 What are Complex Interventions?

Complex interventions are conventionally defined in the MRC framework as interventions with several interacting components (MRC, 2008), with the dimensions of complexity including the components of the intervention, behaviours, outcomes, and tailoring or flexibility of the intervention (MRC, 2008). However, complex interventions are now seen as more than just the component parts (Richards, 2015), with newer definitions considering the complexity of context and implementation (Anderson et al., 2013; Richards, 2015), as well as the variation in participants receiving the intervention (Anderson et al., 2013; Faes et al., 2010).

2.2.2 The Development of a Complex Intervention

It is important to ensure an intervention has been developed to an extent where worthwhile effects can be expected (Craig et al., 2008; MRC, 2008). This can be done by following the stages below:

- *Identification of the evidence base:* the relevant and existing evidence base for the intervention should be identified by a systematic review (Craig et al., 2008; MRC, 2008). If a recent systematic review does not exist it is necessary to conduct one to establish the evidence base, and to update the review as evaluation of the intervention proceeds (Craig et al., 2008; MRC, 2008).
- *Identification/development of theory:* the effectiveness of an intervention will be maximised by an understanding of the theories of potential processes of change. This can be through existing theory and evidence, and can also be supplemented by primary research, such as interviews with stakeholders (Craig et al., 2008; MRC, 2008).
- *Modelling process and outcomes:* “Modeling [sic] refers to defining and combining the components of the intervention” (Faes et al., 2010, p. 2213). Describing the processes (how the intervention works) and outcomes (what is expected to change) can provide important information about the design of the intervention (Craig et al., 2008; MRC, 2008). The modelling of an intervention can involve detailing how decisions about the intervention (such as the appropriate number and duration of sessions, or who should deliver the intervention) were informed (Faes et al., 2010; Lovell et al., 2008). In the modelling of a guided self-help intervention for depression, Lovell et al. (2008) present the findings of meta-analyses and the outcomes of a consensus exercise with experts and stakeholders, and detail how these were incorporated into the developed intervention.

The MRC guidance also highlights the importance of considering implementation early in the development of an intervention and questioning whether it would be possible to use the intervention (MRC, 2008). This includes considering who will use the intervention (such as patients, practitioners and policy makers) and the setting or population in which the intervention will be implemented (MRC, 2008). If an intervention is demonstrated to be effective, the consideration of implementation during development stages may be essential for the eventual adoption of the intervention (Richards, 2015).

2.2.3 Feasibility and Piloting

The second phase of the MRC framework, ‘feasibility and piloting’, involves investigating key uncertainties identified during development (such as acceptability, recruitment, and retention) before conducting an evaluation of the intervention (Craig et al., 2008; MRC, 2008). Pilot studies do not need to be a scale model of the planned evaluation, but they should investigate key uncertainties (Craig et al., 2008; MRC, 2008). Preliminary piloting is important to overcome problems with recruitment, adherence, data collection and intervention delivery that can undermine evaluations of the intervention (Eldridge, Ashby, Feder, Rudnicka, & Ukoumunne, 2004).

Within the literature the difference between feasibility and pilot studies has been clarified (Abbott, 2014). Feasibility and pilot studies are both preliminary studies, and are conducted to establish whether it would be feasible to conduct a full trial (Abbott, 2014). However, the aims of feasibility and pilot studies vary slightly. Feasibility studies help to develop interventions or measures, whilst pilot studies are a miniature replication of a full-sized planned randomised controlled trial (RCT) (Abbott, 2014). Feasibility studies are used to determine issues such as participation barriers; intervention acceptability; service barriers to intervention delivery; and suitability and feasibility of outcome measures (Abbott, 2014). Feasibility studies do not need to include randomisation (Arain, Campbell, Cooper, & Lancaster, 2010). Pilot studies aim to assess issues such as whether recruitment, screening and randomisation processes work; whether blinding is effective; and participant retention (Abbott, 2014).

Preliminary studies (feasibility and pilot studies) investigate issues of practicality and do not assess the effectiveness of interventions (Abbott, 2014). However, if a proof-of-concept is necessary, as it is not known whether the intervention might be potentially effective, a case series or small trial can be used to indicate whether an intervention might plausibly be effective (Abbott, 2014).

To investigate the key uncertainties and practicalities of the developed intervention both qualitative and quantitative methods are often needed (Craig et al., 2008). Observational research with qualitative methods can be used to investigate implementation or feasibility considerations (Richards, 2015). The findings from the ‘feasibility and piloting’ phase may lead to a full-scale evaluation or may find that subsequent research is needed to refine the design of the intervention before conducting an evaluation (MRC, 2008).

2.3 Methodology and Methods used in this Dissertation

2.3.1 Following the MRC Framework

The development of the intervention in this dissertation was informed by the MRC framework (Craig et al., 2008; MRC, 2008) in the following ways:

Identification of the evidence base. A systematic review (Study One, Chapter Three) was conducted to identify the existing evidence base for behavioural activation (BA) interventions for depression in people with long term conditions (LTCs).

Identification of theory. The existing theory and evidence for BA as an intervention for depression has been reviewed in Chapter One.

Modelling process. The developed intervention is described in Chapter Four. This chapter details how the systematic review (Study One), contact with experts, other psychological interventions delivered to people with dementia and guidance co-produced by people with dementia informed decisions about the intervention. Interviews were also conducted with people with dementia and informal carers to further develop and refine the intervention workbook (Study Two, Chapter Four).

Assessing feasibility. A preliminary feasibility case series (Study Three, Chapter Five) was conducted to investigate key uncertainties identified during development and to help develop the intervention. This included uncertainties around recruitment, the feasibility of delivering the intervention and intervention acceptability. Outcome measures were also collected to provide preliminary data for the intervention.

Implementation considerations. To consider whether it would be possible to use the intervention (MRC, 2008. p.9), qualitative research considered potential barriers to the intervention (Study Two, Chapter Four), and investigated the acceptability of the workbook (Study Two; Study Three, Chapter Five) and intervention (Study Three).

2.3.2 Systematic Review

As discussed above, a relevant systematic review should be consulted or, if necessary, conducted as part of the development of a complex intervention (Craig et al., 2008; MRC, 2008). As a systematic review of BA interventions for depression in LTCs had not been conducted before, this was undertaken as the first stage of intervention development. With a large number of research studies published yearly, and a variation in the quality of the research, making informed decisions about healthcare interventions can be difficult (Clarke, 2004). These decisions should be informed by the best available evidence (Gopalakrishnan & Ganeshkumar, 2013). Results from individual studies should not be interpreted in isolation (Glasziou, Vandenbroucke, & Chalmers, 2004). Instead, decisions should be based on the entirety of best evidence (Murad et al., 2014). Systematically identifying, appraising and combining all relevant evidence can help inform decisions about the evidence base for interventions and can overcome the biases of relying on the evidence from single studies (Clarke, 2004). Additionally, systematically reviewing existing literature and evidence minimises research waste and the risk of conducting unnecessary research (Chalmers & Glasziou, 2009; Clarke, 2004).

Systematic reviews are conducted with scientific design and methods that are explicit, pre-specified and reproducible (Centre for Reviews and Dissemination [CRD], 2009). A systematic review uses a systematic search to collate all the evidence that answers a specific research question and fits pre-specified eligibility criteria (Moher et al., 2015). This, therefore, provides a reliable and scientifically conducted review of the research (Petticrew & Roberts, 2006) and reduces bias by identifying all relevant studies on the specified research topic (Petticrew & Roberts, 2006; Uman, 2011). The features of a systematic review are: clearly articulated questions; pre-determined inclusion and exclusion criteria; a comprehensive search for all research; quality appraisal of the included studies; analysis of extracted data; synthesis of findings; and a transparent report of methods (Aromataris & Pearson, 2014). Systematic reviews can be used to investigate the effectiveness of interventions, policies or services; associations between interventions and outcomes; and to explore risk or protective factors (Petticrew & Roberts, 2006).

2.3.3 Qualitative Research

The MRC guidance states qualitative research is often needed along with quantitative methods to investigate key uncertainties and practicalities of the developed intervention (Craig et al., 2008). This section provides an overview of qualitative research and the methods used in this thesis. This section also discusses the quality of qualitative research and strategies to strengthen the trustworthiness of data.

Qualitative research aims to understand or explain social phenomena (Barbour, 2000; Pope & Mays, 1995). The views and experiences of participants are of importance in qualitative research (Pope & Mays, 1995) and their accounts, thoughts and beliefs are explored through their own words (Avis, 2005). Qualitative research considers ‘what’, ‘why’ and ‘how’ questions, rather than the ‘how many’ questions of quantitative research (Pope & Mays, 1995, p. 43). In qualitative research, researchers aim to establish a thorough understanding about a phenomena or aspect of life (Dew, 2007) such as an understanding of how people experience treatments or interventions (Dew, 2007).

2.3.3.1 Qualitative research in this dissertation. Qualitative methods are used in this dissertation as key issues, such as intervention acceptability and ideas for further development of the intervention, need to be investigated through the views, experiences, and opinions of participants. This research takes a pragmatic approach, emphasising the consequences and end results of research (Everest, 2014; Feilzer, 2009) and using an appropriate method for the research questions (Feilzer, 2009). The methods of data collection and analysis used in this dissertation are discussed below.

Data collection methods. Interviews are a common method of data collection in qualitative health care research (Britten, 1995; Taylor, 2005) and aim to collect data to investigate the “insider perspective” (Taylor, 2005, p. 39). Interviews collect data on participants’ experiences and perspectives in their own words through open-ended questions (Braun & Clarke, 2013, Chapter 4). Interviews must be the ‘*best* method’ to collect data for the research questions and should fit with the methodological approach, rather than being simply a convenient data collection method (Taylor, 2005, p. 53). Interviews are an appropriate method of data collection for research aiming to understand the opinions and experiences of participants (Gray, 2014). Therefore, they are an appropriate data collection method for understanding participant’s views on the acceptability of the intervention (Studies Two and Three), opinions on potential barriers (Study Two) and experiences of receiving and delivering the intervention (Study Three).

Data analysis methods.

Thematic analysis. Thematic analysis is a method for identifying patterns of meaning and themes across a dataset (Braun & Clarke, 2013, Chapter 8), with clearly identified phases for the analysis and reporting of themes (Braun & Clarke, 2006). Thematic analysis can be used flexibly with different epistemological or ontological assumptions and many different research questions and types of data (Braun & Clarke, 2013, Chapter 8). As such, thematic analysis as an approach is theoretically flexible (Braun & Clarke, 2014). Thematic analysis has been used for research in psychology (Braun & Clarke, 2006) and disciplines with a focus on health (Braun & Clarke, 2014), and is a useful approach for researchers conducting applied research (Braun & Clarke, 2014). Due to the flexibility regarding theoretical assumptions and appropriateness for applied research, thematic analysis was the method of analysis for Study Two.

2.3.3.2 The quality of qualitative research. Qualitative research may be criticised for a lack of reproducibility and generalisability, or findings that may be subject to researcher bias (Mays & Pope, 1995). As such it is important to consider the quality of qualitative research and strategies that can be employed to strengthen the trustworthiness of qualitative research. The quality of qualitative research relates to the validity and reliability of the research (Silverman, 2005). However, there is some debate about the use of the terms validity and reliability in qualitative research (Long & Johnson, 2000; Rolfe, 2006), sometimes being referred to by terms such as credibility, transferability, applicability, dependability and auditability (see Johnson & Waterfield, 2004). Trustworthiness is another term commonly used, concerned with determining confidence in the ‘truth’ of the findings for the participants involved, based on validity, reliability, and the objectivity of the researcher (Lincoln & Gubba, 1985, p. 290). Nevertheless, despite the debate on appropriate terminology, the terms validity and reliability are applicable to qualitative research in a broad context (Noble & Smith, 2015). Validity refers to findings being representative of the data and phenomenon (Long & Johnson, 2000), with internal validity the “truthfulness and representation of the reality of the participants” (Holloway, 2005, p. 277). Reliability refers to the consistency of methods used in qualitative research (Long & Johnson, 2000).

To strengthen the trustworthiness of findings, methodological strategies can be incorporated by qualitative researchers (Johnson & Waterfield, 2004; Noble & Smith, 2015; Patton, 1999). Incorporating these strategies increases confidence that the reported findings are representative of the views and experiences of the participants (Lietz, Langer, & Furman, 2006). However, it is advised that the strategies are “embedded in a broader understanding of the rationale and assumptions behind qualitative research” (Barbour, 2001, p. 1115). The strategies to strengthen the quality and trustworthiness of qualitative research can be used during data collection (Johnson & Waterfield, 2004) and data analysis (Patton, 1999). These strategies can include purposive sampling; multiple researchers analysing data; participant checking of the data and findings; reflexivity; and a clear detailed audit trail of decisions (Johnson & Waterfield, 2004). Some of the strategies, and those used in this dissertation, are now discussed.

When analysing qualitative data one aspect of thoroughness, and important for the validity of findings, is the examination of negative or deviant cases that contradict the pattern or themes identified by the researcher (Mays & Pope, 1995; Patton, 1999). The validity of qualitative research may be questioned if the researcher does not actively identify or discuss deviant cases, as the findings may then not accurately represent the phenomena or theme across all participants (Silverman, 2005). Deviant cases should be explored by the researcher, with an attempt at an explanation of why the data varies (Mays & Pope, 1995).

Another strategy that can be used during data analysis is ‘analyst triangulation’ (Patton, 1999, p. 1195), using multiple researchers to independently analyse the data and then compare and discuss their findings (Lietz et al., 2006; Mays & Pope, 1995; Patton, 1999). It is not necessary or important for all analysts to agree, but is more to check the researchers’ coding strategies and interpretation of data (Barbour, 2001). Furthermore, multiple researchers may only analyse a selection of the data due to the time and cost of multiple analysts coding the entire dataset (Barbour, 2001). It is important to use multiple analysts to reduce biases that can occur with single researchers, such as interpretive bias and selective perception (Patton, 1999), and to improve the consistency of the methods and representativeness of the data.

Additionally, the reporting of qualitative research is important in regards to reliability and assessment of quality. Qualitative researchers should aim to report methods transparently (Tong, Sainsbury, & Craig, 2007). It is important to report the methods and data in detail so other researchers could analyse the data using the same method and come to similar conclusions (Mays & Pope, 1995), ensuring the consistency of methods. Additionally, detailed reporting of data collection and analysis allows others to assess the quality of the research (Patton, 1999) and shows those reading the research that methods were reliable and the conclusions reached are valid (Silverman, 2005). Furthermore, the reporting of qualitative research should include reflexivity, considering details about the researcher and their relationship with the participants (Tong et al., 2007). Reflexivity involves the researcher being self-aware and critical of their role in the research, and having an awareness of procedures and issues (Holloway, 2005). For research involving interviews, following the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007) will ensure research is reported comprehensively and explicitly.

2.3.4 A Case Series to Investigate Feasibility Issues and to Inform Intervention Development

A case series, “an uncontrolled observational study involving an intervention and outcome for more than one person” (Ryan et al., 2013, p. 35), was chosen to investigate the key uncertainties of the developed intervention (Craig et al., 2008; MRC, 2008) and to inform further intervention development (Abbott, 2014) (Study Three). The MRC framework encourages a pragmatic approach to choosing methods of evaluation, including observational and experimental methods (Craig & Petticrew, 2013). Whenever possible, and appropriate, it is sensible to use a simpler study design (Shanyinde, Pickering, & Weatherall, 2011). A case series was the most pragmatic and parsimonious design to address the aims and objectives of Study Three. It is not necessary to utilise a control group to investigate issues such as acceptability, feasibility and delivery, or to inform intervention development. Other study designs, such as an RCT, would be more appropriate once the intervention is finalised.

Other studies (Jansen & Morris, 2016; Malins et al., 2016) have used a case series design to investigate the same uncertainties as those being investigated in Study Three. For example, Malins et al. (2016) utilised a case series design to determine the feasibility of recruiting participants (long-term frequent attenders in primary care) to receive CBT, and to determine the acceptability of the intervention. Additionally, case series have also been used to help develop and modify interventions, such as CBT for anxiety in people with dementia (Paukert et al., 2010; Spector et al., 2012). For the development of one of these interventions, a version of the intervention was ‘field tested’ with three individuals with dementia and their carers, with information generated on modifications needed to improve the feasibility of the intervention (Spector et al., 2012). The data collected was then used to develop the next version of the intervention manual (Spector et al., 2012).

2.4 Chapter Two Summary

This chapter has provided an overview of the methodology and methods used in this dissertation. This chapter has discussed the MRC framework (Craig et al., 2008; MRC, 2008), systematic reviews, qualitative research in the development of interventions and the qualitative methods used in this dissertation. Additionally, justification was provided for conducting a case series to investigate key uncertainties (Craig et al., 2008; MRC, 2008) and to help develop the intervention. The following chapter presents a systematic review (Study One) of BA for depression in people with LTCs. This systematic review was conducted, following the MRC framework (Craig et al., 2008; MRC, 2008), as the first stage in intervention development.

Chapter Three: A Systematic Review of Behavioural Activation Interventions for Depression in People with Long Term Conditions

3.1 Introduction

This chapter presents a systematic review of behavioural activation (BA) interventions for depression in people with long term conditions (LTCs). The term 'LTC' in this review refers to chronic physical health conditions. This systematic review was conducted as the first stage in the development of the intervention in this dissertation (Craig et al., 2008; MRC, 2008). The aims of this systematic review were: to identify the extent to which different forms of BA have been used as a treatment for depression in adult patients with a range of LTCs; to identify adaptations made to any BA intervention used to treat depression in people with LTCs; and to examine the effectiveness of the different types of BA (Harris, Farrand, & Dickens, 2013). The objectives of this systematic review (with regards to the development of the intervention in this dissertation) were: to identify the evidence base for BA in LTCs (Craig et al., 2008; MRC, 2008); to identify a LTC to target for intervention development; and to inform the development of the intervention.

3.2 Methods

This review was conducted following the Centre for Reviews and Dissemination (CRD)'s guidance (CRD, 2009) and has been reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Moher et al., 2009). This review is registered with the PROSPERO International Prospective Register of Systematic Reviews (registration number: CRD42013004500) and the protocol for this systematic review has previously been published as an open access article (Harris et al., 2013) (see https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/2046-4053-2-105). The additional documents from the published protocol (the search strategy and data extraction form) have been included in the Appendices.

3.2.1 Eligibility Criteria

Studies meeting the following criteria were included in this review:

- **Population:** adults (≥ 16 years) with i) a diagnosis of depression/a depressive disorder (according to a diagnostic interview) or an elevated level of depressive symptomatology (scoring above a cut-off on a validated self-report scale) based on patient and/or informant report and

ii) a LTC, “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies” (DoH Long Term Conditions Team, 2012, p.3).

- **Intervention:** a BA intervention for depression involving strategies to increase pleasant/rewarding activities, and/or reduce escape and avoidance behaviours, by increasing a range of activities.
- **Comparators:** no exclusion.
- **Outcomes:** whether participants are depressed following a diagnostic interview (with the participant and/or informant); and/or scores on a validated self-report scale examining severity of depressive symptomatology (completed by the participant and/or informant); and/or scores on a validated clinician-administered measure for depression (administered to participant and/or informant).
- **Study design:** no exclusion based upon methodology employed.
- **Other:** if published in a language other than English, an English translation must be available publically.

The above eligibility criteria includes three amendments that were made to the criteria reported in the protocol (Harris et al., 2013). Firstly, informant report was added to the population and outcomes criteria as, for people with cognitive impairment (and/or communication problems), informants may be used to provide information about a patient’s mood (Teri, Mckenzie, & Lafazia, 2005). Secondly, validated clinician administered measures were added to the outcomes criteria. Finally, ‘and/or’ replaced ‘or’ in the outcomes of interest. These changes were made during the initial stages of the review process.

3.2.2 Search Strategy

The following electronic databases were searched with the predefined search strategy (see Appendix 3.1): The Cochrane Library (from inception); Medline (from 1946); Cumulative Index to Nursing and Allied Health Literature Plus (CINAHL Plus) (from 1950); The Allied and Complementary Medicine Database (AMED) (from 1950); Excerpta Medica DataBase (EMBASE) (from 1974); and PsycINFO (from 1967). If available on the database a human filter was applied. These databases were searched on the 14th and 15th January 2013, with the searches updated on the 15th May 2015.

The search strategy included terms associated with ‘behavioural activation’ and ‘depression’, including the appropriate medical subject headings for the database being searched. Terms associated with LTCs were not included in the search strategy as preliminary work did not identity acceptable search terms or a definite list that was sufficiently sensitive or specific to identify all LTCs. As such LTCs were screened for manually.

In addition to the electronic searches the reference lists of potentially relevant reviews identified through screening were searched, authors of the included studies were contacted for any unpublished research, and forward and backward citation searching was conducted on the included studies.

3.2.3 Study Selection

After conducting the electronic searches, and removing duplicate records, the titles were manually screened by SH for LTCs and behavioural based interventions. Abstracts were then independently assessed for inclusion by two reviewers (SH and SW), with any disagreements discussed and resolved. If necessary a third reviewer was involved in discussions. A cautious and over inclusive approach was taken when abstract screening, with abstracts kept for full paper screening if insufficient detail was provided to make a decision, for example, the LTC(s) in the sample was unclear (e.g. an elderly population); the intervention was vague (e.g. ‘psychotherapy’); or the abstract reported cognitive behavioural therapy (CBT) but did not specify intervention components.

For conference abstracts where eligibility was unclear the authors were contacted for additional information. If no response was received, the abstracts were excluded. For dissertations that could not be freely accessed, attempts were made to find the contact details of authors. If the details could not be found (or no response was received), the full dissertations were not accessed and reviewed due to time and funding limitations.

Full text articles were assessed for eligibility by SH and a second independent reviewer (LT). Where there was uncertainty in the full text about LTCs in the population, authors were contacted for clarification. If no reply from the author was received, and a LTC(s) was not specified in the study inclusion criteria, the full text was excluded. Any disagreements about inclusion were discussed between reviewers, with involvement of the third reviewer if consensus could not be reached.

3.2.4 Data Collection

Data was extracted by two researchers (SH and JW), independently, using a standardised electronic data extraction form (on Microsoft Excel) (see Appendix 3.2) adapted from Woodford, Farrand, Richards and Llewellyn (2013). Missing information was requested from the authors, along with intervention manuals. Extracted data included characteristics of the study methodology, participants, statistical approaches and results. Also extracted were details on the intervention, including: BA components, delivery mode, interventionist, practitioner training, individual or group delivery, intervention duration, number and length of sessions, treatment setting, whether the intervention was manualised, treatment integrity and adaptations. Information on components and/or adaptations was extracted from treatment manuals (if available from the authors) in addition to information provided in the paper.

The data extraction form was modified following piloting on a sample of the included studies. Modifications to the data extraction spreadsheet included additional columns for analyses conducted in the studies and separate spreadsheet tabs for quality/risk of bias assessment. The data extracted by the researchers was compared and discrepancies were resolved by discussion.

3.2.5 Study Quality and Risk of Bias

The protocol for this review (Harris et al., 2013) stated one reviewer would assess quality, with this checked by a second reviewer. However, to help minimise potential bias in the review process, the scientific quality and risk of bias for included studies was assessed independently by two reviewers (SH and LT for observational studies; SH and JW for RCTs), with any disagreements discussed and resolved. This is with the exception of the blinding of self-report assessment for included randomised controlled trials (RCTs), as the decision was made at a later date to assess clinician administered and self-report measures separately. The ratings for the blinding of self-report assessment were, however, discussed with the second reviewer.

As the Downs and Black (1998) checklist specified in the protocol (Harris et al., 2013) was not appropriate for the observational studies included in this review (due to a lack of control group in the studies), an instrument developed for case series (Yang et al., 2009) was used to assess the scientific quality (design, conduct, reporting and analysis) of the included observational research. A rating of 1 was given if the study met the criteria (and a rating of 0 if the study failed to meet the criteria). When using the instrument discussions were had between the reviewers regarding the appropriateness of two of the items (appropriate methods of recruitment and clear inclusion/exclusion criteria) for single case studies. It was decided, for these items, that case studies were to be scored 1 if the participant was assessed as having depression on a validated measure.

Risk of bias was assessed for the included RCTs using the Cochrane Collaboration's Risk of Bias tool (Higgins, Altman, & Sterne, 2011). The risk of bias was assessed over five domains of bias (selection, detection, attrition, reporting and other) with a rating of low, unclear or high risk of bias given (Higgins et al., 2011). Studies were not assessed for performance bias due to difficulties blinding participants, therapists and other professionals in studies involving psychotherapy (Ekers et al., 2014). For the blinding of outcome assessment, clinician administered and self-report measures were assessed separately.

3.2.6 Data Synthesis

The characteristics of the included studies and interventions have been summarised in tables and the adaptations to the interventions narratively reviewed by LTC. The effectiveness of BA has also been narratively reviewed as the RCTs were not sufficiently homogeneous (with regards to participants, interventions, outcomes and methodology) to conduct a meta-analysis (Deeks, Higgins, & Altman, 2011). In addition to the heterogeneity, a meta-analysis was also deemed inappropriate due to the small size of the included RCTs; medium sized trials of high quality are important to ensure the results of a meta-analysis are trustworthy (Egger & Davey Smith, 1995). With smaller studies there is the potential for super-realisation bias (Cronbach et al., 1980), potentially finding larger effects as ideal conditions can be maintained and the quality and delivery of the intervention may be monitored more closely.

The narrative synthesis of effectiveness examines the relationship between characteristics of individual studies and study findings, as well as comparing and contrasting across studies (Popay et al., 2006). As with other narrative systematic reviews (Bennett, Shafran, Coughtrey, Walker, & Heyman, 2015; Holley, Crone, Tyson, & Lovell, 2011) the main findings of the studies are reported, and the statistically significant and non-significant findings have been tabulated (Popay et al., 2006).

3.3 Results

3.3.1 Study Selection

Details of study selection from the initial search, including reasons for exclusion, are presented in Figure 3.1. In total 26,806 records (including published articles, book chapters, conference abstracts, and dissertations) were identified from AMED (n=106); CINAHL Plus (n=1,672); The Cochrane Library (n=2,450); EMBASE (n=9,697); Medline (n=7,148); and PsycINFO (n=5,733). Following title and abstract screening, 223 full text articles were assessed for eligibility. When searching for the full text of a conference abstract included from abstract screening (Lincoln, Thomas, Walker, MacNiven, & Howarth, 2012) a published article was identified (Thomas, Walker, Macniven, Haworth, & Lincoln, 2013) and this full text was assessed for eligibility. Fifteen studies (19 records) from the database search were included. Five of the 19 records were associated with five of the included studies. These included: a design and methods paper (Mitchell et al., 2008); a research protocol (Teri, 1994); an intervention manual/workbook (Hopko & Lejuez, 2007); a case study of a participant from one of the included studies (Meeks, Teri, Van Haitsma, & Looney, 2006); and a paper reporting additional data for an included study (Hopko, Robertson, & Carvalho, 2009). These records were given the same study identifier as the relevant included study. One record reported two studies (Meeks, Looney, Van Haitsma, & Teri, 2008), and as such this record was split into two studies to be included. Two additional studies for inclusion (Hopko, Lejuez, & Hopko, 2004; Meeks, Van Haitsma, Schoenbachler, & Looney, 2015) were identified from forward and backward citation searching and contact with authors. One of these studies was received from an author as an unpublished paper that was subsequently published during the process of this review (Meeks et al., 2015). In total 17 independent studies were included in the narrative synthesis.

3.3.1.1 Updated search. Details of study selection from the updated search, including reasons for exclusion, are presented in Figure 3.2. In total, 6,269 records were identified from AMED (n=5); CINAHL Plus (n=674); The Cochrane Library (n=532); EMBASE (n=2,296); Medline (n=1,531); and PsycINFO (n=1,231). Following title and abstract screening, a total of 48 full text articles (including conference abstracts where additional information had been obtained from authors) were assessed for eligibility. One study (a conference abstract) (Kirkness et al., 2015) was included in the systematic review with additional study details provided by one of the authors. Four other records were included as they were related to studies included from the initial search, and were given the same study identifier as these studies. These records included additional data for an included study (Hopko et al., 2013) and depression scores previously reported in an included paper (Humphreys, Thomas, Phillips, & Lincoln, 2015). The other two records were the published paper identified for the conference abstract in the initial search (Thomas et al., 2013) and the published paper for the study received from the author in the initial search (Meeks et al., 2015). In total, from the initial and updated searches, 18 independent studies were included in this review.

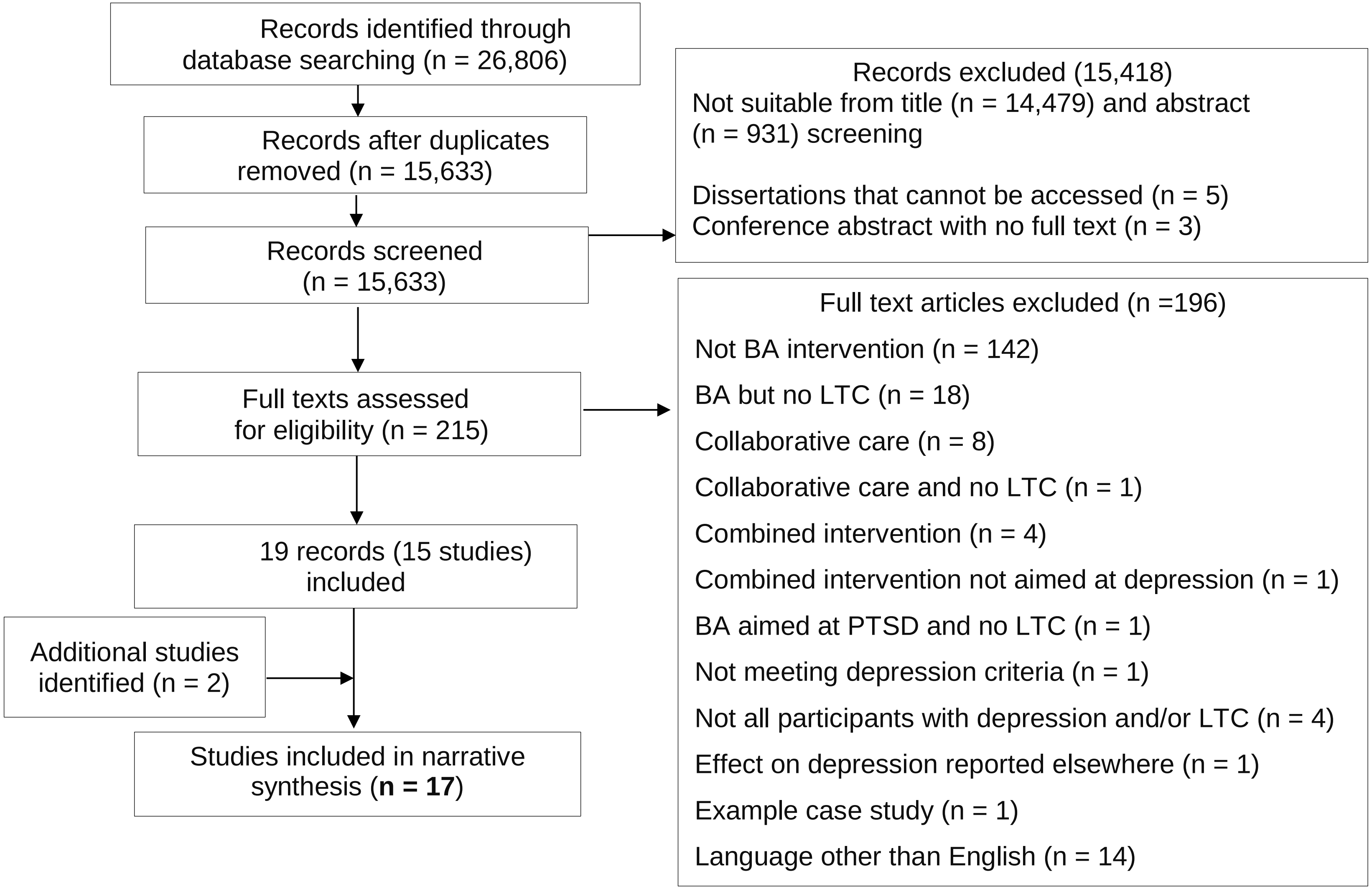


Figure 3.1 Initial Search PRISMA Flow Diagram

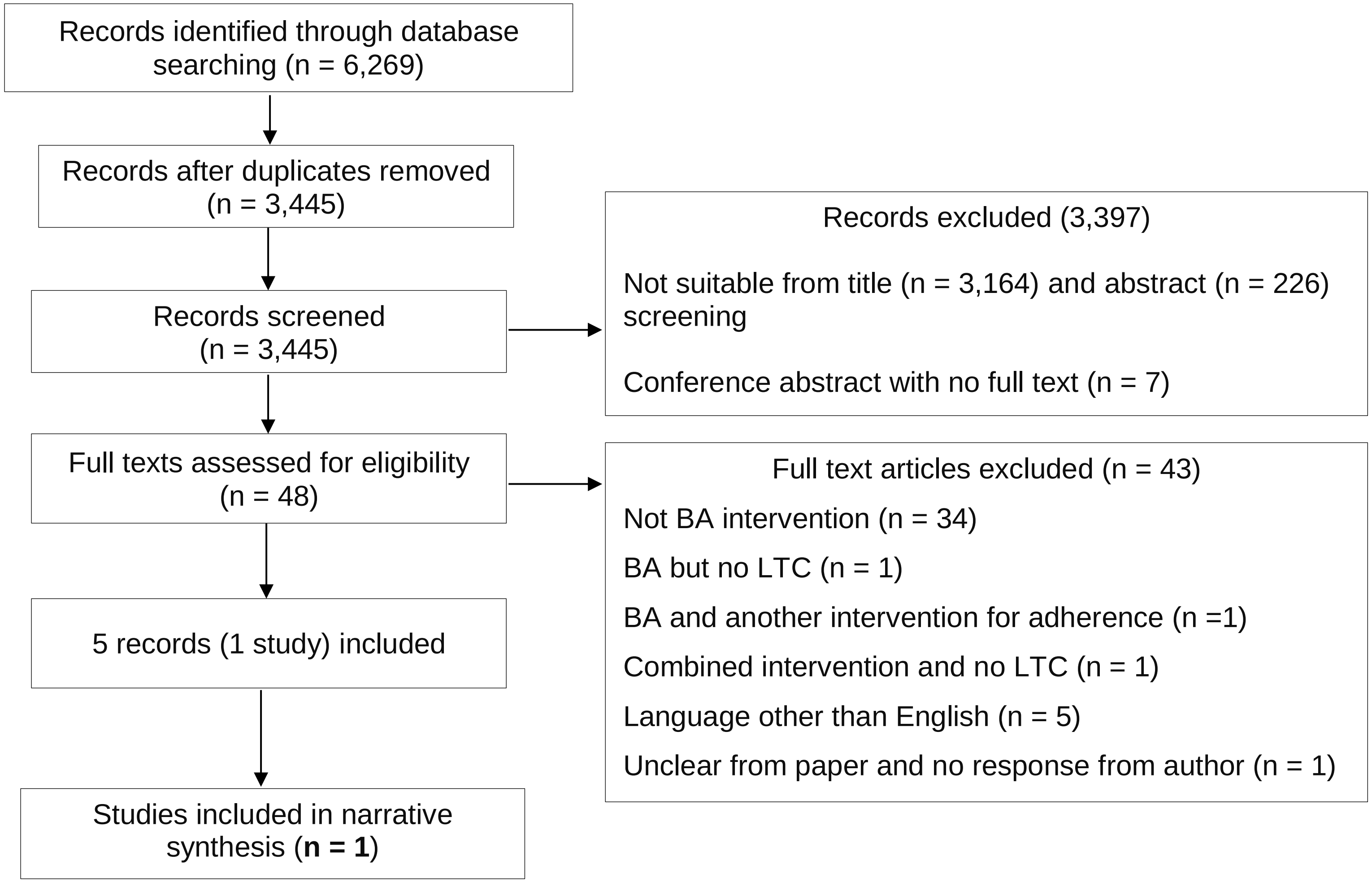


Figure 3.2 Updated Search PRISMA Flow Diagram

3.3.2 Study Characteristics

Table 3.1 presents the characteristics of the included studies. The study numbers (see Table 3.1) are used throughout the synthesis to refer to the included studies. Overall 8 RCTs (660 participants), 6 case studies (6 participants) and 4 case series (19 participants) were included. The number of participants in RCTs ranged from 20 to 105, with the smallest RCT [Study 10] designed to investigate the feasibility of the intervention. Two of the RCTs utilised cluster randomisation, randomising by nursing home [12] and ward [18]. Three studies compared BA to usual care [13,16,18], two compared to treatment as usual [10,12] and one study compared BA to problem solving therapy [5]. The other two RCTs were multi-arm studies, with Study Number 7 comparing BA delivered in person, BA delivered by telephone and usual care, and Study Number 15 comparing BA, problem solving, typical care and waiting list control.

3.3.2.1 Participant characteristics. Overall the LTCs of participants in the identified studies included: cancer (4 studies); nursing home residents with multiple conditions (4 studies); dementia (3 studies); stroke (3 studies), with one of these studies involving participants with aphasia [16]; arthritis (1 study); colitis (1 study); vascular disease (1 study); and one case study [17] with multiple conditions (including heart failure, chronic obstructive pulmonary disease, diabetes and arthritis). Although the specific medical conditions were not listed for three of the nursing home studies [9,10,12] a mean number of diseases was reported for all three studies. Two of the dementia studies recruited patient-carer dyads [14,15] and outcomes were also collected for the carers. For studies reporting mean ages these ranged from 46.6 [4] to 84.1 years [18]. The ages of participants in case studies ranged from 28 [3] to 71 years [8].

The participants in 14 studies met the criteria for depression/a depressive disorder according to diagnostic interview including: major depression [1,4-6,14,17]; major depressive episode [2]; dysthymic disorder [3]; major or minor depression [15]; a depressive disorder [11]; a diagnosis of clinical depression [13]; major depressive disorder, minor depression or intermittent depressive disorder [9,10]; and depression in dementia [18]. Diagnosis was also confirmed for participants in Study Number 7 after screening with a self-report measure. The participants in Study Number 12 met the criteria for a depressive disorder or scored above a cut-off on a validated self-report scale. In one RCT [16] participants were included if they scored above a cut-off on one of two self-report measures. The participant in the final study [8] was included in this review as their baseline score on a self-report measure was above a cut-off score detailed in the literature (Smarr & Keefer, 2011).

The baseline severity of depressive symptoms (mild, moderate, or severe) was calculated for the following self-report and clinician administered measures: the Hamilton Rating Scale for Depression (HRSD; Hamilton, 1960); the Beck Depression Inventory I & II (BDI-II; Beck, Steer, & Brown, 1996; BDI-I; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961); and the Geriatric Depression Scale (GDS; Yesavage et al., 1983). The severity was calculated based on cut-off scores reported in the literature (Beck, Steer, & Carbin, 1988; Cusin, Yang, Yeung, & Fava, 2010; Smarr & Keefer, 2011). Baseline severity was not calculated for the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) as there are no cut-off scores for severity (Smarr & Keefer, 2011). Details of diagnosis at baseline were extracted from the papers, and for Study Number 18 probable major depression was calculated using scoring guidelines (Alexopoulos, 2012) for the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988).

Table 3.1 *Study Characteristics of Included Studies*

Study No. & Reference	Study Design	N	Participant Characteristics	Baseline Depression	Anti-depressant(s)	Control	Country
[1] Armento & Hopko (2009)	Case Study	1	*LTC*: Breast Cancer *Age (years)*: 58 *Sex*: Female	Moderate (self-report) Severe (clinician rated)	Yes, stabilised 8 weeks	N/A	USA
[2] Czirr & Gallagher (1983)	Case Study	1	*LTC*: Rheumatoid Arthritis *Age (years)*: 62 *Sex:* Male	MDE Mild to moderate (self-report)	NR	N/A	USA
[3] Hopko et al. (2004)	Case Study	1	*LTC*: Colitis *Age (years)*: 28 *Sex*: Female	Dysthymia disorder Mild to moderate (self-report)	No	N/A	USA
[4] Hopko et al. (2005)	Case Series	6	*LTC:* Cancer *Age (years):* M = 46.4, SD = 14.1 *Sex*: Female	Moderate (clinician rated)	2 Ps: No 4 Ps: Yes, stabilised	N/A	USA
[5] Hopko, Armento, et al. (2011)	RCT	80 I: 42; C: 38	*LTC*: Breast Cancer *Age (years):* M = 55.4, SD = 11.9 *Sex*: NR	Moderate (clinician rated and self-report)	I: 57% Yes (stabilised 88%) C: 47% Yes (stabilised 94%)	PST	USA
[6] Hopko, Magidson, & Lejuez (2011)	Case Study	1	*LTC:* Breast Cancer *Age (years):* 47 *Sex:* Female	MDD Severe (clinician rated and self-report)	No	N/A	USA

[7] Kirkness et al. (2015)	RCT	100 I in-person: 35; I telephone: 37; C: 28	*LTC:* Stroke *Age (years):* I in-person: M = 58.5, SD = 12.3; I telephone: M = 61.7, SD = 13.5; C: M = 60.7, SD = 12.4 *Sex:* I in-person: 51% Female; I telephone: 49% Female; C: 50% Female	Moderate (clinician rated)	Anti-depressants recommended in all 3 arms. %s NR	Usual Care	USA
[8] Lichtenberg, Kimbarow, Mackinnon, Morris, & Bush (1995)	Case Study	1	*LTC:* Vascular disease *Age (years)*: 71 *Sex:* Female	Mild (self-report)	NR	N/A	USA
[9] Meeks, Looney, et al. (2008)	Case Series	5	*LTC:* Multiple *Age (years)*: M = 66, SD = 6.4 *Sex:* NR	Mild (clinician rated and self-report)	80% Yes	N/A	USA
[10] Meeks, Looney, et al. (2008)	RCT	20 I: 13; C: 7	*LTC:* Multiple *Age (years):* I: M = 76.9, SD = 11.5; C: M = 79.4, SD = 4.3 *Sex:* NR	I: Mild (self-report) Moderate (clinician rated) C: Mild (clinician rated and self-report)	70% Yes (of randomised sample)	TAU	USA
[11] Meeks, Sublett,	Case Series	4	*LTC:* Multiple *Age (years):* range	P1: MDD partial remission; P2:	NR	N/A	USA

Kostiwa, Rodgers, & Haddix (2008)			47 - 81* *Sex:* Male	Bipolar, current episode MDE severe; P3: MDD partial remission; P4: MDD severe P1: Mild, P2-4: Severe (self-report)			
[12] Meeks et al. (2015)	RCT	82 I: 42; C: 40	*LTC:* Multiple *Age (years):* M = 75.16, SD = 12.11 *Sex:* 65.4% Female	69.1% MDE, 30.9% other depressive disorders I: Mild C: severe (self-report)	I: 78.6% Yes C: 85% Yes	TAU	USA
[13] Mitchell et al. (2009)	RCT	101 I: 48; C: 53	*LTC:* Stroke *Age (years):* I: M = 57, range 25 - 88; C: M = 58, range 29 - 88 *Sex:* I & C: 39.6% Female	Moderate (clinician rated)	I: 60.4% Yes C: 64.2% Yes (77% of each group prescribed and took anti-depressants during treatment period)	Usual Care	USA
[14] Teri & Uomoto (1991)	Case Series	4 (dyads – patient and carer)	*LTC:* Dementia (Alzheimer's disease) *Age (years):* M = 78 *Sex:* 50% Female	P1 & P3: Moderate, P2 & P4: Mild (clinician rated) P1: moderate to severe, P2: Mild	NR	N/A	USA

				to moderate (self-report completed by carer)			
[15] Teri, Logsdon, Uomoto, & McCurry (1997)	RCT	72 (dyads – patient and carer) I: 23; I^1: 19; C^1: 10; C^2: 20	*LTC:* Dementia (Alzheimer's Disease) *Age (years):* I: M = 72.8, SD = 8.2; I^1: M = 78.5, SD = 7.9; C^1: M = 79.5 SD = 6.9; C^2: M = 76.8, SD = 8.2 *Sex:* I: 70% Female; I^1: 26% Female; C^1: 60% Female; C^2: 35% Female	% 75 Major depression 25% Minor depression Mild (clinician rated) Mild to moderate (self-report completed by carer)	NR	BT-PS (I^1) TCC (C^1) WLC (C^2)	USA
[16] Thomas et al. (2013)	RCT	105 I: 51; C: 54	*LTC:* Stroke with aphasia *Age (years):* I: M = 68.5, SD = 13.1; C: M = 65.5, SD = 23.9 *Sex:* I: 43% Female; C: 31% Female	Low mood	I: 29% Yes C: 26% Yes	Usual Care	UK
[17] Turvey & Klein (2008)	Case Study	1	*LTC:* Multiple *Age:* 56 *Sex:* Male	Moderate (clinician rated) Severe (self-report)	Yes, stabilised 1 year	N/A	USA

[18] Verkaik et al. (2011)	RCT	100 I: 65; C: 35	*LTC:* Dementia (type not established) *Age (years):* I: M = 83.4, SD = 7.2, range 62 - 99; C: M = 84.1, SD = 7.1, range 66 - 96 *Sex:* I: 83.9% Female; C: 80% Female	I & C: Probable major depression (clinician rated)	I: 45.2% Yes C: 25.7% Yes	Usual Care	The Netherlands

Note: * = actual ages are not given to protect anonymity; BT-PS = Behaviour therapy-problem solving; C = control; I = intervention; LTC = long term condition; M = mean; MDE = major depressive episode; MDD = major depressive disorder; NR = not reported; P = participant; Ps = participants; PST = Problem solving therapy; RCT = randomised controlled trial; SD = standard deviation; TAU = Treatment as usual; TCC = Typical care control; UK = United Kingdom; USA = United States of America; WLC = Wait list control.

3.3.2.2 Intervention characteristics. Details of the characteristics of the interventions delivered in the included studies are presented in Table 3.2. Adaptations to the BA interventions to accommodate LTCs are also included in Table 3.2 and are reviewed in more depth below. A taxonomy for different types of BA (simple and complex) established by Ekers et al. (2014) has been adopted when classifying the interventions below. Simple BA is defined as predominately self-monitoring and activity scheduling, whilst complex BA additionally includes behavioural components such as functional analysis and/or values focussed components (Ekers et al., 2014).

Simple BA interventions were delivered in 13 of the included studies [2,7-18]. Two of the simple BA interventions were delivered in multiple studies. The Living Well With Stroke intervention was delivered in two studies [7,13], with the intervention compressed into fewer sessions, following pilot work, in Study Number 7. Although the Living Well With Stroke intervention does involve a session on changing negative thoughts and behaviours, it was considered a BA intervention as it does not directly target cognitions. The intervention uses problem solving to identify solutions to negative thoughts, such as distractions or engaging in pleasant activities. Focussing on the function of thinking (rather than the content of thoughts) and using rumination as a cue to action is present in other BA interventions (Addis & Martell, 2004), as well as interventions delivered in several of the included studies [1,5,6,17]. The Behavioural Activities Intervention (BE-ACTIV) was delivered in four studies [9-12], with the first of these [9] a pilot to develop the treatment manual. Manuals were received from the authors for both of these interventions. Therapy manuals were also received for the interventions delivered in Studies 16 and 17. The other studies delivering simple BA interventions referenced a published protocol [2], published work describing the intervention [15], interventions which were adapted [8,18] and an intervention on which the sessions were modelled [14].

Five studies delivered complex BA interventions [1,3-6], with these interventions involving a values focussed component regarding goals and values in life areas. Two studies [3,4] referenced a published treatment manual/patient guide for Brief Behavioural Activation Treatment for Depression (BATD; Lejuez, Hopko, & Hopko, 2002, 2001), and a therapist manual for BATD for treating cancer patients with depression was received from the author for the intervention delivered in Study Number 5. The other two studies [1,6] referenced a published self-help workbook of BA for depressed cancer patients (Hopko & Lejuez, 2007) that includes a chapter on Behavioural Activation Treatment for Cancer (BAT-C).

Table 3.2 *Characteristics of Interventions Delivered in Included Studies*

Study No.	Intervention	Sessions	Setting	Delivery	Intervention Components	Adaptations for LTC
[1]	BAT-C *Type of BA:* Complex *Manualised:* Yes	*No. of sessions:* 8 *Duration:* 8 weeks *Length:* 1hour *Delivery:* Face to face	Medical centre Oncology Clinic	*Interventionist:* Doctoral PhD student *Training:* Yes *Measure of treatment integrity:* Yes, patient compliance	Rationale; self-monitoring with daily diary; identification of life values & goals; activity hierarchy; master activity log & behavioural checkout; exposure and relaxation exercises for generalised anxiety (health-related concerns); regular exercise in activity log for stress management skills; rumination-cued activation.	Tailored psychoeducation; behavioural exposure exercises; relaxation exercises.
[2]	'Depression in the Elderly' protocol *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* Unclear *Duration:* 7 weeks *Length:* NR *Delivery:* Face to face	NR	*Interventionist:* First author of paper, MSc. *Training:* NR *Measure of treatment integrity:* No	Rationale; identifying types of pleasant & unpleasant events; self-monitoring, daily log of pleasant & unpleasant events, ratings of quality of mood, & arthritis pain & disability; increasing pleasant events & decreasing unpleasant events.	Progressive relaxation.
[3]	BATD *Type of BA:* Complex *Manualised:* Yes	*No. of sessions:* 10 *Duration:* Weekly *Length:* 2 x 1hour, over time reduced to between 30 -	Outpatient Psychological Clinic	*Interventionist:* Psychology intern *Training:* Yes *Measure of*	Rationale; activity & goal selection; weekly self-monitoring of activities; identification of life values & goals; activity hierarchy; master activity log &	Consultation with physician and nutritionist; discussions around symptoms.

		45mins *Delivery:* Face to face		*treatment integrity:* No	behavioural checkout; reward incentives.	
[4]	BATD *Type of BA:* Complex *Manualised:* Yes	*No. of sessions:* 9 *Duration:* 9 weeks *Length:* approx.1 hour *Delivery:* Face to face	Cancer Institute	*Interventionist:* Clinical psychology graduate students *Training:* Yes *Measure of treatment integrity:* Yes, therapist adherence & competence; patient adherence	Psychoeducation; assessing function of depressed behaviour; rationale; self-monitoring (weekly or daily diary); identification of life values & goals; activity hierarchy; master activity log & behavioural checkout; reward incentives.	
[5]	BATD for cancer patients with depression *Type of BA:* Complex *Manualised:* Yes	*No. of sessions:* 8 *Duration:* 8 weeks *Length:* approx.1 hour *Delivery:* Face to face	Cancer Institute	*Interventionist:* Advanced clinical psychology (doctoral) students *Training:* Yes *Measure of treatment integrity:* Yes, therapist	Psychoeducation; assessing function of depressed behaviour; rationale; motivational exercises on pros & cons of behavioural change; self-monitoring daily diary; identification of life values & goals; activity hierarchy; master activity log & behavioural checkout; anxiety reduction strategies to	Tailored psychoeducation; behavioural exposure exercises.

				adherence & competence	reduce aversive experiences (muscle relaxation, assertiveness training, graduated exposure); rumination-cued action.	
[6]	BAT-C *Type of BA:* Complex *Manualised:* Yes	*No. of sessions:* 8 *Duration:* 8 weeks *Length:* 1 hour *Delivery:* Face to face	Cancer Institute	*Interventionist:* Doctoral student *Training:* Yes *Measure of treatment integrity:* Yes, patient compliance	Rationale; self-monitoring with daily diary; identification of life values & goals; activity hierarchy; master activity log & behavioural checkout; exposure and relaxation exercises for generalised anxiety (health-related concerns); regular exercise in activity log for stress management skills; rumination-cued activation.	Tailored psychoeducation; behavioural exposure exercises.
[7]	Living Well With Stroke *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 6 *Duration:* NR *Length:* Arm A average 35 mins; Arm B average 25 mins *Delivery:* Arm A Face to face; Arm B Telephone	Patient's home	*Interventionist:* Psychosocial nurse practitioner *Training:* Yes *Treatment integrity:* Yes, therapist adherence	Psychoeducation; identifying pleasant events; planning & scheduling pleasant events; problem solving; coping with caregiving (if carer involved); changing negative thoughts & behaviours; maintaining gains.	Adapted written materials; American Stroke Association materials; carer involvement; carer issues addressed.
[8]	Behaviour Therapy (behavioural	*No. of sessions:* 8 *Duration:* NR *Length:* 5 -	Rehabilitation Unit	*Interventionist:* Occupational therapist	Rationale; mood ratings; relaxation and mood monitoring; increasing	Combined within OT sessions.

	treatment combined with occupational therapy) *Type of BA:* Simple *Manualised:* Yes	10mins relaxation, 20 - 30mins pleasant activity, 45mins OT *Delivery:* Face to face		*Training:* Yes *Measure of treatment integrity:* No	pleasant events (pleasant events incorporated into OT sessions); reinforcement for functional gains.	
[9]	BE-ACTIV *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 10 *Duration:* 10 weeks, 6 weeks of sessions, 4 weeks of maintenance sessions *Length:* NR *Delivery:* Face to face	Nursing Home	*Interventionist:* Clinical Psychologist (PI) and a member of nursing home staff for 6 sessions; nursing home staff only for maintenance sessions *Training:* Experienced Clinical Psychologist; training for staff members. *Measure of treatment integrity:* Yes,	Rationale; assessment/ identification of pleasant events; scheduling pleasant events; encouraging family involvement; confronting obstacles; increasing pleasant events; progress review; maintaining gains; problem solving; reinforcement of patient, staff member and family.	Collaborative association between psychologist & nursing home staff members; pleasant event schedule-nursing home version; family involvement.

				patient adherence		
[10]	BE-ACTIV *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 10 *Duration:* 10 weeks *Length:* 30 - 40 mins with patient *Delivery:* Face to face	Nursing Homes	*Interventionist:* Clinical Psychologist (PI) *Training:* Experienced Clinical Psychologist; training for staff members *Measure of treatment integrity:* Yes, patient adherence	Rationale; assessment/ identification of pleasant events; scheduling pleasant events; encouraging family involvement; confronting obstacles; increasing pleasant events; progress review; maintaining gains; problem solving; reinforcement of patient, staff member and family.	Collaboration with nursing home staff members; pleasant event scale-nursing home version; family involvement.
[11]	BE-ACTIV *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 10 *Duration:* 10 weeks *Length:* NR *Delivery:* Face to face	Prison Nursing Home	*Interventionist:* Doctoral students in clinical psychology *Training:* NR for Doctoral students, training for staff member *Measure of treatment integrity:* No	Rationale; assessment/ identification of pleasant events; scheduling pleasant events; confronting obstacles; increasing pleasant events; progress review; maintaining gains; problem solving.	Involvement of staff (recreational therapist); pleasant event scale-nursing home version.

[12]	BE-ACTIV *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 10 *Duration:* 10 weeks *Length:* NR *Delivery:* Face to face	Nursing Homes	*Interventionist:* Clinical psychology Doctoral students *Training:* Yes for therapists; training for staff members *Measure of treatment integrity:* Yes, assessed for patient, therapist and staff member	Rationale; assessment/ identification of pleasant events; identify family members for involvement (if appropriate); scheduling pleasant events; encouraging family involvement; confronting obstacles; increasing pleasant events; progress review; maintaining gains; problem solving; reinforcement of patient and family.	Collaboration with staff facilitators; pleasant event schedule-nursing home version; family involvement;
[13]	Living Well With Stroke *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 9 *Duration:* 8 weeks *Length:* Mean 60 mins, range 30 - 70 mins *Delivery:* Face to face	Patient's home or neutral location	*Interventionist:* Psychosocial Nurse Practitioners *Training:* Yes *Measure of treatment integrity:* Yes	Psychoeducation; identifying pleasant events; planning & scheduling pleasant events; problem solving; coping with caregiving (if carer involved); changing negative thoughts & behaviours; maintaining gains.	Adapted written materials; American Stroke Association materials; carer involvement; carer issues addressed.
[14]	Pleasant Event Scheduling *Type of BA:* Simple	*No. of sessions:* 8 *Duration:* NR *Length:* 1 hour *Delivery:* Face to face	NR	*Interventionist:* PhD Clinical Psychologist *Training:* Yes *Measure of*	Rationale; mood ratings and daily monitoring of pleasant events; identifying, planning and increasing pleasant events;	Carers taught strategies; pleasant events schedule-elderly version; strategies for

	Manualised: No			*treatment integrity:* No		behavioural disturbances.
[15]	Behaviour Therapy-Pleasant Events *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 9 *Duration:* 9 weeks *Length:* 1 hour *Delivery:* Face to face	NR	*Interventionist:* Geriatricians *Training:* Experienced Geriatricians, intervention training NR *Measure of treatment integrity:* No	Rationale; mood ratings and daily monitoring of pleasant events; identifying, planning & increasing pleasant events; carer problems addressed; plans for continuing pleasant events & problem solving.	Carers taught strategies; carer problems addressed; pleasant events schedule-Alzheimer's disease; maximising cognitive function; strategies for behavioural disturbances.
[16]	Behavioural therapy *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* Up to 20, mean = 9.07, range 3 - 18, SD = 2.63 *Duration:* over 3 months *Length:* mean = 58 mins, range 30 - 89, SD = 10.71 *Delivery:* Face to face.	Patient's place of residence	*Interventionist:* Assistant psychologists *Training:* Yes *Measure of treatment integrity:* Yes	Rationale; activity monitoring; goal definition; mood monitoring; identification of pleasant events; activity scheduling; problem solving (e.g. graded task assignment); relapse prevention.	Communication resources; family or carer involvement if available; suggestions for adapting therapy for aphasia.
[17]	Hybrid BA & IPT *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* 12 *Duration:* 12 weeks *Length:* 3 x 1hour, 9 x 30 mins	Patient's home	*Interventionist:* Clinical Psychologist (PI) *Training:* Experienced	IPT; behaviour monitoring and assessment; identifying enjoyable or meaningful activities; problem solving challenges; activity scheduling; mood monitoring;	IPT; taking into account functional impairment; telephone delivery.

		Delivery: 3 sessions face to face, 9 telephone		psychologist *Measure of treatment integrity:* No	pacing; distraction activities for rumination; discussing maintenance.	
[18]	Pleasant-Activities-Plans *Type of BA:* Simple *Manualised:* Yes	*No. of sessions:* Unclear *Duration:* 11 weeks *Length:* Unclear *Delivery:* Face to face	Psychogeriatric Nursing Home Wards	*Interventionist:* Certified Nurse Assistants *Training:* Yes *Measure of treatment integrity:* No	Nursing guideline to increase individualised pleasant activities and decrease unpleasant events; identification of preferred and disliked activities; information collected on present depressive symptoms and contexts symptoms occur in; planning of activities; necessary adaptations made to plans; plans integrated into daily care.	Certified Nurse assistants developing Pleasant-Activities-Plans; potential for relatives or activity therapists to be involved in activities.

Note: BA = Behavioural Activation; BAT-C = Behavioural Activation Treatment for Cancer; BATD = Brief Behavioural Activation Treatment for Depression; BE-ACTIV = Behavioural Activities Intervention; IPT = interpersonal psychotherapy; No. = number; NR = not reported; OT = Occupational Therapy; PI = Principal Investigator; SD = standard deviation.

Adaptations to interventions for LTCs. The main adaptations made to the included BA interventions to accommodate LTCs were: involving others in the delivery and/or support of the intervention (carers, family, staff members, other professionals); including additional treatment components (interpersonal psychotherapy, exposure exercises, relaxation); taking into account functional and cognitive impairment; and ensuring psychoeducation, materials and inventories were tailored to and appropriate for the population. The adaptations are now reviewed by LTC.

Cancer. Adaptations to BA for people with cancer included tailoring the psychoeducation to the population and incorporating behavioural exposure exercises. In the BAT-C intervention [1,6] psychoeducation was around cancer and cancer's relation to emotional experiences and behavioural changes. In the BATD manual [5] patients are helped to understand the relationship between depression and cancer. These interventions also included exercises to help patients confront cancer, and to increase exposure and acceptance of cancer. These exercises were in the form of journal assignments around being diagnosed with and living with cancer. For the patient in Study Number 1, relaxation and exposure exercises were incorporated into treatment for generalised anxiety, particularly to target health related concerns regarding diagnosis.

Dementia. Adaptations for people with dementia included: the involvement of carers in the intervention, the use of inventories with suitable activities, maximisation of cognitive function and the targeting of behavioural disturbances.

In the interventions delivered in Studies 14 and 15, carers were actively taught behavioural strategies to improve depression in the person with dementia. Carers rated mood and monitored the frequency and duration of pleasant events. Carers also monitored changes in depression while implementing strategies to increase pleasant events [15]. The rationale for involving the carer in therapy was due to the unlikelihood that the person with dementia could learn new skills, remember treatment content and understand the rationale independently (Teri, 1994). However, the level of caregiver involvement is influenced by factors such as the degree of cognitive impairment and nature of the caregiving role (Teri, Logsdon, Wagner, & Uomoto, 1994). In these interventions the carers and dementia participants participated in varying degrees. For the intervention in Study Number 15, one session focussed on the carer, targeting caregiver problems including depression, stress, anger and burden. Carers were also encouraged to plan pleasant events for themselves and develop a support system. The intervention in Study Number 18 was a nursing guideline, and as such certified nurse assistants (CNAs) were responsible for the development, facilitation and evaluation of activities. However, there was the potential for others to be involved as identified activities could involve CNAs, activity therapists or the dementia participant's relatives.

During the interventions in Studies 14 and 15, examples of common pleasurable activities that are appropriate for the population were provided, using a pleasant events schedule for older people (Teri & Lewinsohn, 1982) [14] and an Alzheimer's disease version (Teri & Logsdon, 1991) [15]. These inventories were used to help generate ideas and plan pleasant activities. As behavioural disturbances can interfere with engaging in activities, strategies for identifying and confronting behavioural disturbances also formed part of the interventions. For the intervention in Study Number 15 the carer was also taught to maximise cognitive function as the availability of enjoyable activities is reduced by cognitive impairment, and cognitive and functional impairment can increase the potential for patient carer conflict (Teri, 1994). Clinical strategies (for example using one-step commands and putting labels on cabinets) were discussed in this intervention and tailored to the individual (Teri, 1994).

Stroke. For stroke patients, adaptations to BA also included carer involvement in therapy, however only as a supportive role, rather than being actively taught strategies as in Studies 14 and 15. Additionally, appropriate materials and resources were utilised during therapy.

For stroke patients with aphasia [16] family members and carers could play an important role in therapy by helping with homework tasks, supporting and praising achievements, and providing encouragement. However, patients may not have support, and the treatment manual was designed with the potential lack of support taken into consideration. For the Living Well with Stroke intervention the participant could opt to have a carer or family member join the sessions [13]; participation from family members was encouraged as they were seen as supporters of the participant's efforts and potential allies (Mitchell et al., 2008). This intervention also included a session for the carer (if involved) to address caregiver burden and depression, to discuss resources that may help the carer to help themselves, and to identify areas the carer needed or wanted support (Mitchell et al., 2008).

To ensure the written materials for the Living Well with Stroke intervention were appropriate for the population, stroke survivors who had experienced depression assisted in adapting materials previously used for patients with Alzheimer’s disease (Mitchell et al., 2008). Additionally, materials from the American Stroke Association were given to participants to help understand stroke recovery. For stroke patients with aphasia [16] communication resources such as letter charts, pictures and photographs, were used in the intervention, and guidance was provided in the manual on ways to adapt to the aphasic patient’s deficits.

Nursing home residents with multiple conditions. Others were also involved in the delivery and support of the BE-ACTIV intervention [9-12] with this intervention developed with extensive staff input. BE-ACTIV is a collaborative intervention involving a mental health therapist and a member of staff from the activities department in the nursing home, with family involvement in supporting the intervention also encouraged. The intervention was initially designed to be delivered by both the consultant and a member of the nursing home activities staff, however following the manual development pilot [9] the responsibility of staff members was reduced. The staff facilitators were invited to several sessions, met weekly with the therapist and assisted the resident to carry out planned activities [12]. During later sessions the staff member may have increased their involvement and conducted a session(s). The pleasant event schedule-nursing home version (Meeks, Heuerman, Ramsey, Welsh, & White, 2005) was developed for the BE-ACTIV intervention and was used to identify and rate pleasant events appropriate for the population. When delivered to residents in the prison nursing home [11] the staff member helped to identify activities that were feasible within the setting.

Multiple conditions. The adaptions to the intervention delivered in Study Number 17 were to accommodate functional impairment, including the addition of interpersonal psychotherapy (IPT), less extensive BA techniques, and telephone delivery. The therapy is a hybrid intervention combining IPT and BA. The IPT in this intervention had a focus on grief and loss and role transition, to help the patient come to terms with functional impairment. The focus on grief and loss is important to teach participants to readjust expectations so they can set realistic goals [17]. With regards to the BA components the manual indicates there is less emphasis on avoidance in this therapy than in other BA interventions (for example Addis & Martell, 2004; Jacobson et al., 2001) as the loss of behaviours may be due to functional decline rather than an avoidance pattern. Additionally, behavioural monitoring and goal setting is not as extensive as in other BA interventions (for example Addis & Martell, 2004). To take into account the participant's limited functioning, pacing, adjusting expectations and adapting old behaviours were also part of the therapy. Delivering this intervention primarily over the telephone is also considered an adaptation to accommodate LTCs as the authors identify the fact chronically ill patients are often homebound and cannot or will not be able to travel to a remote medical centre.

Colitis. Others were also involved in supporting the intervention delivered to a patient with colitis [3], specifically the patient's physician and nutritionist were consulted. This consultation was important for structuring activities and behaviours that were less likely to exacerbate colitis symptoms. Brief discussions were also had with the patient around the uncertainty associated with inflammation and the worsening of affective problems after physical symptoms.

Vascular disease. The interventionist delivering BA in Study Number 8 was an occupational therapist rather than a professional whose prime responsibility is the delivery of psychological therapy. This was identified as an adaptation to accommodate LTCs due to the medical rehabilitation unit setting in this study; the authors state inpatient stays are short, so psychologists would not be able to deliver many sessions during that time. On the contrary, occupational therapy is provided on a daily basis so delivering BA during occupation therapy sessions is more appropriate for this population and setting.

Rheumatoid arthritis. One additional component was added to the intervention delivered in Study Number 2, a progressive relaxation technique was taught in early therapy sessions.

3.3.2.3 Depression outcomes. The depression outcome measures and time points utilised in the included studies are presented in Table 3.3. To be included in this review clinician administered and self-report measures needed to be validated, however no specific levels of reliability or validity were pre-determined. Evidence for the validation of the measures is presented in Appendix 3.3.

Diagnostic interviews are utilised in four studies [6,10,12,15] with diagnostic recovery (unchanged, improved, remitted, or worsened) the primary outcome in Study Number 12. Clinician administered measures were used in 12 studies [1,4-7,9,10,13-15,17,18] and self-report measures completed in 15 studies [1-6,8-12,14-17]. A modification of the Philadelphia Geriatric Centre Positive and Negative Affect Rating Scale was utilised in Studies 9 and 10, however the validation of the modification is unknown, therefore this measure was not included. Informants completed measures in four studies [14-16,18], although it was unclear whether the clinician administered measure in Study Number 14 was completed by the carer and/or person with dementia. For the diagnostic interview in Study Number 12 information was corroborated, when necessary, with family, staff or nursing home charts.

For the included RCTs there is variability in the reporting of outcomes (see Appendix 3.4) with studies reporting means and standard deviations (SD) [5,10,12,16]; mean change and SD [13,15]; percent reduction in scores [7]; number and percent with diagnosis [10]; number and percent meeting diagnostic recovery codes [12]; percent in remission [13]; number and percent with a clinically significant improvement [15]; and estimated mean score and standard error [18]. Three studies do not report outcomes at all time points: the number and percent with diagnoses is not reported at baseline in Study Number 10; diagnostic outcomes are only reported at post intervention in Study Number 12; and all measures are only reported post intervention for the BA intervention in Study Number 15 as outcomes at follow-up are for both active treatments combined.

Table 3.3 *Depression Measures and Time Points for Included Studies*

Study No.	Diagnostic interview	Clinician administered measure	Self-report measure(s)	Time Points
[1]		HRSD	BDI-II CES-D	Pre intervention; post intervention; 3 months FU; 6 months FU
[2]			BDI	Pre intervention; post intervention; 3 months FU (however no score reported)
[3]			BDI	Pre intervention; post intervention
[4]		HRSD	BDI-II CES-D	Pre intervention; post intervention; 3 months FU
[5]		HRSD	BDI-II CES-D	Pre intervention; post intervention; 3 months FU; 6 months FU; 9 months FU; 12 months FU;
[6]	ADIS-IV	HRSD	BDI-II	Pre intervention; post intervention
[7]		HRSD		Pre intervention; post intervention; 21 weeks FU; 12 months FU
[8]			GDS	Pre intervention; post intervention
[9]		HRSD*	GDS	Pre intervention; post intervention
[10]	DSM-IV diagnosis*	HRSD*	GDS	Pre intervention; post intervention; 24 weeks FU
[11]			GDS	Pre intervention; post intervention
[12]	Mood disorders section of the SCID-I/NP		GDS	Pre intervention; post intervention; 3 months FU; 6 months FU
[13]		HRSD		Pre intervention; post intervention; 21 weeks FU; 12 months (primary time point); 24 months FU
[14]		HRSD *HRSD for carer*	BDI (completed by carer on patient) *BDI for carer*	Pre intervention; post intervention (for 2 participants)

[15]	SADS (carer interviewed about patient) *SADS for carer depression*	CSDD (interview with patient and carer) HRSD for patient (extracted from SADS) *HRSD for carer (extracted from SADS)*	Modified BDI (completed by carer for patient) (Logsdon & Teri, 1995)	Pre intervention; post intervention; 6 months FU
[16]			SADQ-H 21 (completed by relative or carer) VAMS ‘sad’ item (completed by independent assessor)	Pre intervention; post intervention; 6 months (primary time point)
[17]		HRSD	BDI-II	Pre intervention; post intervention; 4 months FU
[18]		CSDD Dutch version (interview with primary CNA) MDS-DRS Dutch version (observational scale, interview with primary CNA)		Pre intervention; post intervention; 10-12 weeks FU

Note: * = derived from modified form of the mood disorders section of SADS; ADIS-IV = Anxiety Disorder Interview Schedule for Diagnostic and Statistical Manual-IV (Brown, Di Nardo, & Barlow, 1994); BDI = Beck Depression Inventory (Beck et al., 1996, 1961); CES-D = Centre for Epidemiological Studies of Depression Scale (Radloff, 1977); CNA = certified nurse assistant; CSDD = Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988); DSM = Diagnostic and Statistical Manual; FU = follow-up; GDS = Geriatric Depression Scale (Brink et al., 1982); HRSD = Hamilton Rating Scale for Depression (Hamilton, 1960); MDS-DRS = Minimum Data Set Depression Rating Scale (Burrows, Morris, Simon, Hirdes, & Phillips, 2000); No. = number; SADS = Schedule for Affective Disorders and Schizophrenia (Endicott & Spitzer, 1978); SADQ-H = Stroke Aphasic Depression Questionnaire Hospital version (Lincoln, Sutcliffe, & Unsworth, 2000); SCID-I/NP = Structured Clinical Interview for DSM, non-patient research version (First, Spitzer, Gibbon, & Williams, 2002); VAMS = Visual Analogue Mood Scale (Stern, 1997)

3.3.3 Effectiveness of BA

The results of the individual studies (the included RCTs) are presented in Table 3.4. Overall significant findings ($p \leq 0.05$) were reported in six studies [5,12,13,15,16,18]. Significant differences were reported when BA was compared to control, specifically: BA compared to usual care at post treatment and follow-up [16], post treatment and 1 year follow-up [13] and follow-up for 1 measure [18}; BA compared to treatment as usual at post treatment [12]; and BA compared to typical care and waiting list at post treatment [15]. These studies with significant findings involve participants with dementia [15,18], stroke [13,16] and nursing home residents with multiple conditions [12], and all deliver simple BA interventions. Significant findings are reported in three of the largest RCTs [13,16,18]. The quality of the studies reporting significant findings is moderate to low [12,13,15,16,18] (see Section 3.3.4 for risk of bias).

Non-significant findings comparing BA to usual care and treatment as usual were found in two studies [7,10]. Both of these studies are small; Study Number 10 is a very small feasibility RCT, and with two treatment arms and one control in Study Number 7, the number of participants in each condition is also relatively small. With only a conference abstract and some additional details provided by the author for Study Number 7 it is difficult to compare and contrast the non-significant findings in this study (for the Living Well With Stroke intervention) to Study Number 13, which found significant differences between the Living Well With Stroke intervention and control. One noticeable difference, however, is with the delivery of the intervention, with fewer sessions and shorter face to face sessions on average in Study Number 7. Additionally, it was also difficult to assess the risk of bias in Study Number 7; although the author provided additional information several aspects still remained unclear. Therefore it is not clear whether the findings may be related to the risk of bias in this study. Non-significant findings were also reported for BA compared to problem solving [5,15] as problem solving therapy also significantly improved depression [5]. A significant improvement in depression for patients receiving problem solving compared to controls was also reported in Study Number 15.

Other significant findings reported were regarding improvements in depression for participants receiving BA. These include: significant pre to post treatment improvements in self-reported and clinician rated depression in cancer patients [5]; a significant difference between pre intervention self-reported depression and scores at all time points in nursing home residents [12]; and a significant improvement in clinician rated depression at 6 months in dementia patients [15]. These significant findings are for both complex [5] and simple [12,15] BA interventions.

Table 3.4 *Main Findings from Included Randomised Controlled Trials*

Study No.	ITT analysis	Main findings	Follow-up
[5]	✓	• Significant pre to post improvement in BDI-II & HRSD in BA group (and PST). • No significant Group X Time interactions for BDI-II & HRSD. • No significant main effect of treatment condition for CES-D.	• Robust treatment gains maintained at 12 months.
[7]	NR	• Reduction in HRSD scores in both intervention arms (face to face and telephone delivered) and control, but no significant difference.	• No significant difference between groups in HDRS reduction at 21 weeks and 1 year.
[10]	✓ for diagnosis X for GDS & HRSD	• For diagnostic recovery, no significant difference between improved residents in treatment compared to control.	
[12]	✓ for diagnostic outcomes X for GDS	• Significant difference between BA and control for diagnostic outcomes. • When collapsed to improved/not improved, no significant difference between groups for the proportion of those improved. • When collapsed to remitted/not remitted, significant difference in proportion remitted, in favour of BA. • Significant difference between baseline and post treatment GDS.	• No significant difference between groups for diagnostic recovery at 3 & 6 months. • Significant difference between baseline GDS and 3 and 6 months post treatment.
[13]	X	• Significantly greater decrease in HRSD in BA group compared to control (when controlling for baseline HRSD scores). • Significantly more of the intervention group in remission (HRSD ≤ 9).	• Intervention group favoured at all time points. Significantly greater decrease in HRSD in BA group compared to control (when controlling for baseline HRSD scores) at 1 year (primary end point). Not significant at 21 weeks and 24 months.

			• For % in remission intervention group favoured at all time points. Significant difference at 21 weeks and 1 year. Not significant at 24 months.
[15]	✓ for post-treatment X for follow-up	• Significant differences on change scores between treatment conditions for HRSD, CSDD & BDI. • Significant improvement for patients in BA group as compared to the two control conditions. • No significant difference between BA & PST.	• Patients maintained significant improvement over pre-test scores for HRSD & CSDD at 6 months.
[16]	X for primary analysis ✓ for sensitivity analyses	• Primary analysis showed allocation to BA (when baseline values and communication impairment controlled for) was significant for SADQ-H and VAMS ‘sad’ item. • Group allocation (when controlling for baseline values) no longer significantly predicted SADQ-H 10-item in sensitivity ITT analysis. VAMS ‘sad’ item remained consistent.	• At 6 months group alone was a significant predictor of SADQ-H, (also significant when baselines values and communication impairment controlled for). No significant effect of group allocation on VAMS ‘sad’ item. • In sensitivity ITT analysis group allocation alone a significant predictor of SADQ-H scores. After controlling for baseline values group allocation did significantly predict VAMS ‘sad’ item.
[18]	✓ for those with complete covariate data		• Significantly different quadratic trend in BA & control groups from pre-test to follow-up for MDS-DRS (in favour of BA group), not significant for CSDD.

Note: BA = Behavioural Activation; BDI = Beck Depression Inventory; CES-D = Centre for Epidemiological Studies of Depression Scale; CSDD = Cornell Scale for Depression in Dementia; GDS = Geriatric Depression Scale; HRSD = Hamilton Rating Scale for Depression; ITT = intention-to-treat; NR = not reported; PST = Problem Solving Therapy; SADQ-H = Stroke Aphasic Depression Questionnaire Hospital version; VAMS = Visual Analogue Mood Scale.

3.3.4 Quality Assessment and Risk of Bias

The ratings of scientific quality for the included case series and case studies are presented in Table 3.5. Overall the quality scores ranged from 5 to 13, with only three studies [1,4,9] scoring the maximum of 13. Three studies [2,8,14], the oldest papers included in this review, scored below 10. Independent and objective subject assessment was the main aspect of quality that studies did not meet the criteria for [2,3,6,8,11,14,17].

Overall the quality of the included RCTs (see Table 3.6) was sub-optimal. None of the studies were rated as low risk of bias across all domains. For Study Number 7 some domains were rated as having unclear risk of bias due to insufficient information available to make a judgement (with the absence of a published paper). The risk of selection bias cannot be ruled out in the majority of studies, with the method used to conceal group allocation from investigators not reported in six studies [5,7,10,12,13,15] and three of these studies [10,12,15] also failing to report the methods of random sequence generation. Additionally, five studies were rated unclear risk of attrition bias [7,10,12,13,15]. Of note is the high risk of detection bias for self-report depression assessment in five studies [5,10,12,15,16] and for clinician administered depression assessment in two studies [5,18]. Although the interviews in Study Number 18 were conducted by blinded trained research assistants, the primary nurse assistants were interviewed and provided the information on which the measures were scored. The nurse assistants were also responsible for delivering the intervention.

Table 3.5 *Study Quality of Included Case Studies and Case Series*

	Study Number									
	[1]	[2]	[3]	[4]	[6]	[8]	[9]	[11]	[14]	[17]
Clear rationale/aim	1	1	1	1	1	1	1	1	1	1
Appropriate study design for aim	1	1	1	1	1	1	1	1	0	1
Adequate description of disease/condition	1	1	1	1	1	1	1	1	1	1
Clear rationale for treatment protocol	1	0	1	1	1	1	1	1	1	0
Treatment protocol adequately described	1	1	1	1	1	1	1	1	0	1
Details of methods/ procedures adequate for replication	1	1	1	1	1	0	1	1	0	1
Therapeutic effects defined	1	0	1	1	1	0	1	1	0	1
Clear inclusion/exclusion criteria	1	1	1	1	1	1	1	1	0	1
Appropriate methods of patient recruitment	1	1	1	1	1	1	1	1	1	1
Independent and objective subject assessment	1	0	0	1	0	0	1	0	0	0
Relevant and complete data	1	0	1	1	1	0	1	1	0	1
Appropriate data analysis for study design	1	1	1	1	1	1	1	1	1	1
Results clearly reported for all outcome measures	1	0	1	1	1	0	1	1	0	0
Total Score	13	8	12	13	12	8	13	12	5	10

Table 3.6 *Risk of Bias Assessment*

Study Number	Random sequence generation	Allocation concealment	Blinding of clinician administered outcome assessment	Blinding of self-report outcome assessment	Incomplete outcome data	Selective reporting	Other sources of bias
[5]	Low	Unclear	High	High	Low	High	Low
[7]	Low	Unclear	Low	N/A	Unclear	Unclear	Low
[10]	Unclear	Unclear	Low	High	Unclear	Low	Low
[12]	Unclear	Unclear	Low	High	Unclear	Low	Low
[13]	Low	Unclear	Low	N/A	Unclear	Unclear	Low
[15]	Unclear	Unclear	Low	High	Unclear	Low	Low
[16]	Low	Low	N/A	High	Low	Low	Low
[18]	Low	Low	High	N/A	Low	Low	Low

Note: N/A = not applicable

3.4 Discussion

This systematic review was conducted to identify the extent to which different types of BA have been used as an intervention for depression in people with LTCs; to identify adaptations made to accommodate LTCs; and to examine the effectiveness of the different types of BA. This review identified 10 observational studies (25 participants) and 8 RCTs (660 participants), with simple BA interventions delivered in the majority of studies (13/18), and only one RCT employing a complex BA intervention. Less research has been conducted on BA for depression in LTCs than in the general population (Cuijpers et al., 2007; Ekers et al., 2014; Mazzucchelli et al., 2009) with the most recent systematic review identifying 26 RCTs (1524 participants) of BA for depression in adults (Ekers et al., 2014). With Ekers et al. (2014) having established the simple and complex BA taxonomy utilised in this review, it is possible to compare the use of the different types of BA in the general population and in people with LTCs. Currently more RCTs investigating simple BA interventions for depression have been conducted in both the general population (Ekers et al., 2014) and in people with LTCs.

This systematic review has identified and narratively reviewed adaptations made to BA for people with LTCs, providing an overview of adaptations that can be incorporated into interventions for people with LTCs and, specifically, helping to inform development of the BA intervention in this dissertation. Adaptations were made to the interventions delivered in all but one study [4], with efforts made to ensure the psychoeducation, materials and inventories of several interventions were tailored to and appropriate for the population. This is a key adaptation that should be incorporated, with recent research highlighting the importance of tailoring interventions to the specific LTC to ensure standard interventions are effective (Wroe, Rennie, Gibbons, Hassy, & Chapman, 2015). Tailoring and adapting interventions to specific LTCs can be done with the involvement of patients, with previously depressed stroke survivors assisting in the adaptation of intervention materials in Study Number 13. This may help to ensure the intervention is appropriate for the population and, potentially, more likely to be acceptable. With adaptations needed to improve the acceptability of interventions for people with LTCs (Hind et al., 2010), and necessary to ensure standard interventions are effective in people with LTCs (Wroe et al., 2015), the adaptations identified in this review (where appropriate) could be incorporated into the design and/or delivery of interventions for people with LTCs.

With regards to the effectiveness of BA for depression in people with LTCs, this review has identified initial promising findings in participants with dementia [15,18], stroke [13,16], cancer [5] and nursing home residents with multiple conditions [12]. BA was found to significantly ($p \leq 0.05$) improve depression (with a complex and two simple BA interventions) [5,12,15], and significant differences ($p \leq 0.05$) were reported when compared to usual care/treatment as usual and waiting list (for simple BA interventions) [12,13,15,16,18]. However, these results should be considered with caution. Although three of the largest RCTs reported significant differences compared to control [13,16,18], overall the sample sizes of the included RCTs are small. Additionally, the quality of the included studies is not optimal. Although not all the findings were so promising, the non-significant findings in Studies 7 and 10 should also be interpreted with caution due to the small size of the studies. As Study Number 10 was conducted as a feasibility RCT the findings regarding effectiveness are likely to be misleading due to problems associated with low power and small samples sizes (Abbott, 2014). Overall, more high quality and adequately powered RCTs are needed to improve confidence in the findings regarding the effectiveness of BA for depression in people with LTCs.

The effectiveness of BA for depression in the general population is already well established (Cuijpers et al., 2007; Ekers et al., 2014; Mazzucchelli et al., 2009). This review extends the current evidence based for BA interventions and provides initial promising evidence for the effectiveness of BA in more complex populations. Additionally, this review extends the evidence base for the psychological treatment of comorbid depression in LTCs. Nearly all of the RCTs identified in this current review have been conducted after previous systematic reviews have searched for psychological interventions treating depression in LTCs (Rizzo et al., 2011; van Straten et al., 2010). Although Studies 10 and 15 were conducted before the van Straten et al. (2010) review, it is likely these studies were not identified by van Straten et al. (2010) due to the inclusion of 10 medical disorders in their search strategy (as opposed to the manual screening for LTCs conducted in this review).

Of particular importance in this review is the finding that BA improves mood significantly more than usual care in stroke patients [13,16]. Previously no evidence for the benefit of psychotherapy in post stroke depression has been found (Hackett, Anderson, House, & Xia, 2008), including CBT for depression following stroke (Lincoln & Flannaghan, 2003). The effectiveness of BA identified in this review could suggest a simpler intervention like BA (with an exclusive focus on changing behaviour (Dimidjian et al., 2011)) may be more appropriate for comorbid depression in stroke (or individuals with cognitive deficits). This is also supported by the CBT framework for emotional disorders after stroke (Kneebone, 2016), that recommends treatment should become more behavioural as cognitive and communication ability worsen, with therapy likely to focus on elements such as BA for depression.

Overall this review has highlighted a paucity of: a) research on BA for depression in LTCs, b) large high quality studies in these populations and c) BA studies conducted outside of America. As such there is a need for further research in this field and, as discussed above, more high quality adequately powered RCTs are needed before firm conclusions can be drawn on the effectiveness of BA for depression in LTCs. Although there may be no difference with regards to the effectiveness of BA delivered in America and elsewhere, with Ekers et al. (2014) finding no difference between effect sizes for BA studies conducted inside and outside America, research is needed outside of America to investigate whether BA for depression in LTCs can be delivered in different healthcare systems and services. For example, with the agenda to support the psychological needs of people with LTCs in the Improving Access to Psychological Therapies (IAPT) programme in England (DoH, 2011), research is needed to investigate whether BA as delivered in IAPT services (Richards & Whyte, 2011) can be delivered to people with LTCs. A final implication for future research is the need for greater clarity when reporting study methodology and findings. In this review the majority of RCTs failed to report methods of concealment for group allocation, with several of these also failing to report methods of random sequence generation. This emphasises the importance of following the Consolidated Standards of Reporting Trials (CONSORT) guidelines (Schulz, Altman, & Moher, 2010) when reporting RCTs, to allow an accurate assessment of risk of bias and subsequent evaluation of the effectiveness of interventions.

3.4.1 Strengths and Limitations

There are several strengths of this systematic review, with guidance (CRD, 2009) followed to ensure rigorous methods were used. A comprehensive search for studies was conducted, including multiple databases, forward and backwards citation searching and contact with authors. Additionally, the manual screening for LTCs ensured, to the best of our knowledge, all studies with relevant participants were identified. Two independent reviewers screened abstracts and full papers, extracted data and assessed quality to minimise bias in the review process. The potential for publication bias has also been reduced through the identification and inclusion of two unpublished studies [7,12] (with Study Number 12 published during the process of the review).

One limitation of this review is the exclusion of non-English studies, which may have resulted in eligible studies being missed. Indeed, 19 potentially eligible studies for which there were no English translations publically available were excluded at full text stage (due to a lack of translation facilities). However, it is possible that the non-English studies may not have met the eligibility criteria. With the cautious and over inclusive approach taken when screening abstracts, a large number of the full texts assessed against the criteria were excluded from this review. Another limitation of this review is not having searched trial registries as part of the search strategy. Searching trial registries may have identified ongoing studies or other unpublished research that was not found from searching the databases, citation searching or contact with authors. Finally, this review is limited in the conclusions that can be drawn about the effectiveness of BA in people with LTCs, however this is due to the quantity, size and quality of the included studies.

3.4.2 Implications for this Dissertation

This chapter has presented a systematic review of BA interventions for depression in people with LTCs. Findings identified adaptations made to the BA interventions to accommodate LTCs and highlighted initial positive findings for the use of BA in these populations. Firm conclusions on effectiveness of BA among people with LTCs cannot be drawn from the evidence identified due to a paucity of large high quality RCTs and, in particular, a paucity of studies conducted in the context of the United Kingdom (UK) National Health Service (NHS).

One of the main objectives of this review, with regards to developing a BA intervention in this dissertation, was to identify a LTC to target for intervention development. Since the majority of the significant findings have been reported for people with neurological disorders, it was decided that further intervention development would focus on developing BA for people with neurological disorders. Dementia was chosen as the specific neurological condition for intervention development for several reasons.

- Firstly, the decision was guided by policy priority and context, with improving care and outcomes for people dementia having become a policy priority in the UK (DoH, 2009, 2012b, 2015).
- Secondly, there are gaps in the literature identified with regards to people with dementia. No research involving BA for people with dementia has been conducted in the UK at the time of conducting this review. This presents an opportunity to develop an intervention that fits with current services in the UK.
- Thirdly, developing the intervention for people with dementia may benefit more than just the individual with dementia. In Study Number 15, although significant changes in depression for carers were not hypothesised, carers involved in the BA intervention improved significantly more than carers in the control conditions, and a significant improvement in carer depression was maintained at 6 months. With the need to involve carers in therapy (Teri, 1994) other developed BA interventions for people with dementia may also have this beneficial effect on mood for both patients and carers.

As well as informing the population for this dissertation, the findings from this review were also used to inform intervention development. One of the main implications for development is the use of simple BA interventions in people with neurological disorders. This finding informed the type of BA used in the intervention being developed. Additionally, findings potentially suggest more sessions that are longer in length are more appropriate, and potentially more effective, for people with neurological disorders. Chapter Four details how this review informed intervention development with regards to specific adaptations identified.

The following chapter provides additional context for the development of a BA intervention for comorbid depression in people with dementia. The development of the intervention is also presented, including details on how intervention development was informed by this review, literature, contact with experts and guidance co-produced by people with dementia. Study Two, a qualitative study involving people with dementia and carers in the development of the intervention, is also presented in the following chapter.

Chapter Four: Developing a Behavioural Activation Intervention for Depression in People with Dementia

4.1 Introduction

Following the systematic review (Study One) and the decision to focus intervention development on depression in dementia, a behavioural activation (BA) intervention was developed and written for people with dementia and comorbid depression. This chapter presents additional context as to why an intervention should be developed for people with dementia and presents the development of the intervention.

- This chapter starts with a description of dementia, an overview of the prevalence, impact and costs of dementia, and a summary of the prevalence and impact of comorbid depression. It then progresses onto a discussion of the barriers to accessing depression care for people with dementia and provides the rationale for developing a low intensity BA guided self-help intervention for depression in dementia.
- Next, following the modelling element in phase I of the Medical Research Council (MRC) framework (Craig et al., 2008; MRC, 2008), this chapter provides a description of the BA intervention and details how development was informed by the systematic review (Study One), contact with experts, literature, and guidance co-produced by people with dementia (Scottish Dementia Working Group Research Subgroup UK, 2014; South West Dementia Partnership, 2011; The Dementia Engagement and Empowerment Project, 2013) (Section 4.3).
- Finally, Study Two is presented (Section 4.4), a qualitative study involving informal carers and individuals with dementia in the development of the intervention. This study was conducted to consider the acceptability of the workbook, to refine the developed workbook and to identify potential benefits of, and barriers to, the intervention.

4.2 Background

4.2.1 Dementia

‘Dementia’ is a term that describes a set of symptoms including memory problems; difficulties with concentration, communication and reasoning; and changes in mood and behaviour (DoH, 2015). These acquired cognitive deficits, which are caused by neurodegeneration (Prince et al., 2013), interfere with the ability of people with dementia to function and perform everyday activities independently (American Psychiatric Association [APA], 2013). Given different medical aetiologies and variations in the course of dementia (APA, 2013) several different subtypes exist, including:

- Alzheimer's disease (AD)
- Vascular dementia
- Dementia with Lewy bodies
- Parkinson's disease dementia
- Frontotemporal lobar degeneration
- Mixed dementia (Alzheimer's Association, 2015; APA, 2013).

Dementia is a progressive condition for which there is no current cure (DoH, 2015). A systematic review of studies on mortality in dementia has found the median survival time from the onset of dementia to range from 3.3 to 11.7 years (with the majority of studies in the 7 to 10 year period) and median survival time from diagnosis to range from 3.2 to 6.6 years (Todd, Barr, Roberts, & Passmore, 2013).

The prevalence, impact and cost of dementia. Dementia is of global concern, with estimates of 65.7 million people living with dementia worldwide by 2030 and 115.4 million by 2050 (Prince et al., 2013). In the United Kingdom (UK) the estimated prevalence of people living with dementia in 2015 was 850,000, with this expected to increase to over 1 million by 2025 (Prince et al., 2014). Although recent research shows a decrease in the prevalence of dementia over the last 20 years (Matthews et al., 2016; Matthews et al., 2013), there are still an estimated 209,600 new cases of dementia a year in the UK (Matthews et al., 2016).

Dementia impacts on the person with dementia as well as their family and carers. A person with dementia may have difficulties with completing tasks that are familiar, confusion with places or time, difficulties with planning, and problems with speaking or writing (Alzheimer's Association, 2015). People with dementia need care and support, which is mostly provided by informal (or family) caregivers (Brodaty & Donkin, 2009). The care provided to people with dementia tends to be more extensive than that provided to people with other conditions (Alzheimer's Association, 2015). Carers of people with dementia can face a number of issues and difficulties such as social isolation (Brodaty & Donkin, 2009), work-related challenges (Alzheimer's Association, 2015) and an increased risk of various physical health problems (Brodaty & Donkin, 2009). Additionally, dementia carers have a higher prevalence of mental health disorders compared to the general population and to carers of people with other illnesses (Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015).

Dementia also has impacts that extend beyond the individual and family, causing extensive costs to society and services. The economic impact of dementia in the UK is large, with an estimated total for 2013 of £26.3 billion, averaging £32,250 per person (Prince et al., 2014). Costs include those incurred by health and social care, unpaid care, police costs associated with missing person enquiries and research expenditure (Prince et al., 2014). The needs of people with dementia can be complex and can be increased by the prevalence of co-morbidities (Dowrick & Southern, 2014). Healthcare costs associated with dementia have been costed in the region of £4.3 billion, which represents approximately 3.4% of the total NHS spending in 2013 (Prince et al., 2014). Figures for public and privately funded social care costs are larger at £10.3 billion in 2013 (Prince et al., 2014).

With the prevalence of dementia, impact on people's lives, cost to the economy and toll on health and care services, improving dementia care and outcomes has become a policy priority in the UK (DoH, 2009, 2012b, 2015). With no cure for dementia (DoH, 2015) it is a priority to ensure people 'live well' with dementia (Clare et al., 2014; DoH, 2009). This involves "maximising life satisfaction, reaching one's potential for well-being, and experiencing the best possible quality of life in the context of the challenges that dementia presents for individuals, relationships and communities" (Clare et al., 2014, p. 11). This is one of the key reasons for the decision to focus on dementia in this dissertation.

4.2.2 Dementia and Comorbid Depression

Depression is common in people with dementia and is prevalent across the different dementia subtypes (see Cipriani, Lucetti, Carlesi, Danti, & Nuti, 2015). For example, estimates of 19 to 45% have been reported in vascular dementia and most estimates of the prevalence of depression in AD fall between 30 and 50% (Cipriani et al., 2015). As discussed in Chapter One, comorbid depression in LTCs is associated with poorer outcomes and prognosis (Naylor et al., 2012) and there is evidence for these associations in people with dementia (Janzing, Bouwens, Teunisse, Van't Hof, & Zitman, 1999; Kales, Chen, Blow, Welsh, & Mellow, 2005; Suh, Yeon, Shah, & Lee, 2005). For example, research has demonstrated significantly higher ($p<0.05$) levels of functional impairment in people with dementia and depression compared to a dementia-only group, as well as significantly higher rates of nursing home placement (Kales et al., 2005). Additionally, research has found significant associations between depression and mortality in people with dementia (Janzing et al., 1999; Suh et al., 2005). Poorer outcomes are also reported for carers; comorbid depression in people with dementia is associated with carer psychological morbidity (Brodaty & Luscombe, 1998), distress and depression (Teri, 1997).

Improving depression in people with dementia is one way to help individuals with dementia to live well. However, depression in people with dementia is often missed or mismanaged in primary care (Curran & Loi, 2012; Thyrian et al., 2016). As discussed below, there are issues with the assessment of depression in dementia and the availability of suitable interventions that may make accessing psychological treatment more difficult.

Issues with the assessment of depression in dementia. One difficultly that can be faced when assessing depression in dementia is with the reporting of symptoms. Reporting depressive symptoms may be difficult for people with dementia as it involves understanding questions, accurately recalling experiences over a timeframe and articulating responses (Teri et al., 2005). Although self-report measures such as the Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986) have been validated in people with dementia (Feher, Larrabee, & Crook, 1992; Isella, Villa, & Appollonio, 2001), the accuracy of self-reported depression in dementia can be affected by the individual's ability to accurately evaluate and report abilities and limitations (deficit awareness) (Snow et al., 2005). Information may therefore need to be collected from others, and carers can be important sources of information, especially when the accuracy of self-report becomes questionable (Teri et al., 2005). However, research has found that informants can have difficultly distinguishing dementia symptoms from symptoms of depression (Snow et al., 2005) and the evidence regarding the quality of informant report is mixed. Although research has shown caregiver reports to be closely associated with clinician assessment of mood (Teri & Wagner, 1991), another study has shown significant disagreements between informant report and clinician rating for depression (Stella et al., 2015). Additionally, informants have been found to report a greater number of depressive symptoms than the person with dementia reports themselves (Burke et al., 1998; Snow et al., 2005).

Additionally, there can be difficulties diagnosing depression in dementia as the appropriateness of diagnostic manuals can be questioned. Manuals such as the Diagnostic and Statistical Manual of Mental Disorders (DSM; APA, 2013) underestimate depression in people with dementia (Cipriani et al., 2015). Diagnostic criteria for depression that are non-dementia specific (such as the DSM) have decreased validity in people with AD and do not have the sensitivity to accurately differentiate between depressive symptoms and symptoms of cognitive decline (Mortby, Maercker, & Forstmeier, 2012). With difficulties diagnosing depression in people with dementia, specific diagnostic criteria have been developed for depression of AD (Olin et al., 2002). These criteria were designed with the recognition of the overlap in signs and symptoms of depression and dementia, and developed to facilitate recognition of depression of AD whilst reducing the heterogeneity of methods used for diagnosing depression in dementia (Olin, Katz, Meyers, Schneider, & Lebowitz, 2002). The criteria for depression of AD were derived from the DSM criteria for major depressive episode, however fewer symptoms are required for a diagnosis and the frequency and duration of symptoms is also less than the DSM criteria (Olin et al., 2002). The presence of withdrawal/social isolation and irritability were added as symptoms, and the anhedonia criteria were revised to focus on decreased pleasure or affect regarding usual activities and social contact (Olin et al., 2002). With these issues assessing and diagnosing depression in people with dementia it may be difficult to identify individuals with dementia who need to access treatment for depression.

The availability of suitable psychological treatments. Another important issue with regards to accessing treatment is the availability of suitable psychological interventions for depression in dementia. A guide for people in the early stages of dementia highlights that cognitive behavioural therapy (CBT) is available through NHS provision such as the Improving Access to Psychological Therapies (IAPT) programme in England (Alzheimer’s Society, 2016; Guss et al., 2014) or from private therapy services (Guss et al., 2014). However, the suitability of current interventions delivered in IAPT may need further consideration. Recent research has identified difficulties translating general adult mental health services within IAPT to people with complex LTCs (Highfield et al., 2016) and highlighted the importance of adapting standard low intensity IAPT interventions for specific LTCs (Wroe et al., 2015). Treatments for depression need to be adapted for people with dementia to take into account the acquired cognitive deficits and impairments in social and occupational functioning (Teri et al., 2005). The development and adaptation of interventions (such as those delivered in IAPT) is needed to ensure people with dementia can access suitable psychological treatments.

4.2.3 Developing an Intervention for Depression in Dementia

When developing an intervention it is important to consider the setting in which the intervention is likely to be delivered (Richards, 2015). Developing an intervention that could be delivered in current health services helps to reduce research waste (Richards, 2015). In England, psychological treatment recommended by NICE for depression and anxiety is provided in the IAPT programme (Clark, 2011). The IAPT programme involves a Step 2 low intensity service delivering some form of CBT based self-help supported by a psychological wellbeing practitioner (PWP), and a Step 3 high intensity service delivering high intensity interventions supported by a high intensity therapist (Clark, 2011). People with mild to moderate depression or anxiety (with the exception of social anxiety and post-traumatic stress disorder) are initially offered low intensity interventions supported by PWPs (Clark, 2011). To fit with this provision of psychological interventions for depression in England, the decision was made to develop and adapt a low intensity BA guided self-help intervention (IAPT Step 2) based on the model currently delivered in the IAPT programme (Richards, 2010; Richards & Whyte, 2011). If evidence regarding intervention effectiveness is established, this would enable the intervention to be more easily implemented into services. Furthermore, this also fits with the agenda to support the psychological needs of people with LTCs in IAPT (DoH, 2011).

What is a low intensity intervention? Low intensity is a term that refers primarily to the methods of delivering interventions (Bennett-Levy, Richards, & Farrand, 2010). The purpose of low intensity CBT interventions “is to increase access to evidence-based psychological therapies in order to enhance mental health and wellbeing on a community-wide base, using the minimum level of intervention necessary to create the maximum gain” (Bennett-

Levy et al., 2010, p.8). Compared to high intensity interventions, low intensity CBT interventions:

- have less practitioner patient contact time and/or
- use practitioners trained in low intensity CBT who may not have high intensity qualifications and/or
- use less intense CBT resource content and/or
- provide more rapid access to interventions (see Bennett-Levy et al., 2010).

There are several levels of support that may be provided in low intensity self-help interventions: self-administered (no support), minimal contact (provision of rationale/overview of materials) and guided self-help (initial support session with overview of materials and rationale, with regular support sessions to discuss progress and process issues) (Farrand & Woodford, 2013b). With self-help interventions it is the materials (for example a workbook) that provide CBT expertise (Bennett-Levy et al., 2010). With variants of self-help where support is provided (for example guided self-help) the practitioner provides guidance and support in the application of the CBT self-help intervention (Bennett-Levy et al., 2010). With low intensity BA as delivered in IAPT, BA strategies are learnt from written materials and low intensity workers provide verbal information and support (Richards, 2010). Low intensity interventions are effective in people with affective or common emotional disorders (Farrand & Woodford, 2013b) and for people with LTCs, self-help interventions have been shown to improve depression (Farrand & Woodford, 2015; Matcham et al., 2014).

4.3 The Development of a Low Intensity BA Guided Self-Help Intervention for Depression in People with Dementia

4.3.1 Intervention Development

The development of the BA intervention in this dissertation, **BE**havioural **A**ctivation for **M**ood in **D**ementia (BEAMD), was informed by the systematic review (Study One), expert opinion, literature, and guidance co-produced by people with dementia (Scottish Dementia Working Group Research Subgroup UK, 2014; South West Dementia Partnership, 2011; The Dementia Engagement and Empowerment Project, 2013). Tables 4.1 to 4.4 provide specific details on how these elements informed intervention development.

Following the decision to focus on dementia, the type and severity of dementia for which to develop the intervention was informed by contact with experts, research on the pathologies of dementia (Schneider, Arvanitakis, Bang, & Bennett, 2007) and CBT interventions delivered to people with dementia (Spector et al., 2015; Stanley et al., 2013) (see Table 4.1).

Findings from Study One led to the decision to use a simple BA intervention (Richards, 2010) and adaptations identified in Study One were incorporated into the development of materials. The findings from Study One also informed carer involvement in the intervention and modification of activities (see Table 4.2). Decisions on support session length were informed by guidance co-produced by people with dementia (Scottish Dementia Working Group Research Subgroup UK, 2014; South West Dementia Partnership, 2011) (see Table 4.3).

The workbook for BEAMD was written and designed by SH with input and feedback on drafts from PF and CD. The workbook was based on self-help materials used in a recent randomised controlled trial (RCT) (Farrand et al., 2014) and was created using Microsoft Publisher. Guidance on writing dementia friendly information (The Dementia Engagement and Empowerment Project, 2013) was followed to inform the style, language, layout and formatting of the workbook (see Table 4.3).

Following development of the workbook (Version 1, Appendix 4.1), the experienced BA practitioner supporting BEAMD (in Study Three) and a researcher with experience of developing guided self-help interventions were consulted. Discussions were had regarding the intervention and workbook, and the workbook was subsequently modified based on comments from the practitioner and researcher (see Table 4.4).

Section 4.3.2 provides a detailed description of the developed intervention (BEAMD).

Table 4.1 *Literature and Expert Opinion Informing Type and Severity of Dementia*

Aspect of Population	Literature	Expert Opinion	Decision Made
Type of dementia	Post mortem evidence indicates the majority of dementia cases are caused by mixed pathologies, with over 50% of people with dementia having multiple diagnoses (Schneider et al., 2007).	Correspondence with a Clinical Director of Older People's Mental Health indicated a single pathology dementia is probably the exception rather than the rule. If the intervention was only delivered to people with Alzheimer's Disease this would be artificial and lack clinical validity.	BEAMD to be delivered to people with all diagnoses of dementia.
Severity of dementia	CBT interventions for anxiety in dementia delivered to people with mild to moderate severity dementia (Spector et al., 2015; Stanley et al., 2013).	Correspondence with a Consultant in Psychiatry of Ageing indicated mild and moderate dementia equates to about 50 on the ACE-III (although no current validation).	BEAMD to be delivered to people with mild to moderate dementia. Mild to moderate dementia to be identified on the ACE-III as used in current practice in Memory Clinic appointments. Lower cut-off of 50 on ACE-III as based on expert opinion. Upper cut off of 88 (Ballard, Burns, Corbett, Livingston, & Rasmussen, 2013).

Note: ACE-III = Addenbrooke's Cognitive Examination-III; BEAMD = Behavioural Activation for Mood in Dementia; CBT = Cognitive Behavioural Therapy; NHS = National Health Service.

Table 4.2 *Aspects of the Intervention and Intervention Development Informed by the Systematic Review (Study One)*

Aspect of the Intervention	Findings from Systematic Review	Adaptation identified in the Systematic Review and Study Reference	Incorporation into BEAMD Development	Incorporation into BEAMD
Type of BA	Simple BA (Ekers et al., 2014) interventions delivered to people with neurological disorders.			Use of a simple BA intervention (Richards, 2010)
Materials		Tailoring of materials to LTC population (psychoeducation) (Armento & Hopko, 2009; Hopko, Armento, et al., 2011; Hopko, Magidson, et al., 2011).		Case study ‘Bernard’ is written about a person with mild dementia and depression. Bernard has been seen in the Exeter Memory Clinic and referred to the AccEPT Clinic.
		Appropriate materials/ resources for LTC (Mitchell et al., 2009; Thomas et al., 2013).		Workbook written following guidance for writing dementia-friendly information (The Dementia Engagement and Empowerment Project, 2013) (see Table 4.3).
		Involvement of people with LTC to ensure appropriateness of written materials (Mitchell et al., 2008).	People with dementia, and informal carers of people with dementia, involved in reviewing version 1 of the workbook (Study Two).	

Support	Carer involvement in BA delivered to people with neurological disorders (Mitchell et al., 2009; Teri et al., 1997; Teri & Uomoto, 1991; Thomas et al., 2013; Verkaik et al., 2011).	Informal carer (a family member or friend with some form of daily contact with the person with dementia) involved in the intervention as a support aide - attending support sessions and supporting BEAMD between sessions.
Activities	Adapting old behaviours/activities to be accomplished with new limited functioning (Turvey & Klein, 2008).	Use of selection, optimisation, compensation model (Baltes & Baltes, 1990). An activity or goal is selected for readjustment, an alternative means of achieving the activity can then be identified and the likelihood of success optimised through reserves or resources (for example carer support).

Note: AccEPT = Accessing Evidence-Based Psychological Therapies; BA = Behavioural Activation; BEAMD = Behavioural Activation for Mood in Dementia; LTC = long term condition.

Table 4.3 *Aspects of the Intervention Informed by Guidance Co-produced by People with Dementia*

Aspect of the Intervention	Guidance	Incorporation into BEAMD
Workbook	Use of style, language, layout, formatting and photographs to make information dementia-friendly (The Dementia Engagement and Empowerment Project, 2013).	<u>Style:</u> Simple but not patronising language. Written concisely without unnecessary words. One subject per sentence. Inclusion of a glossary to explain terms and concepts. <u>Photographs:</u> Photographs used in the workbook rather than illustrations. <u>Making sense of content:</u> Different colours for different steps in the workbook. Use of bold text, bullet points and headings. Manageable chunks of information. Important information presented in boxes. <u>Layout:</u> Use of Arial font, minimum size 14 point. White space around text. Photographs placed to split information into manageable chunks. <u>Format:</u> Amount of information kept as minimal as possible.
Support Sessions	People with dementia need time to think, reflect and respond to questions (Scottish Dementia Working Group Research Subgroup UK, 2014). It may take longer for people with dementia to process information and respond (South West Dementia Partnership, 2011).	Initial assessment session a maximum of 50 minutes long, with subsequent support sessions up to 40 minutes. Longer than standard low intensity sessions in IAPT (Richards & Whyte, 2011) to allow the person with dementia time to think about questions, process information and respond.

Note: BEAMD = Behavioural Activation for Mood in Dementia; IAPT = Improving Access to Psychological Therapies.

Table 4.4 *Discussions Informing Workbook Changes*

Discussion with	Key points taken from discussion	Changes to the workbook
Experienced BA therapist (supporting BEAMD in Study Three).	Importance of linking mood to behaviour.	Addition of faces to rate mood on the 'My Current Activities Diary' (workbook pages 14 and 15, Appendix 4.4).
Researcher with experience of developing guided self-help interventions.	Include more relapse prevention.	More was added to the low mood warning signs and 'Step 4' was created for relapse prevention. A page was added for the participant to 'check in' with themselves on how they have been feeling and if activities are still being completed following the end of support sessions (workbook page 37, Appendix 4.4). The boxes for the low mood warning signs were also made bigger and the boxes were made to correspond with the Five Areas™ diagram.

Note: BEAMD = Behavioural Activation for Mood in Dementia.

4.3.2 Behavioural Activation for Mood in Dementia (BEAMD)

BEAMD is a guided self-help intervention for depression in people with mild to moderate dementia. The BA intervention is provided in a written format in the workbook 'Live Well Every Day. A programme for people with memory problems' (Version 1) (Harris, Farrand, & Dickens, 2015) (Appendix 4.1). Support is provided by a practitioner in the form of an initial assessment session with an overview of the workbook, followed by regular support sessions to discuss progress and any process issues (Farrand & Woodford, 2013b). As part of the intervention an informal carer also attends the support sessions and helps to support BEAMD between sessions. As with CBT interventions for anxiety in people with dementia (Spector et al., 2015; Stanley et al., 2013), BEAMD was designed for people with mild to moderate dementia. This was to enable the person with dementia to engage with the support sessions (for some or all of each session) and workbook during the week (supported by their carer as and when necessary for that individual). People in the very early stages of dementia are likely to be able to understand the treatment and goals, communicate with the practitioner during sessions and complete work between sessions (Teri et al., 1994).

The BA intervention is informed by the Richards (2010) BA protocol drawn from a depression management clinical trial in the UK (Richards et al.,

2008) and currently delivered in IAPT services (Richards & Whyte, 2011). This is a simple BA intervention involving self-monitoring and scheduling and not including additional components such as functional analysis (Ekers et al., 2014). This BA protocol was chosen to fit with current services and as a simple intervention it places less cognitive demand and burden on the person with dementia. The BA protocol is made up of six steps: 1) explaining the BA rationale 2) identifying routine, pleasurable and necessary activities 3) creating a hierarchy of these activities 4) planning activities 5) implementing BA exercises and 6) reviewing progress (Richards, 2010; Richards & Whyte, 2011). The protocol uses recording tools including diaries and worksheets for self-monitoring and scheduling. Worksheets and diaries were designed for BEAMD and included in the workbook. The six steps of BA in BEAMD, and the relevant sections of the workbook (from Version 1), are now described in more detail:

Information on mood and BA rationale. The written materials provide information on depression (pages 2-5), the Five Areas™ model of depression (situation, relationships and practical problems; altered thinking; altered emotions; altered physical symptoms; and altered behaviour) (Williams & Garland, 2002) and the rationale for BA (pages 10-11). Verbal information on depression and BA is also provided in the support sessions. A baseline of current activities is collected to discuss the link between activities and mood (pages 14-15).

Identification of routine, pleasurable and necessary activities. Routine, pleasurable and necessary activities are identified (workbook pages 18-21), which may be activities that the individual has stopped since becoming depressed (Richards, 2010). However, for people with dementia, identified activities may no longer be possible due to functional and/or cognitive decline. In this situation the person with dementia may need to adjust the activity and find an alternative means to complete the activity. This process can be undertaken following the Selection, Optimisation and Compensation model (SOC; Baltes & Baltes, 1990). An activity or goal is selected for readjustment (selection), an alternative means to achieve the activity can then be identified (compensation), and the likelihood of success can be optimised (optimisation) through reserves or resources (for example with carer support) (Baltes & Baltes, 1990). An example of readjusting an activity and finding an alternative way to complete the activity is provided in the ‘Top Tips’ for identifying activities included in the BEAMD workbook (page 20). ‘Top Tips’ for setting SMART goals (Specific, Measurable, Achievable, Relevant, Time specific) (Farrand & Woodford, 2013a) are also provided in the workbook (page 7).

Hierarchy of activities. The identified activities are structured into a hierarchy that reflects their difficulty to complete (workbook page 23) from least to most difficult.

Planning activities. Identified activities are scheduled into a diary (workbook pages 24-27). ‘Top tips’ for completing the ‘planned activities diary’ are provided on page 25 of the workbook.

Implementing BA exercises. The person with dementia completes the planned activities and is asked to record on the ‘planned activities diary’ whether they were able to complete the activity and what helped or hindered the activity (workbook pages 28-29).

Reviewing progress. With the person with dementia, the practitioner reviews the completed worksheets and diaries in the workbook, provides feedback on progress and helps to problem-solve any difficulties the person with dementia has experienced in implementing the BA exercises (Richards, 2010). The completed diaries are used during support sessions to help the person with dementia reflect on their intervention (Richards, 2010). After reviewing the activities, dependent on progress, the same activities or new activities are scheduled. All decisions made in BEAMD are made collaboratively between the person with dementia, practitioner and, if necessary, the carer. Support from the practitioner is provided to review and plan more activities, with support gradually withdrawn (Richards, 2010). Page 31 in the BEAMD workbook provides a section for the person with dementia to note down any warning signs that may indicate their mood is low, and note specific activities undertaken that may have been beneficial for their mood. This is to help the person with dementia to use BEAMD independently once the support sessions have ended.

4.3.2.1 BEAMD Workbook. The workbook was designed to enable the person with dementia to be as involved with the materials as possible (see Table 4.3). The workbook includes the following worksheets and diaries: ‘My Five Areas™ Diagram’ (page 5), goals (page 7), ‘My Current Activities Diary’ (pages 14-15), types of activities (page 21), hierarchy of activities (page 23), ‘My Planned Activities Diary’ (pages 26-27) and low mood warning signs (page

31). ‘Support Tips’ presented in orange boxes are also included in the workbook to provide ideas about how the carer could support BEAMD. Additionally ‘Bernard’s Story’, a vignette of a man with mild dementia and depression, is presented in the workbook, following Bernard as he completes BEAMD (pages 8-9; ‘How has Bernard been getting on?’ pages 16-17; ‘The end of Bernard’s Story’ page 32). In the vignette Bernard has attended the Exeter Memory Clinic and been referred to the Accessing Evidence-Based Psychological Therapies (AccEPT) Clinic to receive BEAMD. This was written into the vignette as this recruitment method was to be used for participants recruited to receive BEAMD in Study Three.

Terminology. Throughout the workbook and study information the workbook is referred to by the less formal term ‘booklet’. Additionally, depression is referred to as ‘low mood’. The term ‘memory problems’ is used in the workbook and during support sessions (Bartlett & Martin, 2002; Hellström, Nolan, Nordenfelt, & Lundh, 2007) as using the term ‘dementia’ may cause unnecessary harm or distress (Bartlett & Martin, 2002). The term ‘dementia’ is only used in a support session if introduced first by the person with dementia in that session.

4.3.2.2 Support sessions. Support sessions are a maximum of 50 minutes for the initial assessment session, with subsequent support sessions up to 40 minutes long, for a maximum of 12 sessions. Compared to standard low intensity IAPT sessions (Richards & Whyte, 2011), this session length represents additional time to allow for cognitive decline, providing time to think, reflect and respond to questions (Scottish Dementia Working Group Research Subgroup UK, 2014). Providing additional time in this way for people with dementia has been identified as important (Scottish Dementia Working Group Research Subgroup UK, 2014). The pace of the support sessions is also slower than that of standard practice in IAPT with the intervention not being completely introduced in the first session. The rationale for BA is introduced in the second session and activities are not identified until session three (see Appendix 4.2). During the support sessions the practitioner may need to provide support and guidance in the application of the BA steps if the person with dementia (and/or carer) experience difficulties putting the intervention into practice. The practitioner may utilise the ‘sound-bite’ approach during support sessions to help the person with dementia remember small amounts of information, as used in CBT for anxiety in people with dementia (Paukert et al., 2013). This is done by using a short phrase to summarise a key point and repeating this phrase, then asking the person with dementia to repeat this phrase multiple times at spaced repetitions (Paukert et al., 2013). An overview of support session content is included in Appendix 4.2.

4.3.2.3 Carer involvement. Informal carers are involved in BEAMD as a support aide. Carers attend the support sessions for BEAMD and support the intervention between sessions. An informal carer is likely to be a family member or a friend who has some form of daily contact with the person with dementia. It is necessary to involve a carer in the intervention as people with dementia may have difficulties remembering the content of the intervention, understanding explanations or techniques, and learning new skills (Teri et al., 1994). However, BEAMD is designed for the person with dementia, so all instructions and information are directed at them initially.

Carer involvement in the programme is influenced by the level of impairment in the person with dementia (Teri et al., 1994); those with mild dementia may need less support from the carer. People with dementia who are less impaired will be able to take more responsibility for their care (Teri et al., 1994). Additionally, the level of carer involvement may vary for each person as they may have difficulties with different cognitive domains or need support with different aspects of BEAMD. Some of the ways the carer might be involved in supporting the person with dementia through the BEAMD include:

- reminding the person with dementia about support sessions
- providing reminders of the rationale and purpose of BEAMD
- helping to identify, organise and plan activities
- helping to complete the diagrams and diaries in the workbook
- reminding the person with dementia what activities are planned each day
- helping to complete activities
- supporting relapse prevention.

Support tips are provided in the workbook for the person with dementia on how their carer may support them through BEAMD.

4.4 Study Two: Involving People with Dementia and Carers in Intervention Development

Following the above development of BEAMD, the next step in intervention development involved service user input. As it is important to consult with patients when developing an intervention (Richards, 2015), Study Two involved people with dementia and carers in the development of BEAMD. This study was conducted to consider the acceptability of the workbook (including layout, format, design and terminology); to refine and modify (if necessary) the developed workbook; to identify potential benefits of, and barriers to, the intervention; and to inform delivery. This step in the development of BEAMD was undertaken before delivering the intervention to participants in Study Three.

4.4.1 Methods

4.4.1.1 Recruitment. People with dementia (with experience of low mood) and informal carers were recruited from Memory Cafes and Memory Groups in Devon. The term ‘informal carer’ is used loosely in this study to refer to a family member of a person with dementia. SH attended the Memory Groups and Cafes, verbally introduced herself and the research, and handed out the information sheet to interested individuals. Those who were interested in the research were asked to contact SH using the details on the information sheet, and contact details were collected from people who were happy to provide them. In one group SH was unable to attend, the Memory Group co-ordinator handed the information sheet to potential participants. The information sheet was also sent to members on the National Institute for Health Research (NIHR) Clinical Research Network’s database (South West Peninsula), however this did not result in any contact from potential participants.

4.4.1.2 Participants. Eight informal carers of people with dementia and four individuals with dementia were recruited (see Tables 4.5 and 4.6). Participants’ names have been replaced with a pseudonym to maintain anonymity. Where ages were not given for participants these were estimated based on information provided during the interview and/or from meeting the participant. Two couples were interviewed (Pauline and Joseph; Pearl and Dennis) with these interviews conducted separately. Although Pamela mentioned, during the interview, that her husband has not experienced low mood, her interview transcript was still analysed as this study was interested in opinions regarding the acceptability of the workbook and barriers for people with dementia.

Table 4.5 *Informal Carer Demographics*

Name	Gender	Age	Relationship to person with dementia	Type of dementia (in care recipient)	Living arrangements
Pauline	Female	80-90	Wife	AD	Living together
Jane	Female	60-70	Daughter	Vascular	Not living with her mother
Pamela	Female	76	Wife	AD	Living together
Matthew	Male	70-80	Husband	Vascular	Wife in a nursing/care home
Pearl	Female	77	Wife	Mixed AD & Vascular	Living together
David	Male	75-85	Husband	Unspecified with a neurological aspect	Wife in a nursing home
Geoff	Male	80-90	Husband	Vascular	Living together
Mary	Female	70-80	Wife	AD	Living together

Note: AD = Alzheimer's disease

Table 4.6 *Demographics of Participants with Dementia*

Name	Gender	Age	Type of dementia	Living Arrangements
Jennifer	Female	78	AD	Lives alone
Joseph	Male	85	AD	Lives with wife
Alan	Male	85	Type not specified	Lives with wife
Dennis	Male	77	Mixed	Lives with wife

Note: AD = Alzheimer's disease

4.4.1.3 Data collection. Semi-structured interviews with participants were conducted by SH. A verbal description of BEAMD (aim of BA; role of therapist; support sessions; workbook; involvement of carer) was given and opinions were sought on terminology, the role of the carer in the intervention, and potential benefits and barriers. Participants were presented with Version 1 of the developed BEAMD workbook (Appendix 4.1) and were asked for their opinions regarding the layout, design and content of the workbook. The interview also addressed potential changes to the workbook and intervention. The interview schedule (Appendix 4.3) was used flexibly during the interview and was adapted based on responses from participants. For instance, comments were made during the first interview about the participant's openness around having dementia, and following these comments a question on the use of 'memory problems', as opposed to 'dementia', was added to the schedule. Interviews lasted between 22 and 67 minutes and were conducted in the homes of participants, with the exception of one interview conducted at a Memory Cafe location. One interview was ended at 22 minutes as the participant with dementia started to struggle with responding and SH felt the interview was beginning to cause distress. For one carer interview (Geoff) the participant's wife with dementia remained in the room whilst the interview was being conducted.

4.4.1.4 Data analysis. Interviews were audio recorded and transcribed verbatim by SH. Interview transcripts were analysed by SH using thematic analysis (Braun & Clarke, 2006, 2013) with a deductive approach (Braun & Clarke, 2006). Disconfirming cases (Mays & Pope, 1995; Patton, 1999) were sought throughout the analysis. To strengthen the trustworthiness of analysis, four of the transcripts were also coded independently by another researcher (JL) (Johnson & Waterfield, 2004; Lietz et al., 2006; Patton, 1999). These four coded transcripts were then discussed page by page by the researchers. Supervision meetings were used to review and discuss the identified candidate themes, helping to inform the refinement of themes. NVivo 10 (QSR International, 2012) was used to assist in the organisation of data analysis, to code the transcripts and to group the codes into themes.

4.4.1.5 Ethical considerations. This study was approved by the University of Exeter Psychology Ethics Committee (Application 2014/508). NHS ethics was not required as all participants were recruited from the community and only dementia participants with capacity to consent were recruited. The information sheet was written following guidance for writing dementia friendly information (The Dementia Engagement and Empowerment Project, 2013) to maximise the participation of the person with dementia in the decision to consent. Capacity to consent was assessed for persons with dementia using the two-stage test of capacity (Department for Constitutional Affairs, 2007). Informed signed consent was obtained from all participants. All collected data was anonymised and stored securely.

4.4.2 Findings and Implications

Consistent with the research objectives, themes were identified regarding feedback on the workbook and implications for the delivery of BEAMD (see Table 4.7). Overarching themes were used to organise and structure the analysis (Braun & Clarke, 2013, Chapter 10). The themes are explored below along with a discussion on the implications of the findings.

Table 4.7 *Themes*

Overarching Themes	Themes
Workbook Feedback	i) Positive workbook feedback ii) Suitability for people with dementia iii) Workbook changes
Delivery Implications	i) Conceptualising dementia as ‘memory problems’ ii) Potential workbook difficulties iii) The availability of carer support – a barrier to participating in, or engaging with, BEAMD iv) Locations for delivery

4.4.2.1 Workbook feedback.

***i) Positive workbook feedback**.* Reactions to the developed workbook were positive from both informal carers and participants with dementia. Positive comments were made regarding the design, layout and content, with some of the positive comments on aspects of the design that were informed by the guidance for writing dementia friendly information (The Dementia Engagement and Empowerment Project, 2013). Several participants felt the font size was good; the workbook and layout was clear; photographs in the workbook were “*lovely*” (Jane, carer); and the white space around the text aided clarity and emphasised statements.

> Jennifer, person with dementia (PwD): “*The layout is good, good print, widely spaced, I can see it as well because a lot of us are old*”.
>
> Alan, PwD: “…*well it’s nice and clear that’s one good thing and I like the spacing, the spacing of the stuff*… [*Alan reads the workbook out loud*] …*yes it’s easy to read*”.

Additionally, some participants felt the use of different colours for the different steps and having support tips in coloured boxes were both good ideas. One informal carer felt the placement of the photographs in the design and layout of the workbook was important for people with dementia.

> Mary, carer: "*I think that the photographs are good, I like the, the way they're set out and it also gives you a break from words which I think is important for dementia because they can't cope with a lot of words and reading*".

Positive comments were also made regarding the simplicity of the language and worksheets. Mary highlighted this simplicity is what she and her husband need, being a significant benefit when time is limited.

> Mary, carer: "…*I can't get over how simple it is* [the workbook], *I really think it's amazing, if everything we had to deal with was as simple as this you could cope with it*".

> Mary, carer: "…*I think that the way that it's been set out whoever did it, is obviously knowing, you want to do things but you haven't got time to muck about and try and work out what it means, you want it so it is simple, it's set down easily so that you can see immediately and write it down, that's what you want, you don't want a form that you've got to think about what you've got to put down and then spend ages answering it*".

Positive comments regarding the content of the workbook were around the inclusion of the vignette, with participants commenting a case study could be helpful and encouraging.

> Mary, carer: "*…well I think it's good to have a case study isn't it because it helps other people*".

Additionally, positive remarks were also made about the provision of support tips, with Pauline commenting they provide an idea of what is required. Jennifer highlighted the importance of the example activities included in the workbook (page 19) as people with dementia can have difficulties generating examples.

> Jennifer, PwD: "…*I think it's a good idea* [examples in the workbook], *I think it's a very good idea, because they're one of the things that we don't, we don't conjure up like we used to*".

One participant also commented positively about the amount the workbook covers. However, a concern over the quantity of information in the workbook was also raised.

> Jane, carer: "*I wonder whether it's too much information for people to take in*".

Pearl also felt there was a lot of information, however she did acknowledge that the information explains the intervention.

> Pearl, carer: "*It is quite a lot of writing, but on the other hand it's explained you know, it explains what you're doing*".

Overall, the positive comments suggest the workbook may be acceptable with regards to the design, layout and simplicity of the language. However, until BEAMD is delivered to people with dementia (Study Three) it is unknown whether the amount of information is appropriate for people with dementia, and whether the workbook is acceptable when being used and completed.

ii) Suitability for people with dementia. Opinions on the suitability of the workbook indicated people with dementia may be able to cope with it, with one participant with dementia commenting he would be happy to complete it: "*I wouldn't mind filling this in if I had to*" (Alan, PwD). Overall, responses indicated the guided self-help intervention would be more suitable for those with mild to moderate dementia rather than the later stages of dementia. This observation supports the decision to focus the development of BEAMD on people with mild to moderate dementia.

> Pearl, carer: "*Can't be too bad can it* [severity of dementia]*, um, I mean if they get, if they're, they're sort of latter stage of dementia they wouldn't be able to comprehend what it's all about. Um yes I think it's got to be earlier stages and, it's probably the early stages where they've got the dementia-, the depression as well isn't it*".

> Mary, carer: "…*I think that if he's medium or you know early dementia then they could cope with this* [planned activities diary]".

However, based on one carer's experience with his wife, some people with mild to moderate dementia may still experience difficulties with aspects of the workbook.

> Matthew, carer: "…*I don't think, I hope I'm not being negative in what I'm saying to you but I don't think for one minute that my wife would have been able to complete anything like this* [Five Areas™ diagram] *at any stage of her dementia*".

Although BEAMD is developed for mild to moderate dementia, to enable the person with dementia to engage with the intervention, it is acknowledged that difficulties with cognitive domains or functional abilities can vary between each individual with dementia. Based on the above comment from Matthew, some people with mild or moderate dementia could experience difficulties with the workbook. More intensive carer involvement may be required for people with dementia who experience greater difficulty engaging with BEAMD.

iii) Workbook changes. Several small modifications to the design of the BEAMD workbook were suggested. These included the adoption of an additional diary later in the workbook to allow a comparison between diaries, alongside adding guidelines in the boxes on the diaries. One carer (who voiced concern over the quantity of information) suggested the workbook might need to be simplified for people with dementia.

> Jane, carer: "…*I wonder whether it* [the workbook] *needs to be simplified because I honestly do not think that, you're going to have somebody whose very, got a very, very, very mild form I think of the dementia to be able to you know get through all this*".

Discussions were also had with participants around whether the workbook should include examples of completed worksheets for the vignette. The majority of participants felt this would be a good idea and useful to those receiving the intervention. However, there were disconfirming cases regarding the inclusion of example worksheets. One carer felt they were not necessary, and there was a concern people with dementia may use the examples from the tables to complete their own worksheets, which may not reflect what they think.

> Dennis, PwD: "*Yes, I'm not so sure about that* [example completed tables] *because I think what's important is what I'm feeling then and there, if I'm reading that and I think to myself 'that's a good idea, I'll put that down', that isn't what I'm thinking, do you see what I mean*".

Based on responses from the participants, a few small modifications should be made to the workbook before Study Three.

4.4.2.2 Delivery implications.

i) Conceptualising dementia as 'memory problems'. Given that unnecessary harm or distress may be caused by using the term 'dementia' (Bartlett & Martin, 2002), the BEAMD workbook was designed using the wording 'memory problems'. Comments made by participants support the idea that 'memory problems' may be the more appropriate terminology to use. Although some people with dementia may be open about their diagnosis, others may not be accepting of a dementia diagnosis.

> Jennifer, PwD: "*…I know people, um, who when I've said that I've been diagnosed because I'm very open about it, very open, it's, it doesn't upset me that people know, but I've got two or three friends who've been diagnosed and they 'don't let them know, don't let anybody know' ".*

Furthermore, some people with dementia may have forgotten they received a diagnosis.

> Alan, PwD: "…*it's weird you forget that you forget, so there's no knowledge of what dementia is, I have no experience, or and yet I have it, it's weird*".

Therefore, for people with dementia receiving BEAMD who do not remember or may not accept they have a diagnosis, using the term 'dementia' may create unnecessary distress.

Participants were asked specifically about the use of the terminology 'memory problems', with several interviewees commenting this was a preferable term to use. Reasons for the preference of 'memory problems' over 'dementia' included the fact people may not think, or may forget, that they have dementia. Additionally, participants felt dementia can be confusing and 'dementia' may be a new term to people since their diagnosis.

> Pearl, carer: "…*but the actual term* [dementia] *can sometimes be a bit confusing and he, they might forget, whereas memory problems they'll understand, and I think memory problems is probably a better, generic term*".

Furthermore, people may be "*touchy*" (Jennifer, PwD) about dementia and there is a stigma that surrounds dementia.

> Mary, carer: "…*I mean some people might prefer that* [memory problems] *because dementia is still a stigma thing isn't it*".

However, there were disconfirming cases regarding the conceptualisation of dementia as 'memory problems'. Not all the interviewees felt 'memory problems' was the better terminology to use.

> Joseph, PwD: "…*I think dementia would be the best word to use really, because people hear about it on the TV, um and on all sorts of places, um and think if you change the way you write things, um it means you've got two different standards then, um and I think if you've got one thing that you can refer to, you know what it means*".
>
> Mary, carer: "*Oh they've got dementia why pussyfoot round, I think if somebody's got memory problems it's somebody like me, you can never remember anything anyway and is a bit stupid, but dementia is a positive thing which I think should be accepted*".

It is important for the practitioner supporting BEAMD to be aware of how the dyad receiving the intervention would like to refer to dementia, with the terminology used down to personal preference.

> Pauline, carer: "*Um, I'm quite happy to say dementia, or Alzheimer's and so is Joseph but a lot of people aren't. You know that's a very personal thing I think is whether somebody would prefer to say memory problems, because that's what it is, but um, we say dementia quite happily, so either or would make no difference to us*".

The practitioner supporting BEAMD should use 'memory problems' during support sessions unless the person with dementia uses 'dementia', accepts or remembers their diagnosis, and will not be caused unnecessary distress by the term 'dementia'. The practitioner should, however, re-evaluate the use of 'dementia' in each support session. This is consistent with how BEAMD was developed, with 'dementia' only used in a support session if introduced first by the person with dementia.

ii) Potential workbook difficulties. Participants identified the fact that there may be some potential difficulties with the workbook for people with dementia. Some of these difficulties were based on experience and/or abilities of the interviewees with dementia and the family members of the carers interviewed. These potential difficulties include: inability to complete the worksheets, which may be due to tremors, illegibility of handwriting or not wanting to write in the workbook; difficulties with reading the workbook; and problems remembering the content of the workbook.

> David, carer: "…*I'm wondering whether people can actually, with dementia fill, well I suppose some of them can, fill this in you know*".

> Jennifer, PwD: "…*although I can't read very well now because I can't remember what I read, um when I pick it up again tomorrow I can't remember what I read yesterday, so that's quite difficult*".

Interviewees suggested the carer may need to be involved in filling out the worksheets.

> Pamela, carer: "*But he wouldn't want to actually write in here, that would have to be done by the support person you know*".

The description of the intervention above (Section 4.3.2) indicates that people with dementia may need their carer to help complete the diagrams and diaries in the workbook. The support tips included in the workbook also suggest the carer can help the person with dementia fill in the worksheets. The comments from these interviews support the idea that help may be needed when completing the workbook. During the assessment session the practitioner discusses and agrees with the dyad how the carer will support BEAMD (see

Appendix 4.2) and this discussion could also address whether carer support is needed to complete the workbook. Although these potential difficulties have been identified, it is still unknown whether people with dementia are able to use the workbook. This is a key uncertainty of the developed intervention that will be investigated when participants receive BEAMD (Study Three).

iii) The availability of carer support – a barrier to participating in, or engaging with, BEAMD. The ability for people with dementia to participate or fully engage with BEAMD may be hampered by the availability of carer support. Participants highlighted the necessity and importance of involving informal carers in BEAMD. Having no carer or limited carer support would therefore represent a barrier to receiving and engaging with BEAMD. Jennifer, a widow with her sons living away, indicated she would have no one to support her through the intervention. This lack of a carer to participate in BEAMD may also be a problem for others with dementia.

> Jennifer, PwD: "*And I think- I won't be the only person that hasn't got anybody*".

If people with dementia do have informal carers or family members that could be involved in supporting BEAMD, the availability of support from these carers may still be limited. This limited availability may stop carers attending support sessions or supporting activities during the week.

> Jane, carer: "…*my mother of course is a widow, um I'm her only child and I'm not there all the time*".
>
> Mary, carer: "…*another day the carer might not be able to help him* [the person with dementia] *fill in these things* [worksheets] *because they're busy um with things they have to do probably because he can't do it anymore um so and things always crop up that are not planned that take up the time to make everything else not be able to be done*".

Having no carer or limited carer support are barriers that may limit the recruitment of dyads to receive BEAMD as well as limit engagement with the workbook or activities between support sessions. For those receiving BEAMD it may be important for the practitioner to establish the availability of the carer to support, and whether any other commitments may impact on their ability to support the intervention between support sessions. This could be explored with the carer during the assessment session.

iv) Locations for delivery. Participants were informed during the interview that the intervention would initially be delivered to a small number of participants in a clinic at the University of Exeter. One carer suggested delivering BEAMD at the University may be a barrier to recruiting people, as the University may appear intimidating.

> Pamela, carer: "*I think a lot of older people might feel intimated going to the University, they would be um they would think 'ooh, University, ooh (gasp sound!)'* "

Pamela suggested delivering the intervention locally may improve the response rate.

> Pamela, carer: "…*if it was local you'd get, I think you'd get a better response from people, they wouldn't feel intimidated*".

Although no other participants suggested delivering BEAMD at the University may be a barrier to recruitment, Jane and David did suggest it would be better to deliver BEAMD in the person's home. Jane suggested people receiving the intervention may be happier or more orientated in a familiar environment and the practitioner supporting the intervention may be able to better understand the activities the individual likes.

> Jane, carer: "…*I think perhaps the people who are overseeing them can then see the, um, what their homes are like and what they've got at their disposal, and pick out things perhaps you know that um they might be interested in doing by just perhaps by identifying some magazines that they've got hanging around or some books or the garden or, photographs, that sort of thing*".

Pamela also felt there were benefits of delivering the intervention in the person's own environment.

> Pamela, carer: "…*I think you'd get a better response, especially if people could do it in their own environment, you'll, you'll get better response and answers I think than you would if you're sat in a room in the University and they are all a bit (gasp) you know, overawed by it all*".

For Study Three BEAMD needed to be delivered at the University due to the limited funding and resources available for the study. However, in future larger feasibility studies BEAMD could be delivered flexibly with regards to the location of support sessions, with the option to conduct sessions in the participant's home.

4.4.3 Discussion

This qualitative study was conducted as part of the development of BEAMD, to consider the acceptability of the developed intervention workbook; to refine and modify (if necessary) the workbook; to inform delivery; and to identify potential benefits and barriers. The main findings and implications from this study are the following:

- The ability to recruit participants to receive BEAMD, and engagement with the intervention, may be affected by the lack of an informal carer and/or limited carer support. At the beginning of the intervention it may be necessary to establish the carer's ability and availability to support BEAMD.
- Positive feedback suggests the workbook design, layout and simplistic language may be acceptable. However, there are still uncertainties about the appropriateness of the quantity of information and the acceptability of the workbook when being used and completed.
- The developed intervention may be appropriate for people with mild to moderate dementia. However, some individuals with these severities of dementia may still face difficulties with BEAMD, and may need greater levels of carer support. People with dementia may experience some difficulties with the workbook including reading and remembering content and completing worksheets. As participants in this study did not complete the workbook the feasibility of using the workbook is still unknown.
- The practitioner supporting BEAMD should use the term 'memory problems' unless the dementia participant uses 'dementia', accepts or remembers their diagnosis, and will not be caused unnecessary distress by the term 'dementia'.
- Participants suggested implications for delivery, such as delivering locally or in the participant's home, and suggestions were also made for modifications to the workbook.

4.4.3.1 Strengths and limitations. It is important to consider the key strengths and limitations of this study, and to keep these in mind when considering the findings. A key strength of this study is having used methodological strategies to strengthen the trustworthiness of the findings. Having used two researchers to independently code a selection of the transcripts has helped to reduce potential biases, such as interpretive bias and selective perception (Patton, 1999), that can occur when analysis is conducted by a single researcher. Additionally, cases that contradicted the themes were also identified and reported (Mays & Pope, 1995; Patton, 1999). Identifying these disconfirming cases is important for increasing the validity of the findings.

Using these strategies has increased confidence that the findings are representative of the views of the participants (Lietz et al., 2006).

A limitation of this study is not having established the severity of dementia for the dementia participants and the family members of the informal carers interviewed. Knowing the severity of dementia may have allowed for further interpretation of the findings and an understanding of whether the potential difficulties identified may be experienced by those with mild, moderate or severe dementia. This would allow further understanding of the relevance of the comments to the population for which the intervention has been developed. Additionally, showing the participants the developed workbook during the interviews in this study, as opposed to allowing them time before the interview to view the workbook, may have limited the data that was collected. Comments from some of the participants indicated they had been scanning rather than reading the workbook, had not been able to take much in, and would need longer to look at the workbook to consider potential changes. It was, however, not possible to allow the participants to view the workbook before the interview due to the limited time frame for this programme of research.

Finally, it is important to consider the participants' knowledge of the interviewer (Tong et al., 2007) and whether this could have impacted on the findings. In this study the interviewees were aware SH was developing the guided self-help intervention as part of her programme of research and, if asked during interviews, SH was clear about her role in designing and writing the intervention workbook. This knowledge could, potentially, impact on responses from participants as they may not have felt comfortable providing negative feedback on the workbook. However, this being said, participants did feel able to provide negative feedback, with some participants making less positive comments about the quantity of information and the suitability of the workbook for people with dementia. Potential difficulties with the workbook were also identified by participants.

4.4.3.2 Changes to BEAMD workbook. A key aim of Study Two was to identify modifications to the workbook (if necessary) before delivering BEAMD to participants in Study Three. As highlighted above, changes to the workbook were suggested by participants. This section provides details on the changes that were made, where these were added to the workbook, and the suggested changes that were not incorporated into the workbook (see Appendix 4.4 for the modified workbook).

- As the majority of participants felt the inclusion of example worksheets for the vignette would be a good idea, example worksheets for the case study (Bernard) were added on pages 17, 30 and 31 of the workbook (see Appendix 4.4).
- Although additional diaries were suggested, these were not added to the workbook to ensure the number of pages in the booklet was kept to a minimum. Instead, additional diaries on A3 sheets were created for the practitioner to give to participants if, and when, needed.
- The suggested guidelines in the diaries were not added due to formatting difficulties.
- Although one carer suggested simplifying the workbook for people with dementia, the feasibility and acceptability of the workbook (when being completed) was still unknown. The decision was made to not simplify the workbook before Study Three, and to see if simplification was need after participants had received the intervention.

4.5 Chapter Four Summary

This chapter has presented the initial development of a BA guided self-help intervention for depression in people with dementia (BEAMD) informed by findings from the systematic review (Study One), literature, contact with experts and guidance co-produced by people with dementia. People with dementia and informal carers were also involved in the development of BEAMD (Study Two) to consider acceptability, to refine the workbook and to inform delivery. During the development of BEAMD it was clear there were uncertainties around recruitment, acceptability and feasibility. The following chapter presents a case series conducted to investigate the key uncertainties and to help inform further development of BEAMD and future research.

Chapter Five: Informing Further Development of BEAMD: A Preliminary Feasibility Case Series

5.1 Background

Following the initial development of BEAMD (Chapter Four), this chapter presents a preliminary feasibility case series for the developed intervention. This is conducted as part of the ‘feasibility and piloting’ phase of the Medical Research Council (MRC)’s framework, which involves investigating the key uncertainties identified during intervention development (Craig et al., 2008; MRC, 2008). Several uncertainties were identified from the interviews conducted with people with dementia and informal carers (Study Two), as well as from the systematic review (Study One) and literature. The key areas of uncertainty identified during the development of BEAMD were regarding recruitment, feasibility and acceptability. These uncertainties were:

- The ability to recruit dyads to receive BEAMD. Study Two highlighted potential difficulties recruiting people to receive BEAMD as some people with dementia do not have an informal carer, or, for some people, carer support may be limited. This uncertainty regarding the ability to recruit participants was also supported by a paucity of literature, with a lack of data regarding the potential proportion of people with dementia who are eligible for and willing to participate in non-pharmacological interventions (Cooper, Ketley, & Livingston, 2014).
- The feasibility of delivering BEAMD as currently developed. With no behavioural activation (BA) guided self-help interventions for people with dementia identified in Study One, there was a lack of low intensity interventions to inform the delivery characteristics of BEAMD, such as number and length of sessions, as well as a lack of evidence regarding the feasibility of this method of delivery. Some of the key uncertainties include the appropriate length of support sessions and whether people with dementia are able to use the workbook, especially with Study Two highlighting potential difficulties with the workbook.
- The acceptability of BEAMD to participants. Overall there is a lack of qualitative data on the acceptability of psychological interventions for people with dementia as data has been collected through the use of standardised Likert scale questions for client satisfaction (Paukert et al., 2010; Stanley et al., 2013) or as quantitative data on intervention uptake

and withdrawal (Spector et al., 2015). Although one protocol paper reports the use of qualitative interviews with patient-carer dyads (Spector et al., 2012) the qualitative findings are not reported in the results of the study (Spector et al., 2015). Regarding BEAMD specifically, the acceptability of the design, layout and format of the workbook has been investigated (Study Two). However it is still unknown whether the workbook is acceptable when being used by participants and completed by people with dementia. It is important to establish whether a BA guided self-help intervention is acceptable to both the participant with dementia and their informal carer helping to support BEAMD.

- The effectiveness of BA guided self-help interventions for depression in people with dementia. Again, with no BA guided self-help interventions identified for people with dementia in Study One, there is no current evidence base regarding effectiveness. Case series can be used for a proof-of-concept (Abbott, 2014) and have been used to provide preliminary data for modified interventions (Watkins et al., 2007) and for the first application of an intervention to a specific population (Malins et al., 2016).

5.1.1 Aims and Objectives

This feasibility study was conducted to help develop BEAMD (Abbott, 2014) and to inform future research. The aims and objectives of this case series were:

- To collect data on research methods, materials and measures to inform future research. This includes the feasibility of recruitment; acceptability of research materials, methods and measures; and feasibility of completing outcome measures.
- To investigate the feasibility of delivering BEAMD to inform any necessary further development of the intervention protocol.
- To investigate the acceptability of BEAMD to inform any necessary further development of the intervention.
- To provide preliminary outcome data for BEAMD.

5.1.2 Preliminary Work

Before this case series commenced, preliminary work was undertaken to inform the methods in this study. This involved contacting the Clinical Director of the Older People’s Mental Health Directorate, Dr Owens, to discuss the project, and establishing a relationship with the Memory Clinic where participants would be recruited from. SH visited the Memory Clinic on multiple occasions to understand how the Clinic appointments worked and if it was possible to recruit participants from the Clinic. SH investigated the flow of patients through the Clinic and obtained data on the number of dementia diagnoses given monthly in the Clinic. Using data on the prevalence of depression in dementia (Enache, Winblad, & Aarsland, 2011) SH estimated the likely number of dementia patients with comorbid depression. As there was no current screening for depression in the Memory Clinic appointments a measure was implemented as part of clinical practice due to Dr Owens' support for the project and support for assessing and treating depression in people with dementia. The Patient Health Questionnaire-9 (PHQ-9; Kroenke & Spitzer, 2002) was initially implemented as is standardly used in primary care. SH volunteered as an assistant psychologist in the Memory Clinic to ensure the depression measure was completed during appointments. Additionally, the recruitment strategy was discussed with Dr Owens and the amendment to the strategy (see Section 5.2.1) was discussed with Dr Owens and the Memory Clinic Lead. Finally, a successful application was submitted to the Accessing Evidence-Based Psychological Therapies (AccEPT) Clinic, for the delivery of BEAMD within the Clinic.

5.2 Methods

5.2.1 Amendments to the Protocol

Amendments were made to the protocol due to difficulties recruiting participants and identifying depression in patients during Memory Clinic appointments. The amendments were submitted to the Ethics committee who had approved this research and permission was granted to continue the study with the amendments made. The amendments were also approved by the research and development department of Devon Partnership NHS Trust. Details of the amendments are provided in Table 5.1.

Table 5.1 *Protocol Amendments*

Amendment reference	Background to amendment	Amendment details
1.2	Due to difficulties recruiting participants, an amendment was made to allow contact with potential participants who could not be seen at their post diagnostic visit and potential participants who did not respond to the study invitation letter.	• Potential participants were sent a study invitation letter and information sheets, and asked to contact the researcher via telephone, email or by completing the 'Permission to Contact Form' and sending via a freepost envelope. • Non-responders were contacted by a member of the Memory Clinic clinical team to check receipt of the letter and study information, and ask if they were happy to discuss the study with the researcher.
1.3	The Exeter Memory Clinic had introduced the PHQ-9 as part of assessment during appointments. However, due to concerns from the Clinic’s clinicians regarding the sensitivity of the PHQ-9 in people with dementia, the GDS-15 replaced the PHQ-9 in Memory Clinic appointments.	• Depression eligibility criteria changed from ≥10 on the PHQ-9 to a score of >5 on the GDS-15. • For patients who had recently attended the clinic and completed the PHQ-9, their responses to the PHQ-9 were rechecked to establish their potential eligibility using the first 2 items (PHQ-2). Patients scoring positive on either of the items on the PHQ-2 were contacted. Those willing to participate were reassessed with the GDS-15 to confirm eligibility. • Consultant judgement on the presence of depressive symptoms was added to establish potential eligibility (those identified by this method and willing to participate were re-assessed with the GDS-15 to establish eligibility). • The GDS-15 replaced the PHQ-9 at baseline, during intervention support sessions and post-intervention.

Note: GDS = Geriatric Depression Scale; PHQ = Patient Health Questionnaire.

5.2.2 Recruitment

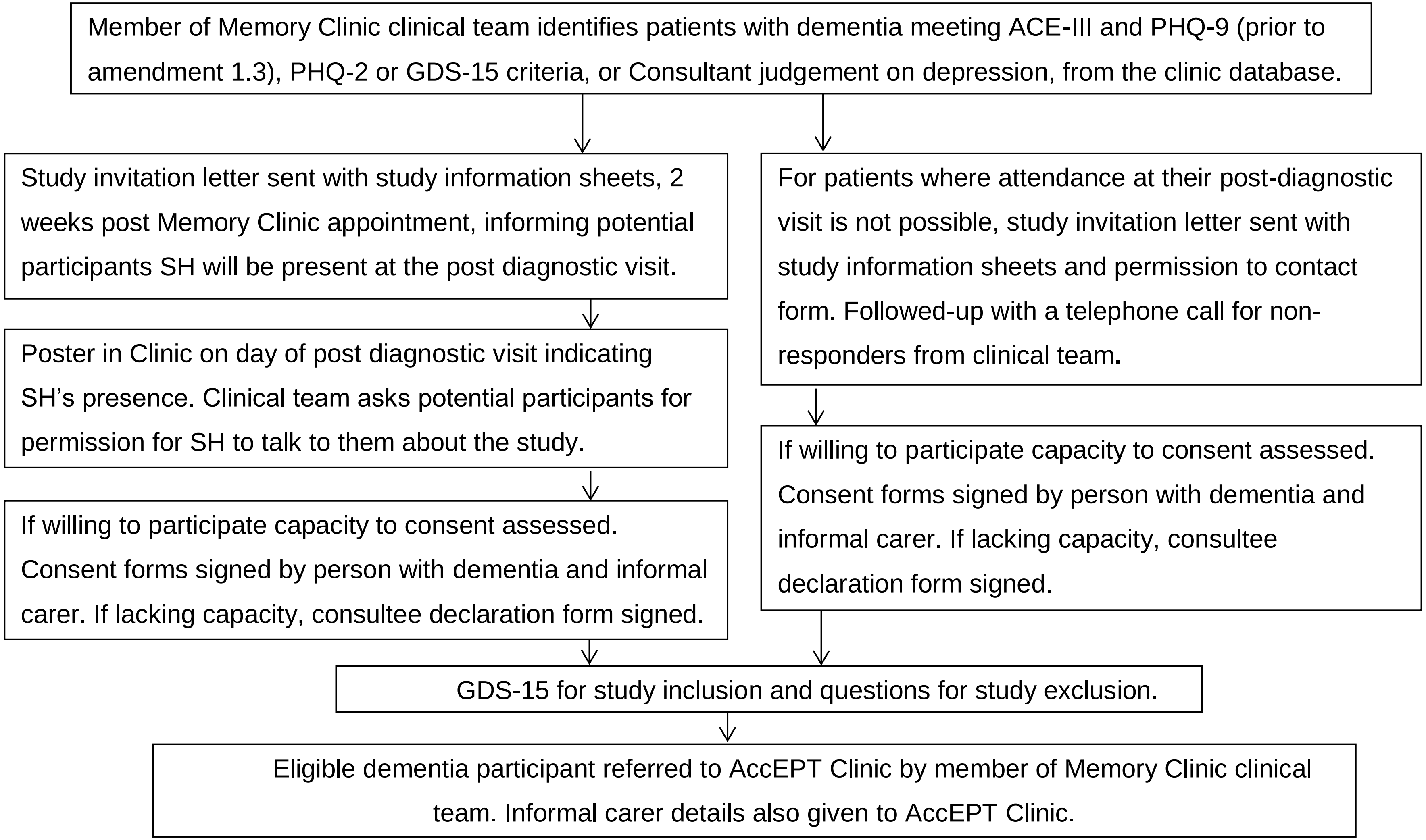
5.2.2.1 Identification of potential participants. A member of the Exeter Memory Clinic team identified potential participants from the clinic database. Potential participants were identified based on a recorded dementia diagnosis (any type), an Addenbrooke's Cognitive Examination (ACE-III; NeuRA, 2012) score between 50 and 88 (inclusively) representing mild to moderate dementia, and their score (or response) on the depression measure completed during their appointment (or consultant judgement on the presence of depressive symptom). Dependent on the measure completed (see background to amendment 1.3, Table 5.1) this was either a score of ≥10 on the PHQ-9 (prior to amendment 1.3), >5 on the Geriatric Depression Scale-15 (short form) (GDS-15; Sheikh & Yesavage, 1986) or a positive response to the PHQ-2.

5.2.2.2 Procedure. A study invitation letter from the patient's consultant alongside study information sheets (one for the person with dementia and one for the informal carer) were sent to potential participants identified from the Memory Clinic database. Potential participants were then approached by SH at their post-diagnostic visit, conducted approximately four weeks after the Memory Clinic appointment. Following amendment 1.2 (see Table 5.1), postal and telephone contact was made with potential participants identified from the clinic database when it was not possible to approach them at their post-diagnostic visit. A different version of the study information letter and information sheets were sent asking potential participants to contact SH via telephone, email or the permission to contact form in a prepaid envelope. A family member or friend was also able to contact SH on behalf of the potential participant. For those who did not respond to the letter a member of the Memory Clinic clinical team conducted a follow-up call to check receipt of the letter and to ask if they would like to discuss the study with the researcher.

5.2.2.3 Informed consent, screening and referral. Informed consent was obtained from both the person with dementia and their informal carer before screening for eligibility. Understanding of the study information was checked and potential participants were provided with the opportunity to ask questions. Capacity to consent was assessed by SH for the person with dementia before their consent form was signed. For those assessed as lacking capacity a consultee declaration form was signed by the informal carer.

The GDS-15 (Sheikh & Yesavage, 1986) was then completed by the person with dementia to determine their eligibility against the inclusion criteria and questions regarding the exclusion criteria were asked. Eligible dementia participants were those with: a diagnosis of probable dementia given by a Clinician in the Memory Clinic and an ACE-III score of between 50 and 88 (identified from the Clinic database); a score of >5 on the GDS-15; and an informal carer, with whom they had some form of daily contact, to attend the support sessions and provide support for BEAMD. The exclusion criteria for participants were: bipolar disorder; current psychosis; substance dependence that may interfere with the receipt of a talking therapy; behaviour posing risk to self or others; currently receiving psychotherapy or counselling; and/or currently on anti-depressant medication and other psychoactive drugs (other than anti-dementia drugs), unless on a stable dose for at least 3 months.

Informed consent, capacity assessment and screening were conducted in the potential participant’s home, with the exception of one potential participant where this was conducted at the University of Exeter. Eligible participants were then referred into the AccEPT Clinic at the University of Exeter by a member of the Memory Clinic team. The full recruitment procedure is presented in Figure 5.1.



Member of Memory Clinic clinical team identifies patients with dementia meeting ACE-III and PHQ-9 (prior to amendment 1.3), PHQ-2 or GDS-15 criteria, or Consultant judgement on depression, from the clinic database.

Study invitation letter sent with study information sheets, 2 weeks post Memory Clinic appointment, informing potential participants SH will be present at the post diagnostic visit.

Poster in Clinic on day of post diagnostic visit indicating SH's presence. Clinical team asks potential participants for permission for SH to talk to them about the study.

If willing to participate capacity to consent assessed. Consent forms signed by person with dementia and informal carer. If lacking capacity, consultee declaration form signed.

For patients where attendance at their post-diagnostic visit is not possible, study invitation letter sent with study information sheets and permission to contact form. Followed-up with a telephone call for non-responders from clinical team.

If willing to participate capacity to consent assessed. Consent forms signed by person with dementia and informal carer. If lacking capacity, consultee declaration form signed.

GDS-15 for study inclusion and questions for study exclusion.

Eligible dementia participant referred to AccEPT Clinic by member of Memory Clinic clinical team. Informal carer details also given to AccEPT Clinic.

Figure 5.1 Recruitment Procedure

5.2.3 Treatment

Dementia participants received BEAMD (see Chapter 4 and Appendix 4.4) supported by a Band 7 Cognitive Behavioural Therapist operating within the AccEPT Clinic at the University of Exeter. The therapist has trained in, and delivered, both low intensity and high intensity BA within the Exeter Improving Access to Psychological Therapies (IAPT) service. The therapist's experience includes treating a number of people with depression secondary to recent trauma/head injuries, memory disturbance and cognitive impairment, and ageing populations challenged by memory loss. The therapist received a two-hour training session before the commencement of therapy. This session was co-delivered by an experienced and registered nurse who had been employed as a Primary Care Dementia Practitioner (PCDP). This component of the training provided an overview of dementia, depression and low intensity BA interventions; explored the complex nature of dementia; focussed on communicating with people experiencing memory loss and/or dementia in a person centred approach; and discussed ways of adapting practice to support someone living with dementia. The PCDP also highlighted his availability to supervise the therapist when any dementia related questions or difficulties arose. The other training component focussing on the workbook, support session content and adaptations made to the intervention was provided by SH.

5.2.4 Data Collection

5.2.4.1 Demographics and medical details. Demographic data and medical details were collected by SH from the person with dementia and carer at baseline, a maximum of two weeks before the assessment session with the therapist. For the dementia participant, demographic data and medical details included age; sex; marital status; length of memory problems; dementia diagnosis; date of diagnosis; ACE-III score from Memory Clinic appointment; and medication. The dementia diagnosis, date of diagnosis and ACE-III score were obtained from the Memory Clinic database. For the informal carer, data collected included: age; sex; relationship to person with dementia; residence (with or apart from person with dementia); and extent of daily contact.

5.2.4.2 Feasibility. To investigate the feasibility of recruitment numbers were recorded for: patients identified from the Memory Clinic database; letters sent; people interested in the research; people meeting the researcher; people screened; eligible participants; participants starting the intervention; and participants completing the intervention. Details were also recorded about the method of recruitment and type of contact with potential participants. Reasons were also recorded for non-participation and for participants not completing BEAMD.

To investigate whether the intervention could be delivered as developed, SH conducted semi-structured interviews with the therapist after the assessment session and last support session for each dyad (person with dementia and carer). For the participants discharged after the assessment session, the therapist was only interviewed after this session. The interviews were conducted with an interview guide (Appendix 5.1) that covered the delivery and implementation of BEAMD. The interview guide was used flexibly (Braun & Clarke, 2013) with regards to the order and wording of questions. If any additional issues arose in the interviews, additional questions were added. The interviews ranged from 23 to 84 minutes. A support session form was also completed by the therapist after each session to report on the number and length of sessions; GDS-15 score; progress through the intervention; problems discussed in the support sessions; process issues; comments on engagement; and carer involvement in the session.

To investigate whether it was feasible to complete measures with participants the number of missing items was recorded. The completion of the GDS-15 was also discussed in the therapist interviews.

5.2.4.3 Acceptability. Semi-structured interviews were conducted with the dementia participants and informal carers to investigate the acceptability of BEAMD (the workbook, therapist support and carer involvement) alongside acceptability of research materials, methods and measures. Interviews were conducted within two weeks of the participant’s last support session. Interview guides (Appendices 5.2 and 5.3) were adapted from the schedule used in a randomised controlled trial (RCT) investigating the acceptability of a written self-help BA and physical activity promotion intervention (Farrand et al., 2014) and were used flexibily throughout the interviews. The interview guides included: acceptability of research materials and methods; acceptability of the workbook; acceptability of support sessions; extent of carer involvement; impact on mood; delivery of the intervention; and any suggested changes. All acceptability interviews (ranging from 35 to 85 minutes) were conducted by SH after the collection of post-intervention outcome measures. Interviews were conducted at the participants' homes, with the exception of one participant (Betty), who was interviewed at the University of Exeter (with her husband Brian present during the interview). Betty's acceptability interview was started at home but was rearranged for another day after she become tired (due to the length of outcome measures and subsequent carer interview) and found it difficult to answer more questions.

5.2.4.4 Outcome measures. The Cornell scale for depression in dementia (CSDD; Alexopoulos et al., 1988; Alexopoulos, 2012), a 19-item clinician-administered instrument, was administered pre- and post-intervention. The CSDD uses a comprehensive interviewing approach with two semi-structured interviews conducted with the person with dementia and an informant (Alexopoulos, 2012), focussing on signs and symptoms of depression occurring during the week before the interview. Scores below 6 are associated with an absence of significant depressive symptoms with scores above 10 indicating probable major depression, and above 18 indicating a definite major depression (Alexopoulos, 2012). The CSDD has high inter-rater reliability ($K_w = 0.67$) and internal consistency ($\alpha = 0.84$) and correlates (0.83) with depressive subtypes of various intensity as classified by Research Diagnostic Criteria (Alexopoulos et al., 1988). Internal consistency for the CSDD (cut-off of 9) is good for both mild Alzheimer's disease (AD) ($\alpha = 0.82$) and moderate to severe AD ($\alpha = 0.81$) (Müller-Thomsen, Arlt, Mann, Mass, & Ganzer, 2005). A sensitivity of 0.90 and specificity of 0.75 for a cut-point of 7 has been reported in mild to moderate AD (Vida, Des Rosiers, Carrier, & Gauthier, 1994).

Measures are collected during each support session as standard practice in IAPT (Richards & Whyte, 2011). However, with the CSDD taking approximately 20 minutes to administer (Alexopoulos, 2012), this was not an appropriate measure for clinical use during sessions. The GDS-15 (Sheikh & Yesavage, 1986) was, therefore, collected during support sessions (by the therapist), as well as at pre- and post-intervention (in addition to the CSDD). The GDS-15 is a 15-item self-report measure (Sheikh & Yesavage, 1986) with a score of > 5 points suggestive of depression for clinical purposes. The GDS is a valid measure of depression in mild to moderate dementia (Feher et al., 1992; Isella et al., 2001) and is recommended for use in psychosocial intervention research in dementia care (Moniz-Cook et al., 2008). The convergent validity of the GDS-15 against the CSDD is 0.77, and a cut off of 4 has a sensitivity of

0.81 and specificity of 0.72 in patients with dementia (Kørner et al., 2006). For mild dementia the internal consistency of the GDS-15 is good (α = 0.83) (Müller-Thomsen et al., 2005). If necessary, items on the GDS-15 were read out loud and answers were marked down by SH or the therapist.

As previous research involving BA for depression in dementia found an improvement in carer mood (Teri et al., 1997) a depression measure for the carer was also included. The PHQ-9 (Kroenke & Spitzer, 2002), a self-rated diagnostic and severity measure of depression, was completed by the carer pre- and post-intervention. As a severity measure the scores range from 0 to 27 with cut-off points of 5, 10, 15 and 20 indicating mild, moderate, moderately severe, and severe depression respectively (Kroenke & Spitzer, 2002). For a score of ≥10, sensitivity (0.88) and specificity (0.88) for major depression is good (Kroenke, Spitzer, & Williams, 2001). Internal reliability (Cronbach α = 0.86 to 0.89) and test-retest reliability (r = 0.84) of the PHQ-9 is good (Kroenke, Spitzer, Williams, & Löwe, 2010).

In addition to depression, the dementia participant's quality of life was measured pre- and post-intervention using the dementia quality of life instrument (DQoL; Brod, Stewart, Sands, & Walton, 1999). The DQoL is for respondents with mild to moderate dementia, and is administered by direct interview to the person with dementia, with responses using Likert scales. The internal consistency reliability ranges from 0.67 to 0.89 and two-week test-retest reliability ranges from 0.64 to 0.90. Correlations with the GDS range from -0.42 to -0.64 (Brod et al., 1999). Written permission was obtained from the author for use of this copyrighted instrument.

Finally, to investigate whether the intervention impacted on positive reinforcement the Environmental Reward Observation Scale (EROS; Armento & Hopko, 2007) was completed by the dementia participant. The EROS was developed to assess the construct of response-contingent positive reinforcement (Lewinsohn, 1974) and scores from 10 to 40, with higher scores suggesting increased environmental reward. Psychometric research with three independent student samples (Armento & Hopko, 2007) reports strong internal consistency (α = 0.85 to 0.90), excellent test-retest reliability (r = 0.85), strong associations between the EROS and commonly administered self-report measures of depression, and a moderate correlation (r = 0.43 to 0.51) with the pleasant events schedule (MacPhillamy & Lewinsohn, 1976). If necessary, items on the EROS were read out loud and answers were marked down by SH.

5.2.5 Analysis

Data regarding the recruitment process and methods of contact was recorded (Figure 5.2) alongside reasons for non-participation, which were recorded, coded and counted (Table 5.2). The demographic data and medical details of participating dyads were recorded (Table 5.3) and data on the number, length (minutes) and delivery of support sessions for each participant was also recorded (Table 5.4). Finally, scores for outcome measures (for each participant) have been tabulated (Table 5.5) with the GDS-15 pre-intervention, post-intervention and support session scores presented in graphs (Figures 5.3 and 5.4).

The semi-structured interviews were recorded and transcribed verbatim by SH with NVivo 10 (QSR International, 2012) used to assist in the organisation of data. Due to the small size of the study, as a result of difficulties recruiting participants, the planned framework analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013) was not conducted. Instead the main points from the interviews, and session support forms, have been summarised.

5.2.6 Ethical Considerations and Approval

This research was approved by the South-Central, Oxford C Research Ethics Committee, a committee flagged to approve research involving individuals lacking capacity (ref. 15/SC/0001). To maximise the participation of individuals with dementia in the decision to consent, appropriate help and support was given by providing information sheets and consent forms written following guidance on writing dementia friendly information (The Dementia Engagement and Empowerment Project, 2013) and providing verbal information and clarification when required. Capacity to consent to participation was then assessed using the two-stage test of capacity (Department for Constitutional Affairs, 2007). If the person with dementia could not i) understand the information about the decision to be made ii) retain the information in their mind iii) use or weigh the information as part of a decision making process or iv) communicate their decision, the individual was assessed as lacking capacity to consent. For those lacking capacity, in accordance with the Mental Capacity Act 2005 (Department for Constitutional Affairs, 2007), the informal carer was asked to consider the wishes, feelings and interests of the person with dementia, and if any advance decisions about participating in research exist, before signing the consultee declaration form. Informed signed consent was obtained from all dementia participants (or the consultee if lacking capacity) and all informal carers participating. All collected data was anonymised and stored securely.

5.3 Results

5.3.1 Participant Recruitment

The Memory Clinic database was used to identify 86 patients with dementia meeting the ACE-III and depression criteria. However, only 83 study invitation letters were sent out as one patient had left the county and two were subsequently deceased. A flow diagram of the recruitment of dementia participants is presented in Figure 5.2. This flow diagram also provides details on the methods of recruitment and contact with potential participants. Twelve potential dementia participants were interested in participating or wanting to meet SH to discuss the study in more detail. After discussing the study, two potential participants decided they did not want to participate, resulting in ten individuals being screened for eligibility. Of these ten potential participants, five meet the eligibility criteria on the GDS-15. However, one eligible dementia participant decided not to participate after further discussion with their informal carer. Four dementia participants (4.8% of those initially contacted) and their informal carers were recruited into the case series.

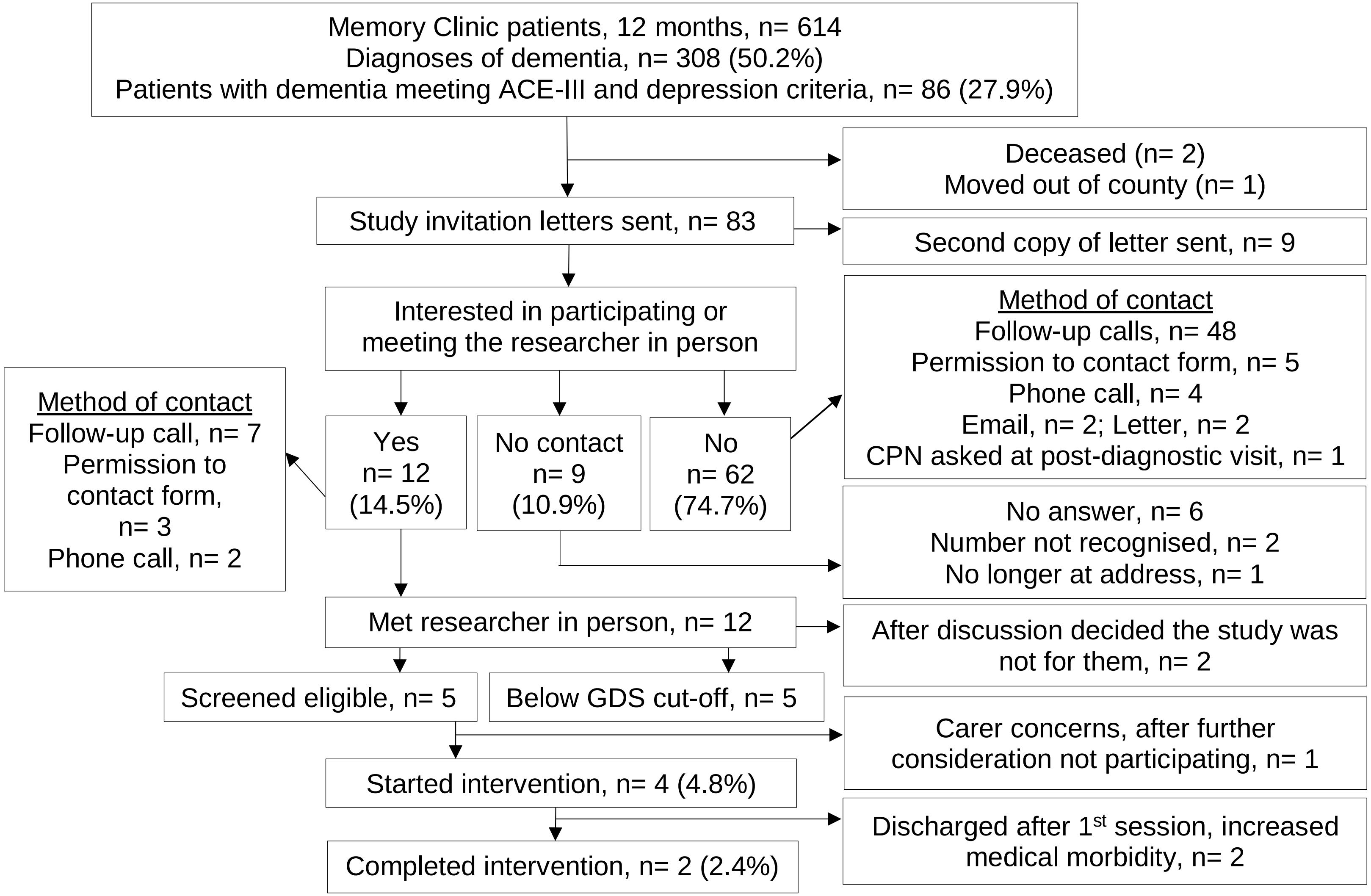


Figure 5.2 Recruitment of Dementia Participants

5.3.2 Reasons for Non-participation

Reasons for non-participation were collected from 64 individuals. This includes the 62 people who were not interested in participating and two who met SH in person to discuss the study, but subsequently decided not to participate. The main method of collecting reasons for non-participation was through follow-up calls (75%) (see Figure 5.2). Some reasons were provided by the carer, with the permission of the person with dementia, through letter, email or via telephone.

In some cases more than one reason for non-participation was given and in total 84 reasons were collected. Of the collected responses (Table 5.2), 64% highlighted barriers to accessing BEAMD (as associated with non-participation), with 18% of responses relating to a lack of informal carer support. Other key barriers included a lack of time (14%) and difficulties traveling to the AccEPT Clinic (12%). Finally, some respondents did not want to participate as they felt they were coping well, with 18% of responses relating to the person not feeling low in mood.

Table 5.2 *Reasons for Non-participation*

Category	Subcategories			N	% of Responses
Coping	Mood	Does not feel low		15	17.86
		Does not need help for mood		1	1.19
			Total	16	19.05
	Does not want help		*Total*	2	2.38
	Currently doing multiple activities		*Total*	1	1.19
	Good family support		*Total*	1	1.19
			Coping Total	**20**	**23.8**
Barriers to accessing BEAMD	No support	Children working and/or living elsewhere		10	11.90
		Partner not interested		2	2.38
		No-one in new location to support		1	1.19
		Others too old to support		1	1.19
		Not told friends about dementia diagnosis		1	1.19
			Total	15	17.85
	Time	Too much going on	*Total*	12	14.29
	Travel	Cannot get to the AccEPT Clinic		4	4.76
		Too far to travel to the AccEPT Clinic		3	3.57
		Does not want to go to the AccEPT Clinic/University		2	2.38
		Physical and mental impact of travel too much for patient		1	1.19
			Total	10	11.90
	Physical health	Poor physical health		3	3.57
		Not physically capable		2	2.38
		Poor physical health, in a care home		1	1.19
		In hospital		1	1.19
			Total	7	8.33

	Confusion	Confused with another study		1	1.19
		Confused with ‘the whole thing’		1	1.19
			Total	2	2.38
	Dementia symptoms	Fast progression/no longer able to express themselves			
			Total	2	2.38
	Difficultly talking	Feels uncomfortable talking to someone they do not know/talking about feelings	*Total*	2	2.38
	Too old		*Total*	2	2.38
	Stress-inducing	Appointments and travelling causes stress	*Total*	1	1.19
	Unavailable	In prison	*Total*	1	1.19
			Barriers Total	**54**	**64.3**
Not interested			*Total*	5	5.95
No reason given			*Total*	5	5.95

Note: BEAMD = Behavioural Activation for Mood in Dementia

5.3.3 Demographic Data and Medical Details

The demographic data and medical details for the four dementia participants and their informal carers is presented in Table 5.3. Participants' names have been replaced with a pseudonym to maintain anonymity. Months since dementia diagnosis relates to the time point at which participants were recruited into the study.

Table 5.3 *Demographic Data*

	Eric	Ruth	Betty	Ron
Gender	Male	Female	Female	Male
Age	85	87	89	79
Diagnosis	Vascular Dementia	Vascular Dementia	Mixed Alzheimer's/ Vascular Dementia	Vascular Dementia
ACE-III	65	73	66	86
Medication	None	Sertraline > 3 months	Amitriptyline ~ 6 months Donepezil	None
Months since diagnosis	3	3.5	8	8
Informal Carer	Pam	Diane	Brian	Daphne
Relationship	Wife	Daughter	Husband	Wife
Carer Age	79	51	89	75
Carer Contact	Co-habiting	Daily	Co-habiting	Co-habiting

Note: ACE-III = Addenbrooke's Cognitive Examination-III.

5.3.4 Study Attrition

Two dementia participants were discharged from the AccEPT Clinic after their assessment session due to increased medical morbidity (Ruth stroke, Ron cancer diagnosis). The informal carers were contacted by SH to discuss the situation and subsequent discharge from the AccEPT Clinic. Withdrawal interviews were not conducted due to the poor physical health of the dementia participants and apparent distress of the carers.

5.3.5 Acceptability of Research Materials, Methods and Measures

The main findings regarding the acceptability of the research materials, methods and measures are summarised below. A more detailed summary from each participant is presented in Appendix 5.4.

Positive comments were made regarding the ease of reading and understanding the information sheet and the consent form was described as straightforward. However, one carer felt the information sheet could be simplified more for the lay-person, particularly the title of the research. Eric did not comment on the materials themselves, focussing instead on his inability to remember seeing the materials.

Pam had been unsure at the beginning about what BEAMD would involve and felt it was hard to understand what it was all about, although it did become clearer when working through the intervention. After receipt of the information sheet, Pam did phone SH to ask more information about practicalities, such as what days the sessions would be on. There were initial concerns from one dementia participant who was worried the intervention may be too complicated to benefit from.

Both dementia participants expressed difficulties with responding to the measures and Eric did not feel as though he understood the question about his mood. Pam felt the baseline data collection was easy to understand, however she also reported they did not necessarily understand why the baseline questions were being asked, but understood more post-intervention. Pam also reported the baseline data collection took longer than expected. Finally, regarding the measures, Brian expressed his dislike of ‘tick-box exercises’ and felt yes or no responses are not appropriate for establishing a person’s thoughts or state of mind.

5.3.6 Delivery of BEAMD

All sessions, with the exception of two assessments and two support sessions, were longer than the designed 50-minute assessment and 40-minute support sessions (see Table 5.4). Session 3 for Betty was especially long, 90 minutes, as she was too anxious to complete the next section and worked through it with the therapist in the session.

As Eric and Pam lived approximately 50 minutes away from the AccEPT Clinic, telephone support sessions were agreed upon for Eric. The sessions were conducted over speaker phone so both Eric and Pam were involved in the session. Eric’s support sessions were weekly with the exception of a mutually agreed 2-week gap between sessions 6 and 7 to allow practice and to phase out the weekly contact. For Betty, session 6 was cancelled and rearranged for the following week due to her ill health. There was also a 2-week gap between the final two sessions for Betty as she went away.

Table 5.4 *Duration and Delivery of Support Sessions*

	Duration and Delivery of Support Sessions			
Session	Eric	Ruth	Betty	Ron
Assessment	50 mins Face to face	50 mins Face to face	55 mins Face to face	64 mins Face to face
Session 2	50 mins Face to face	-	50 mins Face to face	-
Session 3	40 mins Telephone	-	90 mins Face to face	-
Session 4	50 mins Telephone	-	60 mins Face to face	-
Session 5	54 mins Telephone	-	60 mins Face to face	-
Session 6	50 mins Telephone	-	60 mins Face to face	-
Session 7	40 mins Telephone	-	65 mins Face to face	-
Session 8	55 mins Face to face	-		-

Note: Mins = minutes

The positives and difficulties of delivering BEAMD were identified from the therapist interviews and session support forms. Suggestions for BEAMD were also identified. A detailed summary is provided in Appendix 5.5 and the key points are summarised below.

5.3.6.1 Positives. The following positives were identified:

- For one dementia participant (Ruth) the workbook became a good focus during the assessment session and the concept of homework was understood.
- The ‘Low mood and fewer activities cycle’ diagram in the workbook (page 11) worked well, however maybe more so for the carers.
- Cognitive difficulties did not appear to be a problem all the time. In some assessment sessions the participants did not seem to struggle with recall or comprehension.
- Supporting BEAMD over the telephone worked well after sorting initial minor issues with telephone battery life and understanding of teleconferencing.

5.3.6.2 Difficulties delivering BEAMD. The following key difficulties delivering BEAMD were identified:

- Participants experienced difficulties across several aspects, including understanding and comprehending the BA model (Richards, 2010); completing the workbook; carer involvement in supporting BEAMD; and assessment of depression.
- Participants with dementia had difficulty remembering the rationale and understanding the link between behaviour and mood (with faces depicting mood on workbook pages 14 and 15). Several parts of the intervention were too complex and confusing for participants, including the Five Areas™ model (Williams & Garland, 2002) and the identification, organisation and planning of activities. Confusion also existed around the different types of activities (routine, necessary and pleasurable activities) (Richards, 2010). Both the dementia participant and carer also had difficulties completing the relapse prevention section.
- There were also several difficulties with activities or suggested activities, and problem solving was necessary to identity and simplify activities. Suggested activities were limited by physical health problems and completing activities was dependent on physical ability on the day. For some activities, such as driving, the therapist found it was not possible to create a functional equivalent. Additionally there was anxiety at engaging in activities the participant felt they may not be able to do.
- Dementia participants experienced difficulties engaging with the workbook, did not complete the workbook between sessions, and became anxious at the thought of completing it incorrectly. The carers did not complete the workbook for the dementia participant, identifying it as their partner's programme. There were also difficulties recalling information from the workbook, remembering the purpose of exercises, and navigating around the workbook. The therapist was also unsure about comprehension of the vignette.
- The therapist found it difficult to keep the support sessions within the set time. There were several reasons for needing extra time in the support sessions including: participants experiencing difficulties with understanding and comprehension; dementia participants needing time to think; having to re-orientate and upskill the person with dementia (and sometimes the carer) in each session; needing to take the person with dementia through each step of the intervention; dealing with the

dementia participant’s anxiety at completing the next step; and a pre-occupation and focus on physical health problems. The therapist also found the sessions going off in different directions and found it harder to interrupt someone who was struggling to give information.

- For one carer, supporting the programme created additional pressure and one session needed to be used to help with carer distress.
- All dementia participants had difficulties responding to the GDS-15. The GDS requires a binary ‘Yes’/‘No’ response, however, participants wanted to quantify the amount of time or respond ‘sometimes’ to the questions rather than simply providing a binary response.
- Other key difficulties identified by the therapist were regarding cognitive abilities and physical health. There were difficulties remembering parts of the intervention, following the conversation and recalling events or agreed points. Having a poor memory also made filling out the diary difficult. There was also a pre-occupation with ill health and physical health concerns, and a concern about sorting out the physical health problems rather than mental health.

5.3.6.3 Suggestions for BEAMD. Based on his experience of supporting BEAMD, the therapist suggested some ideas for future iterations or delivery of BEAMD. These suggestions are detailed in Appendix 5.5, with some of the key points summarised below.

- It may be an idea to focus more on pleasurable or purposeful activities and not focus on understanding routine, necessary and pleasurable activities (given routine activities did not seem to be a problem due to carer involvement supporting these activities).
- Providing a checklist of pleasurable activities would save time as the person with dementia spent some time thinking of activities.
- A greater understanding of what the person with dementia can and cannot do is needed, which could be achieved by way of a checklist. It is also important to understand sleeping, functional impairments, comprehension, recall, eyesight and barriers to physically filling in the workbook.

- As participants receiving BEAMD wanted to complete activities in a single attempt, it might be important to highlight that activities are better completed ‘little and often’.
- It may be beneficial at the start of BEAMD to determine current demands being placed on the carer. This would permit greater consideration regarding the impact of activities (generated as part of BEAMD) on both the person with dementia and the carer, and whether the carer has the time and ability to provide the required support.
- It may also be beneficial to see the carer separately in each session to help develop an understanding of what is happening.
- A separate workbook is needed for the carer about their role. Carers should complete their own observational diary about the person with dementia and could independently rate mood and pleasurable activities for the person with dementia.
- Be more explicit about the carer engaging in the homework and doing it alongside the person with dementia.
- More support needed for carer mental health.
- The therapist felt the intervention could be delivered at a quicker pace by therapists who have greater clinical experience working with people with dementia.

5.3.7 Acceptability of BEAMD

Comments from the interviews with dementia participants and carers regarding the acceptability of BEAMD are summarised below with a more detailed summary provided in Appendix 5.6. The carers commented on the acceptability of BEAMD for themselves as well as their partners.

5.3.7.1 Workbook. Positive comments were made regarding the workbook, specifically the layout, format, content and helpfulness of the workbook. However, carers reported that both dementia participants experienced some difficulties with the workbook, particularly difficulties with understanding. Eric himself identified a difficulty with remembering the content of the workbook the following day. As a carer, Pam indicated she found it difficult to know what content to write into the diagrams and difficult to understand what Eric might be feeling. Pam felt what she would write may be different to what Eric is feeling and Eric is slow making decisions about what he thinks. Brian reported difficulties with respect to Betty reading the workbook due to macular degeneration. Interestingly however, Betty reported being able to read the information sheet, written in a smaller font than that of the workbook, quite well. She did, however, indicate that she was sometimes reluctant to fill in the workbook, seeing it as a task. Negative aspects of the workbook included the amount of information, and difficulties relating to the vignette with regards to age and physical ability. Brian did not like some of the language in the workbook as he felt it created negative thoughts or ideas of failure. Additionally, Brian also disliked the objective of completing worksheets and homework, as non-completion created distress and worry.

5.3.7.2 Support sessions. The telephone support sessions were acceptable and well-received as it saved travelling to the AccEPT Clinic. However, Pam also felt it was nice to go out for the face to face support sessions. Brian commented on the positive social contact that attending the Clinic had, including talking to the therapist and the Clinic receptionist. Betty felt the support sessions sometimes ended quicker than she would have expected, but was aware that the therapist’s time was limited. The therapist was well-liked by participants and was described as knowledgeable and understanding. One negative, however, was that Brian felt an insufficient account was taken of Betty's physical capabilities and the activities Betty could no longer do were not established.

5.3.7.3 Carer involvement. As a carer involved in supporting BEAMD, Brian was happy to support and saw the benefit of social contact for Betty. The intervention also made him think about what he does with Betty and provided insight into ways to help. No comments were made about the impact on himself. Contrastingly, Pam reported that a lot of the intervention fell onto her, which in turn created a lot of pressure.

5.3.7.4 Suggested changes. The suggested changes to the workbook included changes to the design, layout and tone. These included guidelines on the diaries, additional diary sheets, having the vignette in one place and changing the language or tone of the workbook to avoid suggesting the possibility of failure. Brian’s dislike of completing homework and associated feelings of failure resulted in suggestions that a diary be used rather than the worksheets, and that activities are not planned on specific days to help avoid feelings of failure. Brian also suggested that only the carer should be involved in relapse prevention as it would save reminding the person with dementia that they may feel depressed again. Another suggested change was the need to establish activities that are realistic for the person with dementia, as activities cannot be generalised. Additionally, Pam felt the severity of dementia also needs to be established.

After Pam indicated the intervention created pressure for her, she was asked whether it would be an idea to include a session on how the carer is feeling. She felt this would be an idea as some people can cope whilst others cannot. She suggested this should include what sort of support people can get and from who, having previously commented she does not know when and who to ask, and what they can do.

5.3.8 Outcome Measures

Scores on both the self-rated and clinician administered depression measures decreased for both participants completing BEAMD, with a smaller decrease in self-rated carer mood (Table 5.5). However, there was no change in the overall quality of life score or environmental reward. Overall two items were missing on the DQoL (Betty) and one item on the GDS (Eric) (see Table 5.5). It was, however, still possible to score the measures with the missing items (The Lewin Group, n.d.; Yesavage & Brink, n.d.). The overall quality of life score (DQoL) is a single score from a single item (The Lewin Group, n.d.), and is therefore unaffected by the missing items on the different scales.

Visual inspection of Eric’s GDS-15 scores (Figure 5.3) shows a decrease from the first to last session, with a small increase in session 3. After inspecting the session support form completed by the therapist there were no details recorded that might explain this increase. For Betty the session support form for session 5 indicated she had felt more anxious that week due to her husband’s illness. This may, potentially explain the higher score for session 5 (Figure 5.4). The decrease from session 5 coincided with Betty having had a good 2 weeks with birthday celebrations, which she felt had greatly helped her ‘spirits’.

Table 5.5 *Outcome Measures*

	Eric		Ruth		Betty		Ron	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
GDS-15	11	0*	12	-	7	4	9	-
CSDD	6	0	15	-	7	0	17	-
DQoL (Overall)	3	3	2	-	3	3	3	-
Self-esteem	2	3.75	2.25	-	3	3*	3.25	-
Positive affect/ humour	2.67	3	2.5	-	4	4	4	-
Negative affect	2.82	1.64	2.91	-	2.82	2.7*	3.1	-
Feelings of belonging	3	3.67	2.33	-	3.67	3	3.33	-
Sense of aesthetics	3	3.4	3	-	3.4	3.2	3.4	-
EROS	2.8	2.9	2.2	-	2.9	2.9	2.7	-
PHQ-9 (carer)	7	5	4	-	3	2	13	-

Note: GDS-15 = Geriatric Depression Scale-15; CSDD = Cornell Scale for Depression in Dementia; DQoL = Dementia Quality of Life; EROS = Environment Reward Observation Scale; PHQ-9 = Patient Health Questionnaire-9; * = 1 item missing

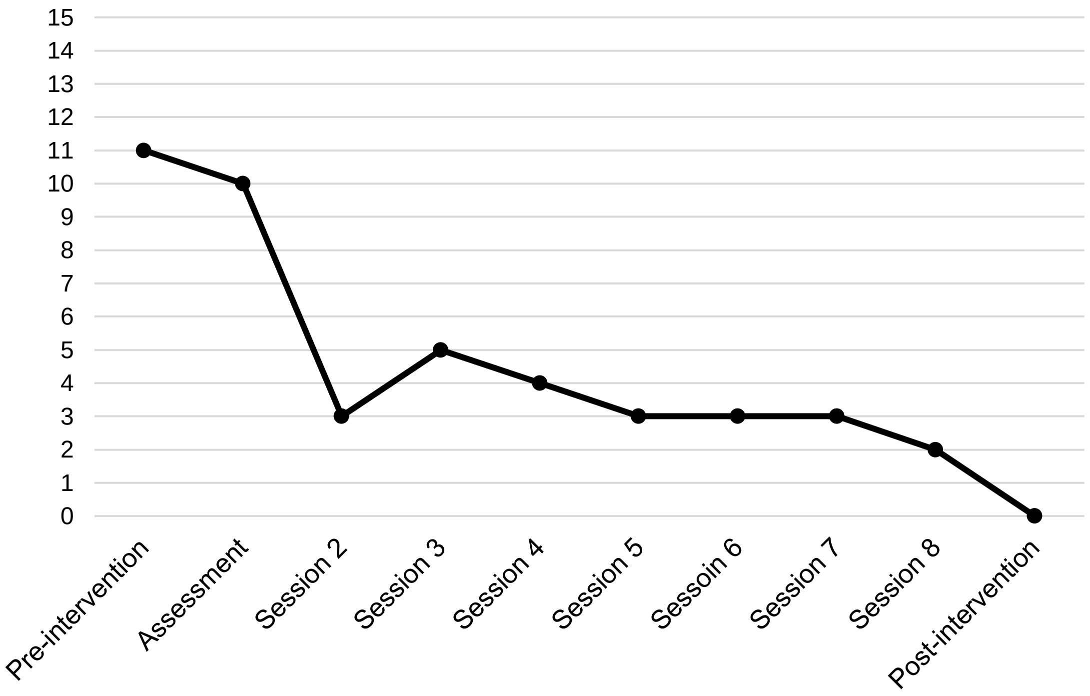


Figure 5.3 Geriatric Depression Scale-15 Scores for Eric

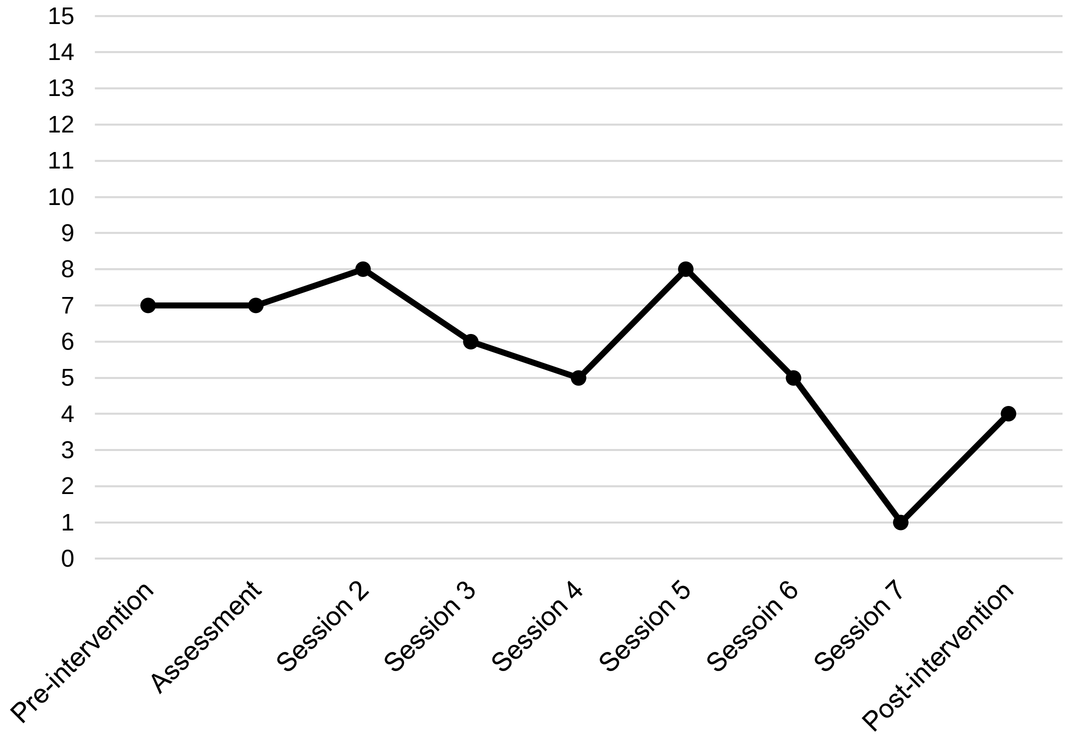


Figure 5.4 Geriatric Depression Scale-15 Scores for Betty

5.4 Discussion

This case series was conducted to investigate the key uncertainties identified during the development of BEAMD (Craig et al., 2008; MRC, 2008). These key uncertainties were the ability to recruit dyads to receive BEAMD, the acceptability of the developed intervention, and the feasibility of delivering BEAMD. These were investigated to inform any necessary further development of BEAMD. Data was also collected on the acceptability and feasibility of research methods, materials and measures to inform future research.

Difficulties were experienced recruiting dyads into this study. Only 12 of the 83 (15%) potential dementia participants that were contacted expressed any interest in participating or meeting the researcher to discuss the study in more detail. Reasons for non-participation included a lack of informal carer support, a lack of time, not feeling low, difficulties with distance and travel to the AccEPT Clinic, and poor physical health. The lack of carer support as a reason for non-participation was unsurprising given that the requirement to involve a study partner (in dementia research) is a barrier if people do not have access to a partner (or the study partner is not able to provide the support needed) (Alzheimer’s Disease International, 2014; Watson, Ryan, Silverberg, Cahan, &

Bernard, 2014). Only 10 potential dementia participants were interested in participating after meeting the researcher, with five of these meeting the eligibility criteria, and one eligible individual subsequently deciding not to participate. Of the four dyads that were eventually recruited into the study, two were discharged after the assessment session (due to increased medical morbidity). Difficulties with recruitment had been expected, as recruitment issues are a major problem in dementia research (Cohen-Mansfield, 2002). As such, attempts were made at the outset to address potential difficulties. For example, the carer inclusion criteria was kept minimal (with dementia participants only required to have some form of daily contact with the carer) in the hope that more carers would then meet the criteria, and travel expenses were offered to cover the cost of attending support sessions. However, recruitment difficulties were still experienced.

Some of the difficulties experienced with recruitment, however, may be due to the small scale of this study and limited resources. Recruiting participants into this study may have been made more difficult by the limited availability and location of support sessions that could be offered to participants, which may have made engaging with the study even more difficult for potential participants. Firstly, with the limited resources available for this study it was only possible to support BEAMD within the AccEPT Clinic at the University of Exeter. Participants were recruited from the Exeter Memory Clinic (which covers a wide area) and difficulties with distance and travel to the University were identified as reasons for non-participation. Additionally, comments indicated that the time to travel to the Clinic was problematic and that the travel would have a subsequent impact on the person with dementia and levels of tiredness. Delivering BEAMD locally, or in participants' homes, may help to overcome this barrier to participation and improve recruitment into the study. Secondly, the therapist was only able to offer support sessions between 8am and 4pm on Tuesdays and Wednesdays. Adult-child carers who are employed, or may have children, are likely to face increased logistical challenges to participating in research (Grill, Monsell, & Karlawish, 2012). The need to attend BEAMD support sessions during working hours may, potentially, have made participating in the study more difficult for carers who are employed. Indeed, children working (and therefore not able to provide support) was given as one of the reasons for non-participation in this study. This, however, may not be such an issue if BEAMD was supported in an IAPT service, given that IAPT services can be provided outside of normal working hours. Nevertheless, support for BEAMD is also needed between support sessions (in addition to attendance at the session) and some carers may not be able to provide this support.

When it became clear there were difficulties with recruitment, additions to the recruitment strategy were discussed. Recruiting from additional sites (or from the community) may have made recruitment more feasible. However, the use of multiple sites and/or community services was not feasible in this study for two reasons. Firstly, with support sessions only provided at the AccEPT Clinic in the University of Exeter, this meant recruiting from the other Memory Clinics in Devon (Torbay and North Devon) would not be feasible due to the distance from Torbay and North Devon to Exeter. This would have been too far for participants to travel to sessions (with it necessary to attend at least the assessment session in person) and travel expenses could not be covered by the limited budget. Indeed, even potential participants identified from the Exeter Memory Clinic felt it was too far to travel to the University. Secondly, to recruit from the community (for example from memory cafes) an amendment would have been required to allow access to medical records for potential participants (to confirm their dementia diagnosis). There was, unfortunately, insufficient time to submit the amendment to the Ethics Committee, wait for approval and then recruit participants before the end of the allocated therapist time in the AccEPT Clinic. However, if feasible, the use of multiple settings and services should be considered for future studies.

With regards to the feasibility of BEAMD, overall there were challenges experienced delivering BEAMD as currently developed. Nearly all the support sessions were longer than the designed time, there was a lack of engagement with the workbook (from both dementia participants and carers) and several parts of the intervention were too complex. Although there were some positive comments regarding the therapist, workbook and telephone support, participants still experienced difficulties understanding and completing the workbook. Additionally, participants disliked some aspects of the workbook, including the amount of information and the language used. These findings suggest changes are needed to make BEAMD more feasible and acceptable.

To help develop the intervention the findings have been used to inform potential modifications to BEAMD and to provide suggestions for future delivery.

These are discussed below (see Section 5.4.3). As with previous research (Hind et al., 2010) this study has highlighted the need to modify and adapt interventions to ensure they are acceptable, and feasible, in people with long term conditions (LTCs). With the small scale of this study (and with only two dyads completing the intervention) it is not possible to determine whether a guided self-help approach is acceptable and feasible in people with dementia (or whether this approach should be rejected). Following the suggested modifications to BEAMD it would be necessary to conduct a larger feasibility study to determine the suitability of this approach for people with dementia.

5.4.1 Strengths

One of the strengths of this case series is the work, and effort, that went into ensuring the study could run and recruit. Without establishing a relationship with the Memory Clinic, and ensuring the introduction of a depression measure into the Clinic's assessment, it would have been harder to identify potential participants for this study. Additionally, when recruitment difficulties were faced, efforts were made to amend the protocol, making it much easier to contact potential participants. Secondly, best practice was followed in this study; the depression and quality of life measures utilised have been validated in people with dementia and several of the measures used (CSDD, GDS-15 and DQoL) are recommended for psychosocial intervention research in dementia care (Moniz-Cook et al., 2008). The qualitative data collected in this study has enabled a clear understanding of the barriers to recruitment and has provided detailed feedback on intervention acceptabiltiy and feasiblity. The therapist interviews also provided the opportunity for practitioner input on potential modifications to the intervention, based on the therapist's experience of supporting BEAMD. With feasibility studies conducted to help develop interventions (Abbott, 2014), the interviews conducted within this study were essential to inform further development of BEAMD.

Importantly, a good working relationship and rapport was established with the dementia participants and carers in this study, with SH meeting all participants on multiple occasions (discussing the study with participants, obtaining consent and collecting pre- and post-intervention measures) before conducting the interviews. Interviewers need to establish a relationship with interviewees that will facilitate the interview process (Taylor, 2005), and having established rapport, participants were happy to be interviewed and respond to the questions (with the exception of Betty becoming too tired to be interviewed, although no problems were experienced in her rescheduled interview). This rapport may have helped participants to feel more comfortable giving their honest views and opinions on BEAMD. Even though participants were aware SH had developed the intervention and written the workbook, a factor that could have impacted on their willingness to express negative opinions, participants were encouraged to be honest (with it stressed that feedback would help to develop the intervention) and both positive and negative comments were made by participants during the interviews.

5.4.2 Limitations

It is important to discuss the limitations of this study. Firstly, with only two dyads completing BEAMD our understanding of the acceptability, feasibility and delivery of the intervention is limited. With a small sample size, data on acceptability and feasibility may not be generalisable to other individuals with dementia. For example, BEAMD may be more acceptable or feasible in younger dementia participants or people with very mild dementia. However, some of the suggested modifications (see below) may still be appropriate and/or beneficial for other dementia participants. Additionally, with only one therapist involved in supporting BEAMD in this study, comments made by the therapist (during the feasibility interviews) may not reflect the thoughts or opinions of other therapists or practitioners more commonly employed to support BA guided self-help interventions, or practitioners more experienced with dementia. Secondly, as highlighted above, the participants were aware SH had developed the intervention and there is a possibility that this could have impacted on their responses. However, with limited resources available for this study it was not possible for the interviews to be conducted by a researcher who had not been involved in the development of BEAMD.

Finally, only one self-report measure, completed by the dementia participant, was collected during support sessions. Despite the validation of the GDS-15 in people with mild to moderate dementia (Feher et al., 1992; Isella et al., 2001), participants experienced some difficulties responding to the measure. Including an informant rating of depression during the support sessions (alongside the dementia participant’s self-report) may have increased confidence in the accuracy of the self-reported scores.

5.4.3 Implications for Intervention Development

The findings from this case series have been used to inform suggested modifications to BEAMD and suggestions for future delivery. These are discussed below.

Simplifying BEAMD further. It is clear that participants had difficulties understanding the intervention, suggesting simplification may be needed. Two aspects of the intervention that could be simplified are i) Step 2 in the intervention (see workbook pages 18 to 27, Appendix 4.4), as participants found the identification, organisation and planning of activities confusing and ii) the categories of activities (routine, pleasurable and necessary (Richards, 2010)) as confusion existed around the different types of activities.

As currently designed, Step 2 in BEAMD includes the identification, organisation and planning of activities. However, this step appears to be too complex and confusing. It may, therefore, be more appropriate to slow the pace of the material and to split Step 2 into smaller steps. Each of the smaller steps could then be focussed on in different support sessions and as homework between the sessions. Indeed, the use of smaller steps at each session and smaller homework assignments is one way in which BA has been adapted for older adults with cognitive impairment (Pasterfield et al., 2014), and this may be more appropriate for BEAMD. When dementia participants are involved in support sessions (as with BEAMD) it may be that more sessions spread over a longer period of time (to allow the pace to slow down) is more appropriate for guided self-help. However, it would be necessary to investigate whether this pace is feasible and acceptable to participants receiving the intervention.

Additionally, the categories of activities that form the basis of the BA protocol (Richards, 2010) used in BEAMD may need to be simplified. This would also help to simplify Step 2. Based on the therapist’s experience in this study, routine activities were not problematic for the participants as the carers were involved in routines. Focussing purely on pleasant activities may be more appropriate and help to ease the confusion over the types of activities. This would be more consistent with other BA interventions delivered to people with dementia, with these focussed on increasing pleasant activities (Teri et al., 1997; Verkaik et al., 2011) rather than different types of activities (such as routine and necessary activities). Simplifying the intervention, and/or slowing the pace of the material, may help to keep support sessions within a maximum of 40 minutes.

Carer involvement. In this case series there was a lack of carer involvement, particularly with regards to the carers not completing the workbook. Equal partnership and active collaboration with carers is a facilitating factor for delivering interventions that involve family carers (Eassom, Giacco, Dirik, & Priebe, 2014). Therefore, it is important to mobilise carer support and active engagement at the beginning of the intervention. At the start of the intervention current demands on the carer should be determined. There should also be questions addressing whether the carer has the time and ability to support BEAMD (and activities generated as part of the intervention). This may help to determine if the carer is engaged and willing to participate, and may also reduce the potential for additional burden or pressure on the carer created by supporting BEAMD (as experienced by Pam).

A more active carer role in BEAMD could also be created with the use of a separate carer workbook, with carers completing their own observational diaries (worksheets) for the person with dementia. As the dementia participants experienced difficulties completing the worksheets, having the carer complete an observational diary may help to provide more details on the dementia participant’s current activities. Furthermore, with the addition of a workbook for the carer, the emphasis would not be solely on the completion of the worksheets in the dementia participant’s workbook. This may help to reduce the anxiety the dementia participants felt with regards to completing the workbook incorrectly. Two workbooks (one for the person with dementia and one for the carer) are currently being used in a more recently developed BA written self-help intervention for mood, wellbeing and quality of life in people with dementia (PROMOTE) (Farrand et al., 2016).

Developing a separate workbook for the carer in BEAMD could also provide the opportunity to include additional information to help with carer burden and to address any carer mental health concerns. This is a particularly important consideration given the prevalence of depression and anxiety in carers of people with dementia (Sallim et al., 2015). One support session could also be used to address carer depression, stress and burden, as included in other BA interventions for depression (Mitchell et al., 2009; Teri et al., 1997), with Pam indicating that a session on how the carer is feeing may be needed.

This session could also address where support for the carer could be obtained from and carers could be signposted to support or referred to supportive agencies.

Case study. Participants found it difficult to relate to the vignette in the workbook with regards to the age and physical abilities of ‘Bernard’. With the prevalence of comorbid medical conditions in people with dementia (Bunn et al., 2014; Dowrick & Southern, 2014) the case study may need to be modified to include physical health difficulties for ‘Bernard’. It is also important to think about the multi-morbidity in people with dementia, with a survey of people with dementia in England, Wales and Northern Ireland finding some respondents were living with up to 12 other medical conditions (or disabilities) (Dowrick & Southern, 2014). Alternatively, rather than just modifying the ‘Bernard’ vignette, a couple of case studies could be provided in the workbook with a range of physical health and cognitive difficulties to highlight the heterogeneous nature of dementia. However, the practicality and feasibility of this would need to be considered.

Assessing depression in support sessions. Although participants expressed difficulties with the dichotomous system of responding to the GDS-15, the GDS is a valid measure of depression in mild to moderate dementia (Feher et al., 1992; Isella et al., 2001). However, there can still be difficulties with self-reporting in people with dementia, with deficit awareness affecting the accuracy of self-reported depression (Snow et al., 2005). It may, therefore, be beneficial to also collect a carer rating of depression during support sessions. Logsdon and Teri (1995) have modified the GDS to allow a carer to complete the measure, with the internal consistency of the measure comparable to the self-report version. The GDS could therefore be completed by both the dementia participant and carer during support sessions. However, the BEAMD manual would need to address what would happen if there was a substantial disagreement between the carer and dementia participant ratings.

Delivery. BEAMD should be delivered flexibly to accommodate carer availability, travel difficulties and physical health problems. As discussed above, for adult-child carers of people with dementia, other commitments such as employment may mean they face increased logistical challenges to participating in research (Grill et al., 2012), or in this instance participating in support sessions. Support sessions may, therefore, need to be outside of working hours to enable adult-child carers to support the intervention and attend sessions. BEAMD could also be supported in community settings, participants' homes or via the telephone to overcome difficulties with travel or location.

Additionally, it may be helpful to provide flexibility over i) the scheduling of support sessions and ii) the scheduling of activities in the intervention to accommodate challenges presented by other comorbid medical conditions. Support sessions may not be weekly depending on the physical health of the person with dementia each week or the sessions may need to be arranged around hospital appointments. With regards to activities, the dementia participant's ability to engage with the intervention and activities may be dependent on their health on the specific day. Pacing (an adaptation to BA identified in Study One) may be necessary to take into account limited functioning or comorbid physical health conditions. This involves providing greater flexibility when scheduling activities or setting goals, for example completing an activity in the next 3 to 5 days rather than on a specific afternoon (Turvey & Klein, 2008). This would allow for good and bad days and variations in functioning. Not planning activities on specific days was also suggested in Brian's acceptability interview to help avoid feelings of failure. Completing a questionnaire of comorbid physical health conditions and functional impairment at the beginning of BEAMD (which could be completed by the person with dementia, the carer or both) would provide practitioners with a greater understanding of how the individual's physical health may impact on their ability to complete activities.

Support sessions. It may be beneficial to consider the involvement of the person with dementia in the support sessions, especially as the need to re-orientate and upskill the dementia participant, and to allow them time to think, contributed to the additional length of the sessions. It may be more appropriate for the carer and person with dementia to be involved in varying degrees, for example some sessions involving only the carer, as in other BA interventions for people with dementia (Farrand et al., 2016; Teri et al., 1997). This, in addition to the simplification of the intervention, may help to keep support sessions to time and make the delivery of BEAMD more feasible.

Practitioner supervision. The therapist commented the intervention could potentially be delivered at a quicker pace by practitioners more experienced with dementia. Regular supervision (for the practitioner supporting

BEAMD) with experienced dementia practitioners or professionals is important and may help to increase the speed at which the intervention could be delivered. Supervision may help to address difficulties the therapist experienced with regards to memory deficits in participants. The specialist supervision could also provide guidance on the best way to support dementia participants who are not able to remember the intervention content. Research on IAPT practitioners supporting people with LTCs and mental health problems has highlighted the importance of specialist training and supervision (Highfield et al., 2016). Additionally, it has been proposed that input from specialists (clinical health psychologists) may be beneficial when delivering interventions to people with LTCs with regards to supervision, sharing experiences of LTCs and training/teaching (Kellett et al., 2016).

5.4.4 Implications for Future Research

Following the above suggested changes to BEAMD, feedback on this second iteration of the intervention would need to be sought from service users and experts in dementia and/or CBT/BA guided self-help. After receiving this feedback (and making additional modifications that arise from the feedback), the feasibility and acceptability of the modified intervention would need to be investigated (see Chapter Six for a detailed discussion of future research). The findings from this study present the following implications for the conduct of a future study investigating the next iteration of BEAMD:

- The information sheets and consent forms appear to be understandable, however the title of the research could be simplified.
- To help overcome some of the identified barriers to participation (specifically the difficulties with distance and travel, and a lack of carer support due to work) BEAMD should be delivered more flexibly with regards to the location and time of support sessions. Additionally, recruiting from various settings (including NHS services and community outreach) may aid recruitment.
- Follow-up calls to non-responders were key for increasing contact with potential dementia participants and should therefore be utilised in future research.
- Although a few items were missing on the outcome measures it was still possible to score the measures with the missing items. Any future research for BEAMD should continue to collect these measures as well

as including a carer rated GDS (Logsdon & Teri, 1995), as discussed above.

5.4.5 Chapter Five Summary

The study presented in this chapter was conducted to help develop BEAMD. The key feasibility and acceptability uncertainties of the intervention were investigated. Difficulties were experienced with recruitment to the study and issues regarding the feasibility and acceptability of the intervention were highlighted. The findings from this study have helped to inform potential changes to the intervention and the conduct of any future research investigating the acceptability and feasibility of BEAMD. The MRC framework is an iterative approach to developing and evaluating interventions (Craig & Petticrew, 2013), and following the findings from this case series more development of the intervention, and investigation of feasibility and acceptability, is needed.

Chapter Six: General Discussion

This chapter presents a general discussion of this programme of research including:

- A brief summary of the rationale for this dissertation.
- A summary of the aims and objectives of this dissertation.
- A summary of the studies included in this dissertation and the main findings from each study.
- A discussion of the strengths and limitations of the research.
- A consideration of the contributions of this research and the practical and clinical implications arising from the research findings.
- An overview of potential future research.
- An overall conclusion.

6.1 Dissertation Summary

Around 15 million people in England are living with one or more long term condition (LTC) (DoH, 2012a), “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies” (DoH, 2012a, p. 3). This figure is projected to increase to around 18 million people by 2025 (House of Commons Health Committee, 2014). Depression is common in people with LTCs (Egede, 2007; Moussavi et al., 2007) and is associated with a decrement in health (Moussavi et al., 2007), worse quality of life (Goldney et al., 2004; Yohannes et al., 2010), higher degrees of functional disability (Egede, 2007) and an increased risk of mortality (Barth et al., 2004; Satin et al., 2009). Targeting and treating depression in people with LTCs is therefore important, and there has been increased efforts to ensure the treatment of depression in people with LTCs in England, with the Improving Access to Psychological Therapies (IAPT) programme extended to support the psychological needs of people with LTCs (DoH, 2011).

Meta-analyses have shown psychological interventions can improve depression in people with LTCs, but the reported effect sizes have generally been small to moderate (Dickens et al., 2013; Farrand & Woodford, 2015; Rizzo et al., 2011; van Straten et al., 2010; Whalley et al., 2014; Xing et al., 2016). As such, there is a need for continued development in psychological therapy for people with LTCs. One potential candidate for additional development is behavioural activation (BA), a structured psychotherapeutic approach reported to be as effective as CBT for depression in adults (Cuijpers et al., 2007; Ekers et al., 2008; Mazzucchelli et al., 2009; Richards et al., 2016) whilst also more cost effective (Richards et al., 2016). Additionally, meta-analyses have reported moderate-to-large effect sizes for BA as a treatment for depression in adults (Cuijpers et al., 2007; Ekers et al., 2008; Ekers et al., 2014; Mazzucchelli et al., 2009). BA interventions are simple, making them suitable for a wide range of populations (Mazzucchelli et al., 2009). Low intensity interventions based on BA techniques are recommended for depression in people with LTCs (NICE, 2009) and for some LTCs it is recommended that cognitive behavioural therapy (CBT) becomes more behavioural, for example focussing on BA for depression (Kneebone, 2016).

6.1.1 Aims and Objectives

The overall aim of this programme of research was to develop a BA intervention for depression in people with a LTC. This dissertation consisted of three studies that formed part of the development of the intervention: a systematic review (Study One), qualitative interviews with carers and people with dementia (Study Two) and a preliminary feasibility case series (Study Three).

- Study One was conducted to identify the evidence base for BA in LTCs (Craig et al., 2008; MRC, 2008), to identify a LTC to target for intervention development and to inform the development of a BA intervention in this dissertation.
- After the initial development of the intervention (BEAMD), Study Two was conducted to consider the acceptability of the intervention workbook; to refine and modify (if necessary) the developed workbook (before Study Three); to identify potential benefits of, and barriers to, the intervention; and to inform delivery.
- Study Three was conducted to help develop BEAMD and inform future research by: investigating the feasibility of delivering BEAMD and intervention acceptability; collecting preliminary outcome data; and collecting data on research methods, materials and measures.

6.1.2 Study One

A systematic review of BA interventions for depression in people with LTCs was conducted. Multiple databases were searched with a predefined search strategy and LTCs were screened for manually. The comprehensive search also included the reference lists of potentially relevant reviews, contact with authors and forward and backward citation searching. Abstract and full text screening, data extraction and quality assessment were conducted by two independent reviewers.

- 10 observational studies and 8 randomised controlled trials (RCTs) were included in the review. LTCs included cancer, dementia, stroke, arthritis, colitis, vascular disease and multiple conditions. Only one study, focussed on stroke patients, was conducted in the UK.
- Simple BA interventions were delivered in 13 studies, with complex BA interventions delivered in the other five studies. Nearly all of the interventions included adaptations to accommodate the specific LTC. Key adaptations identified in the review (and subsequently incorporated into BEAMD) included: the use of appropriate materials/resources; tailoring of the materials to the LTC; the involvement of patients in the development of materials; involving carers in the intervention; and adapting activities to be accomplished with new limited functioning.
- Studies reported improvements in depression (in participants with cancer, dementia and nursing home residents), and significant findings ($p \leq 0.05$) were reported compared to control (in participants with dementia, stroke and nursing home residents). The majority of the significant findings were reported for neurological disorders.
- Overall the quality of the included studies was sub-optimal. No RCTs were rated low risk of bias across all domains.

6.1.3 Study Two

Informal carers and people with dementia were recruited from Memory Cafes and groups in Devon. The participants were presented with the first draft of the workbook and interviewed about their thoughts and opinions on the intervention and the developed workbook.

- Positive comments were made about the workbook, suggesting the design, layout and simplistic language may be acceptable. However, a concern over the quantity of information was raised.
- Participants felt BEAMD may be appropriate for people with mild to moderate dementia. However, some people with these severities may

still face difficulties with the intervention. Potential difficulties with reading the workbook and completing worksheets were also identified

- Several participants preferred the term ‘memory problems’ to ‘dementia’ as some people may not think, or may forget, they have dementia.
- The majority of participants felt the inclusion of example tables for the vignette would be useful.

6.1.4 Study Three

Participants with mild to moderate dementia and comorbid depression (and their informal carer) were recruited from the Exeter Memory Clinic to receive BEAMD. Data was collected on: the feasibility of recruitment, the delivery of BEAMD and completion of outcome measures; the acceptability of research methods, materials and measures; and the acceptability of BEAMD. The therapist was interviewed after the first and last support session for each dyad and the dementia participants and carers were interviewed after receiving BEAMD.

- Difficulties were experienced recruiting dyads to receive BEAMD. Only 15% of potential dementia participants were interested in participating or discussing the study further and only four dyads were recruited into the study. Some of the main reasons for non-participation included a lack of informal carer support, not feeling low, poor physical health and difficulties travelling to the intervention delivery site.
- Difficulties were experienced delivering BEAMD as currently developed. The therapist experienced difficulties keeping support sessions to time and parts of the intervention were too complex. Additionally, participants experienced difficulties with understanding and comprehension and there was a lack of dementia participant and carer engagement with the workbook. However, some positive comments were made about the therapist, workbook and telephone support.
- The findings were used to inform potential modifications to BEAMD and future delivery of the intervention, including: simplification of the intervention; more active carer involvement; collecting an informant rating of depression; delivering BEAMD flexibly; and ensuring specialist dementia supervision.

6.2 Strengths of this Dissertation

A key strength of this dissertation is the use of the revised Medical Research Council (MRC) framework (Craig et al., 2008; MRC, 2008) to inform the overall programme of research, ensuring BEAMD was developed systematically with the best available evidence and appropriate theory used to inform development (Craig et al., 2008; MRC, 2008). Informed by the MRC framework, a systematic review (Study One) was conducted to identify the evidence base and to inform the development of the intervention. A published protocol for Study One was followed to reduce the risk of introducing bias (CRD, 2009) and best practice was used when conducting the review. Guidance (CRD, 2009) was followed to ensure rigorous methods were used including: a comprehensive search for studies; the use of two independent reviewers to minimise errors, improve reliability and reduce potential bias (CRD, 2009; Higgins & Deeks, 2011); the use of a standardised data extraction form to ensure consistency, reduce bias and improve validity and reliability (CRD, 2009); and the identification and inclusion of unpublished studies to reduce the potential for publication bias.

Another important strength of this dissertation is the involvement of people with dementia (as well as carers) in the development of BEAMD (Studies Two and Three). This provided the opportunity for the views and opinions of people with dementia (rather than solely carers and/or experts) to inform the development and delivery of BEAMD, thereby increasing the potential to develop an acceptable intervention for the population. Importantly, potential participants in Study Three were identified from a Memory Clinic database and were not selectively recruited. Moreover, Study Three did not exclude participants lacking the capacity to consent, making this more representative of patients with dementia.

As with Study One, best practice was also used when conducting Studies Two and Three. In Study Two methodological strategies were incorporated to strengthen the trustworthiness of findings, with two researchers independently coding transcripts (Johnson & Waterfield, 2004; Lietz et al., 2006; Patton, 1999) and disconfirming cases examined to ensure the validity of findings (Mays & Pope, 1995; Patton, 1999). Additionally, in Studies Two and Three, SH was reflexive, considering what the participants knew about the researcher (Tong et al., 2007) (i.e. her involvement in developing the intervention) and any impact this may have had on the findings. Finally, in Study Three, the depression and quality of life measures used have been validated in people with dementia and several of the measures have been recommended for psychosocial intervention research in dementia care (Moniz-Cook et al., 2008).

6.3 Limitations of this Dissertation

Due to the limited time and resources available for this programme of research there are a number of limitations. In Study One a lack of translation facilities resulted in studies without an English translation being excluded from the review. This may have resulted in potential studies being missed and the review may not have identified the full extent of the evidence base for BA in LTCs. Additionally, the exclusion of non-English studies may have biased the findings and conclusions from Study One as positive studies are more likely to be published in English (Egger et al., 1997). However, as discussed in Chapter Three, it is possible that the 19 non-English studies may not have met the eligibility criteria due to the cautious and over inclusive approach to screening. Ongoing studies or other unpublished research may also have been missed in Study One as trial registries were not searched as part of the search strategy.

The limited time for this programme of research, resulting in a tight time frame for the development of the intervention, may also have impacted on the findings from Study Two. Participants in Study Two were only able to view the workbook during the interview. With additional time it would have been possible to enable participants to view the workbook before the interviews, which may have generated more ideas and suggestions for potential changes to the workbook. More suggestions regarding the simplification of the workbook may also have been generated with additional time, or with additional participants. With only one participant in Study Two suggesting the workbook should be simplified, and with limited time for this programme of research, the decision was made to not simplify the workbook before Study Three, and to see if simplification was needed after participants had received the intervention (Study Three). Comments made in the acceptability and feasibility interviews in Study Three were used to inform potential modifications for future developmental work, including suggestions to simplify the intervention.

With regards to the limitations of Study Three, a key weakness is the limited conclusions that can be drawn due to the difficulties with recruitment. With only two dyads completing BEAMD, our knowledge about the intervention is limited, reflecting the potential that findings related to intervention acceptability, feasibility and delivery may not be generalisable to other individuals with dementia, for example younger patients or individuals with different dementia diagnoses. With more time and resources it may have been possible to recruit from multiple sites and settings, thereby recruiting more participants and strengthening our understanding of the acceptability and feasibility of BEAMD.

Another limitation of this programme of research is the lack of consideration regarding implementation at the service level. Implementation was considered at the patient level (Studies Two and Three), however, due to limited time, research was not conducted to investigate issues of service implementation. The intervention was based on the BA model currently delivered in the Improving Access to Psychological Therapies (IAPT) programme (Richards, 2010; Richards & Whyte, 2011) so BEAMD could, potentially, be more easily implemented into the service if evidence of intervention effectiveness is established. However, there was no investigation as to whether BEAMD could be embedded within an IAPT service or investigation of potential service barriers. It is important to investigate these issues early on as the intervention may need to be changed if it cannot be embedded into practice, and potential service barriers may need to be overcome before the intervention could be delivered.

There was also insufficient time in this dissertation to update the systematic review (Study One) at the end of this programme of research. An updated systematic review is necessary to allow readers to judge the relevance of the evidence (Chalmers & Glasziou, 2009) and an update of Study One is needed to put the research in this dissertation into context. Rerunning the searches would identify other new research, in addition to Study Three, to provide an up to date review of BA for depression in LTCs.

6.4 Contributions and Implications

This dissertation has contributed to the field of research on BA for depression in LTCs. Study One is, to the best of the researcher’s knowledge, the first systematic review of BA for depression in LTCs. Additionally, (as informed by Study One), this programme of research reports on the development, acceptability and feasibility of the first BA guided self-help intervention for depression in dementia. This guided self-help approach for people with dementia is of interest, with research currently investigating a BA written self-help intervention to improve mood, wellbeing and quality of life in people with dementia (Farrand et al., 2016). Furthermore, the development of an intervention for depression in dementia is of current importance and interest, with improving care and outcomes for people dementia having become a policy priority in the UK (DoH, 2009, 2012b, 2015).

There are several clinical and methodological implications arising from the studies in this dissertation. Firstly, Study One provides initial cautious support for the use of BA to treat depression in people with LTCs. Secondly, the adaptations narratively reviewed, where appropriate, could be incorporated into the design or delivery of interventions for people with LTCs. There are also implications from Study One for the treatment of post-stroke depression. A previous systematic review identified no evidence for the benefit of psychotherapy (including CBT) in post stroke depression (Hackett et al., 2008). However, Study One identified initial evidence for the effectiveness of BA for post-stroke depression. This finding may suggest a simpler intervention (such as BA) might be more appropriate in this population.

Next there are methodological implications arising from Studies Two and Three (with regards to the recruitment of people with dementia) and clinical implications arising from the findings of Study Three. Study Two has highlighted, as with other interventions for people with dementia (Orgeta et al., 2015; Spector et al., 2012), that it is possible to recruit and involve people with dementia in the development of psychological interventions. Study Three, however, experienced difficulties with recruiting dyads. To overcome difficulties with recruitment, more resources and recruitment from multiple sites and settings may be needed. Additionally, to help overcome recruitment difficulties, and to improve access to interventions, support could be provided to help overcome the barriers to accessing the intervention reported in Study Three. Despite the difficulties with recruitment, Study Three does demonstrate that it was possible to recruit several patients passing through a Memory Clinic, to engage them in a BA guided self-help intervention and for a proportion to remain in treatment. However, it is important to consider how to better modify interventions. As with previous research (Hind et al., 2010), Study Three has highlighted that interventions do need to be adapted and modified for people with LTCs. Simple or simplified interventions may be more acceptable for people with dementia.

There are also clinical implications arising from Study Three with regards to the screening of depression in Memory Clinics. Clinicians from the Memory Clinic raised concerns over the sensitivity of the Patient Health Questionnaire-9 (PHQ-9; Kroenke & Spitzer, 2002) in people with dementia after the PHQ-9 was initially implemented in the Clinic. Although the PHQ-9 has been used with Memory Clinic patients (Nair, Feijo, Nair, Meganathan, & Brooks, 2014) it is unclear whether this measure is appropriate, with validation of the PHQ-9 in primary care having excluded people with dementia (Arroll et al., 2010). As such it is important to ensure appropriate measures, such as the Geriatric Depression Scale-15 (GDS-15; Sheikh & Yesavage, 1986), are used to screen for depression in dementia. If the PHQ-9 is completed in Memory Clinics it may be more appropriate to use a positive response to the first two questions (PHQ-2) as an initial screen for depression (as used in Study Three).

6.5 Future Research

In addition to the clinical and methodological implications, there are also research implications and recommendations arising from the findings in this dissertation. This section first provides recommendations for further research on BA as a treatment for depression in people with LTCs, then recommendations are provided for the further development and evaluation of BEAMD.

6.5.1 Research on BA for Depression in LTCs

Study One highlighted a paucity of research on BA for depression in LTCs, highlighting the need for more research in this field. As the sample sizes in the included RCTs were small, and the quality of the studies sub-optimal, more high quality adequately powered RCTs are needed to help draw firm conclusions on the effectiveness of BA as a treatment for depression in people with LTCs. Additionally, as there is less research involving complex BA, more RCTs delivering complex interventions would help to compare the effectiveness of simple versus complex BA in LTCs. As several of the RCTs included in Study One failed to report methods of random sequence generation and concealment, it is important to ensure any future RCTs of BA for depression in LTCs follow the Consolidated Standards of Reporting Trials (CONSORT) guidelines (Schulz et al., 2010). Reviewers would then be able to make an accurate assessment of risk of bias and subsequent evaluation of intervention effectiveness.

As discussed in Chapter Three, with the majority of studies conducted in America, it is important to investigate whether BA for depression in LTCs can be delivered in different healthcare systems and services. Since updating the systematic review (Study One) in 2015, the protocols for two feasibility studies of BA for depression in LTCs, in the UK, have been published (Farrand et al., 2016; Thomas et al., 2016). These studies should provide data on the feasibility of delivering BA to people with dementia (Farrand et al., 2016) and stroke patients (Thomas et al., 2016) in UK services, as well as details on the acceptability of the interventions. More BA studies based in UK services are, however, still needed for a wider range of LTCs. Additionally, there is the need to develop and evaluate low intensity BA interventions for depression in other LTCs, especially with a low intensity service in the IAPT programme in England (Clark, 2011), and the agenda to support the psychological needs of people with LTCs within IAPT (DoH, 2011).

6.5.2 Recommendations for Further Development and Evaluation of BEAMD

After the findings from the feasibility case series (Study Three), particularly the difficulties delivering BEAMD as currently designed, and issues with understanding and comprehension, it is clear more development is needed. Firstly, BEAMD version 2 should be developed by incorporating the suggestions from the feasibility case series (see Chapter Five). For several of the suggested modifications (the development of a carer workbook, modifying the vignette and incorporating a physical health and functional impairment questionnaire /checklist) service users could be involved. When developing the new carer workbook, and modifying the existing intervention workbook, service users could be involved in informing the content of the workbook vignettes. As participants had difficulties relating to the workbook vignette (Study Three), interviews with people with dementia and carers should be conducted to address the experience of living with dementia and depression. These interviews could then be used to inform the content of the vignettes. These interviews could also help inform the options on the physical health and functional impairments questionnaire or checklist, alongside input from experts in dementia.

Although Study Three highlighted a lack of carer involvement, particularly with regards to carers not completing the workbook, there is justification for spending time on the development of a separate carer workbook for BEAMD. Firstly, the carers in Study Three did not complete the workbook as they identified it as their partner’s book. Carers involved in supporting BEAMD may feel more comfortable having their own workbook to complete, and may be more willing to complete it. Secondly, Study Three was a very small feasibility study with elderly carers; the carers in Study Three, and their lack of engagement with the workbook, may not be representative of carers more broadly. Other carers may be more willing to participate and engage. Indeed, only two potential participants reported a lack of partner interest as a reason for non-participation in Study Three. Further evidence for the willingness of carers to be involved in the support of a psychological intervention comes from the development work for a BA written self-help intervention for mood, wellbeing and quality of life in people with dementia (Farrand et al., 2015). An acceptability questionnaire found 60% of family members and friends completing the questionnaire would be willing to support the intervention. A further 38% reported they ‘maybe’ willing to support the intervention, but further information was wanted (Farrand et al., 2015). Future feasibility work on BEAMD version 2 could consider whether carers found the carer workbook beneficial for engagement and involvement in the intervention.

After the development of version 2, feedback needs to be sought from service users (people with dementia and carers) on this version of BEAMD. This may take the form of interviews (as in Study Two) or, as in the development of other psychological interventions for people with dementia (Orgeta et al., 2015; Spector et al., 2012), focus groups may be conducted. The interviews and/or focus groups would be conducted with a semi-structured schedule addressing the suitability of the intervention and intervention materials, as well as changes to the intervention and workbooks. The schedule may also include questions on whether the person with dementia should be involved in all sessions or whether the person with dementia and carer should participate in varying degrees, as in other BA interventions for people with dementia (Farrand et al., 2016; Teri et al., 1997) (as discussed in Chapter Five). The interviews and/or focus groups would be recorded, transcribed verbatim and analysed using thematic analysis (Braun & Clarke, 2006, 2013) to establish the suitability of version 2 and to inform modifications as part of intervention development.

As well as consulting service users, it is also important to consult experts on the suitability of version 2 and to revise the intervention and/or workbook based on their comments. Following the methods of Orgeta et al. (2015), an online survey could be developed to collect opinions on the suitability of the intervention and workbook, using both Likert scales and open-ended comment boxes. This survey could be completed by healthcare professionals (including professionals working in Memory Services and Primary Care Dementia Practitioners), academics in dementia care and/or CBT/BA guided self-help, and voluntary sector professionals (such as the Alzheimer's Society). Feedback (i.e. necessary modifications) from both the service users and experts would be incorporated into version 2 of BEAMD.

It may also be beneficial to investigate implementation issues (for example the possibility of embedding into an IAPT service and potential service barriers) during the development stage of version 2, as the findings may lead to modifications to the intervention. Additionally, if any service barriers were identified these may need to be overcome before a feasibility study could be conducted within an IAPT service. Psychological Wellbeing Practitioners (PWPs), clinical team leads and commissioners should be consulted on whether BEAMD could be delivered within an IAPT service. This would help to identify any potential service barriers. The normalisation process theory (NPT; May & Finch, 2009; May et al., 2009), a conceptual framework for understanding and evaluating the implementation, embedding and integration of complex interventions (May et al., 2015), could be used to help investigate implementation issues. NPT can be adapted to guide investigation of the feasibility of interventions, before they are implemented, to map any resource or organisational changes that will be required for the intervention to be implemented (May et al., 2015). This could help to map changes that may be needed within IAPT services before BEAMD could be delivered within the IAPT programme.

After this developmental work, a feasibility study would be needed to investigate the uncertainties of this version of BEAMD (such as acceptability and feasibility) (Craig et al., 2008; MRC, 2008). With more resources than were available for Study Three, the feasibility study for version 2 would be a larger single-arm study involving more dyads and practitioners. Participants (dyads) would be recruited from multiple sites and settings, including primary care, community outreach and dementia-specific health settings (Farrand et al., 2016). If current research (Farrand et al., 2016) demonstrates a particularly effective recruitment method, this would be used to inform the methods for this feasibility study. In addition to these settings, participants could also be recruited through Join Dementia Research, a service where people interested in participating in dementia research are matched to appropriate studies (National Institute for Health Research, n.d.). With Study Three having only recruited older individuals with dementia it is important to ensure future research also includes younger individuals with dementia.

A feasibility study investigating BEAMD version 2 would, as in Study Three, include dementia participants who lack capacity to consent to participation. Although people who lack capacity to consent may have difficulties engaging with the intervention, it would not be appropriate to exclude individuals from an intervention that may improve their mental health and wellbeing. It is important to include people who might find the intervention useful in the real world. If an individual was unable to consent, they may still be able to engage with aspects of the intervention or provide valuable insight into the acceptability of the intervention they have received. The process of assessing capacity and obtaining consent from a consultee (for those who are assessed as lacking capacity to consent) does slow down the process of recruitment. Future research should, therefore, allow more time to recruit people lacking capacity to consent. It may also be interesting to investigate whether those who lacked capacity to consent were able to engage with the intervention, and how much carer involvement was needed.

The participant inclusion and exclusion criteria in the next feasibility study would be the same as Study Three, however severity would not be established using the Addenbrooke’s Cognitive Examination (ACE-III; NeuRA, 2012). The ACE-III was used for pragmatic reasons in Study Three as this measure was completed as standard in the Memory Clinic assessment. However, for the BEAMD version 2 feasibility study it would be better to utilise a measure with specified cut-offs for severity. Severity could be assessed with the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), however the Clinical Dementia Rating scale (CDR; Morris, 1993) may be more appropriate, and should be used in future research (instead of the ACE-III). The CDR has been used to assess severity eligibility in other studies delivering psychological interventions to people with dementia (Spector et al., 2015; Stanley et al., 2013) and compared to the MMSE it allows more reliable staging of dementia (Sheehan, 2012). With specified cut-off scores for severity it would be interesting to investigate whether there are any differences in acceptability and feasibility for participants with mild dementia compared to participants with moderate dementia. This could help us to understand whether BEAMD should still be targeted at mild to moderate dementia or whether the intervention may be more appropriate for people with mild dementia and comorbid depression. With only two participants completing BEAMD in Study Three it was difficult to investigate whether there were differences in acceptability or feasibility for different participants and to consider the implications of these differences. With a larger sample in the next feasibility study it may be possible to consider any differences between participants and to use the findings to inform any necessary further development.

BEAMD was based on the BA protocol currently delivered in IAPT (Richards, 2010; Richards & Whyte, 2011) so that it could, potentially, be more easily implemented into a service. BEAMD version 2, therefore, would be supported by PWPs in the feasibility study as it is important to investigate the feasibility of delivering within an IAPT service. Consistent with IAPT services, the support sessions may be outside of working hours as this may be beneficial for informal carers who are still working. BEAMD should also, if needed, be supported in community settings, participants' homes or via the telephone as this may help to overcome difficulties with travel or location. Current research may provide evidence for PWP support of a written BA self-help intervention (PROMOTE) (Farrand et al., 2016), however there are differences between the PROMOTE intervention and BEAMD, for example the length of support sessions. It is therefore necessary to establish the feasibility and acceptability of PWP support for BEAMD.

Some of the suggestions for recruitment and delivery of BEAMD in the next feasibility study come from some of the difficulties with recruitment experienced in Study Three (which may have been due to the small scale of the study and limited resources). The limited days and times available for support sessions, only providing sessions at the University of Exeter and only recruiting from one Memory Clinic may have contributed to the difficulties with recruitment in Study Three. With more resources available for the next feasibility study it would be possible to recruit more widely and from different settings, and to deliver the intervention more flexibly (as discussed above).

Following the design of Study Three the feasibility study for version 2 should collect both quantitative and qualitative data including:

- Quantitative data on the feasibility of recruiting dyads;
- Qualitative data on the reasons for non-participation and withdrawal from the intervention;
- Data on the acceptability and feasibility of research materials, methods and measures;
- Data on amount, length and delivery of support sessions;
- Outcomes for depression (for both the participant with dementia and carer) and quality of life;
- And qualitative data on the acceptability and feasibility of BEAMD to the dyads and PWPs.

In addition data should be collected on PWP competence, adherence to the protocol and training needs (Abbott, 2014). To further investigate issues of implementation the PWP post-intervention interviews should also address issues such as service and patient barriers. The collected data would be analysed to determine the feasibility of recruitment and research methods, the feasibility of delivering the intervention as intended, and intervention acceptability.

Dependent on the findings from this feasibility study it may be that more development of BEAMD is needed. Or, if the intervention and research methods are acceptable and feasible, a pilot RCT would be recommended. This pilot RCT would assess issues such as the randomisation processes; the resources and capacity for trial processes; retention of participants in the allocation groups; and adequate effects of the intervention (Abbott, 2014). It is important to ensure enough work has been conducted in the ‘feasibility and piloting’ phase to be sure the intervention can be delivered as intended and that safe assumptions can be made for the main evaluation study regarding effect sizes, variability, recruitment and retention (MRC, 2008).

6.6 Conclusion

The field of research on BA for depression in people with LTCs is relatively small and more research is needed. With the prevalence of depression in dementia, and the negative consequences of comorbid depression, more research is needed to investigate the use of BA in this population. This programme of research has demonstrated that depressed dementia patients can be identified from a Memory Clinic and recruited into a BA guided self-help intervention. However the recruitment of people with dementia, and their carers, can be challenging. This dissertation has also highlighted the need to adapt BA for people with dementia and to ensure interventions are kept simple, but little is currently known about the acceptability and feasibility of BA guided self-help for depression in dementia. More research, and intervention development, is needed.

Appendices

Appendix 3.1 Ovid SP Embase Search Strategy

Ovid SP Embase from 1974 to 2013 January 10

Search conducted 14th January 2013

Limit to Human

1) (behavio$ adj activati$).ti,ab. (490)

2) (activity adj scheduling).ti,ab. (27)

3) (pleasant event$ or pleasant activit$ or daily diar$).ti,ab. (1,645)

4) (behavio$ adj therap$).ti,ab. (13,897)

5) Exp behavior therapy/ (33,404)

6) (behavio$ adj intervention$).ti,ab. (5,638)

7) 1 or 2 or 3 or 4 or 5 or 6 (45,408)

8) (depression or depressive or depressed or depressive disorder or mood disorder).ti,ab. (238,371)

9) Exp Depression/ (249,639)

10) Exp depressive disorder/ (249,639)

11) 8 or 9 or 10 (332,053)

12) 7 and 11 (9,697)

Appendix 3.2 Data Extraction Form

Data Extraction Form to be used on Microsoft Excel

Researcher performing extraction:
Date of data extraction:

Study Identification Features	
Unique Study Identifier	
Title	
Authors	
Year of publication	
Citation	
Publication type	
Country of origin	
Source of funding	

Study Characteristics & Quality		
Aims/objectives		
Study design		
Study inclusion/exclusion criteria		
Recruitment procedures used		
RCTs		
Randomisation	Sequence Generation	
	Type	
	Allocation Concealment	
	Implementation	
Blinding	Participants	
	Data Collectors	
	Data Analysts	
Incomplete outcome data (attrition and exclusions)		
Selective reporting		
Other sources of bias		

Participant Characteristics	
Age	
Gender	
Ethnicity	
Depression scores	
Method of assessment/diagnosis of depression	
Chronic physical illness	
Other comorbidities	

Intervention Components	
BA Components	
Mode of delivery	
Delivered by	
Training received by practitioner delivering intervention	
Individual/group sessions	
Group size for group-based intervention	
Duration of intervention	
Number of sessions	
Length of sessions	
Treatment setting	
Manualised treatment	Yes No
Measurement of treatment integrity	Yes No
Adaptations to intervention	
Type of control condition	

Outcome Measurements	
Primary outcome measurements	
Quality of primary outcome measurements	
Length of follow-up	

Statistical Techniques	
Power calculation	
Method of dealing with missing data	
Length of follow-up	

Participant Flow	
Randomised to intervention	
Randomised to control	
Lost to follow-up intervention	
Lost to follow-up control	
Analysed intervention	
Analysed control	

Results	
BA Intervention	
Outcome measurement	
Pre-intervention means	

Pre-intervention standard deviation	
Pre-intervention number analysed	
Post-intervention means	
Post-intervention standard deviation	
Post-intervention number analysed	
Control	
Outcome measurement	
Pre-intervention means	
Pre-intervention standard deviation	
Pre-intervention number analysed	
Post-intervention means	
Post-intervention standard deviation	
Post-intervention number analysed	
Qualitative Research	
Main themes	
Main sub-themes	
Observations	
Observed results	

Additional Comments

Appendix 3.3 Validation of Clinician Administered and Self-report Measures Utilised in the Included Studies

Outcome measure	No. of studies	Population(s) in studies	Internal consistency (Cronbach's alpha)	Test-retest reliability (Correlation coefficient)	Validity
HRSD	11	Cancer; stroke; nursing home residents; dementia; multiple conditions	Pooled mean of 0.79 (Trajković et al., 2011); 0.77 in cancer patients (Olden, Rosenfeld, Pessin, & Breitbart, 2009); 0.81 in stroke patients (Agrell & Dehlin, 1989).	0.65-0.98 (Trajković et al., 2011).	Significant correlations between 19 items on HRSD and SCID in cancer patients (Olden et al., 2009); significant correlation with clinical examination in stroke patients (Agrell & Dehlin, 1989); 0.68 correlation with GDS and HRSD in nursing home patients (some patients with dementia) (Anderson, Buckwalter, Buchanan, Maas, & Imhof, 2003).
BDI/BDI-II	8	Cancer; arthritis; colitis; multiple conditions	Mean of 0.86 for BDI in psychiatric patients (Beck, Steer, & Carbin, 1988); 0.91 for BDI-II in psychiatric patients (Beck, Steer, Ball, & Ranieri, 1996); 0.82-0.94 for the BDI-II in medical patients (Wang & Gorenstein, 2013)	0.48-0.86 for BDI in psychiatric patients (Beck et al., 1988).	0.72-0.87 correlation with CES-D, 0.71-0.75 correlation with HRSD in medical patients (Wang & Gorenstein, 2013).
GDS	5	Nursing home residents; vascular disease	0.94 in an elderly community sample (Yesavage et al., 1983); 0.99 in nursing home residents (Lesher, 1986); 0.92 in elderly medical inpatients (Rapp, Parisi, & Walsh, 1988).	0.85 in an elderly community sample (Yesavage et al., 1983); 0.94 in nursing home residents (Lesher, 1986).	0.68 correlation between GDS and HRSD in older adults in nursing home patients (Anderson et al., 2003).

CES-D	3	Cancer	0.84-.90 in the general population and patients (Radloff, 1977); 0.89 in cancer patients (Hann, Winter, & Jacobsen, 1999).	.32-.67 in the general population and patients (Radloff, 1977); 0.57 in cancer patients (Hann et al., 1999).	Significant correlation with the POMS-SF in cancer patients (Conerly, Baker, Dye, Douglas, & Zabora, 2002).
CSDD	2	Dementia	0.84 in people with dementia (Alexopoulos et al., 1988).	0.93 in Turkish people with dementia (Amuk, Karadağ, Oğuzhanoğlu, & Oğuzhanoğlu, 2003).	Significant correlations with HRSD and GDS-30 (Kørner et al., 2006).
Modified BDI completed by carer	1	Dementia	0.86 when completed by carers of people with Alzheimer's disease (Logsdon & Teri, 1995).		Significant correlations with modified GDS and modified CES-D (Logsdon & Teri, 1995).
SADQ-H	1	Stroke (with aphasia)	0.84 in stroke patients (Bennett, Thomas, Austen, Morris, & Lincoln, 2006).		Significant correlation between SADQ-H and HADS total and depression subscale (Bennett et al., 2006).
VAMS	1	Stroke (with aphasia)	0.71 in stroke patients (0.81 when happy and energetic items are removed) (Bennett et al., 2006).		Significant correlation between VAMS and HADS total and depression subscale (Bennett et al., 2006).
MDS-DRS	1	Dementia	0.71 in nursing facilities (Burrows et al., 2000); 0.67 in nursing home residents (including some		0.70 correlation with the CSDD and 0.71 with the HRSD (Burrows et al., 2000); 0.24 correlation with the

	patients with dementia) (Anderson et al., 2003).	HRSD, 0.13 with the GDS (Anderson et al., 2003).

Note: CES-D = Centre for Epidemiological Studies of Depression Scale; CSDD = Cornell Scale for Depression in Dementia; GDS = Geriatric Depression Scale; HRSD = Hamilton Rating Scale for Depression; HADS = Hospital Anxiety and Depression Scale; MDS-DRS = Minimum Data Set Depression Rating Scale; POMS-SF = Profile of Mood States-Short Form; SADQ-H = Stroke Aphasic Depression Questionnaire Hospital version; SCID = Structured Clinical Interview for Diagnostic and Statistical Manual; VAMS = Visual Analogue Mood Scale.

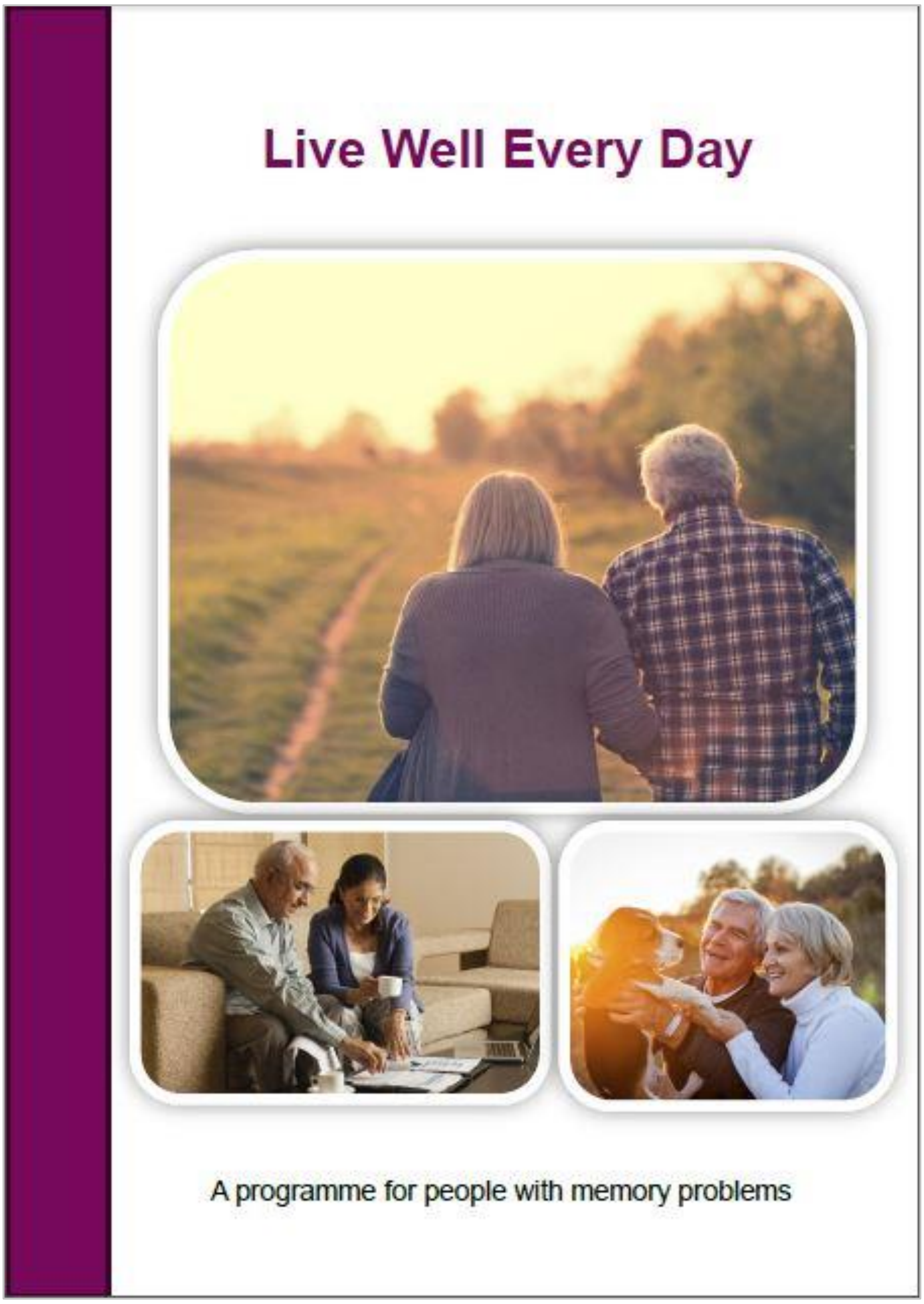
Appendix 3.4 Reporting of Outcomes in Included Randomised Controlled Trials

Study No.	Diagnostic interview	Data reported	Clinician administered measure(s)	Raw data reported	Self-report measure(s)	Data reported
[5]			HRSD	M & SD	BDI-II CES-D	M & SD
[7]			HRSD	Mean % reduction		
[10]	DSM diagnosis	No. & % with diagnosis	HRSD	M & SD	GDS	M & SD
[12]	Mood disorders section of the SCID-IV	Count and % for diagnostic recovery codes			GDS	M & SD
[13]			HRSD	M & SD at baseline; Mean change & SD; % in remission (HRSD ≤ 9)		
[15]	SADS *SADS for carer depression*	N & % with major or minor diagnosis at baseline; N & % clinically significant improvement for patients	CSDD* HRSD score for patient* *HRSD score for carer**	M & SD at baseline; Change score & SD	Modified BDI	M & SD at baseline; Change score & SD
[16]					SADQ-H 21 VAMS ‘sad’ item	M & SD

[18]	CSDD Dutch version MDS-DRS Dutch version)	Estimated M score & SE

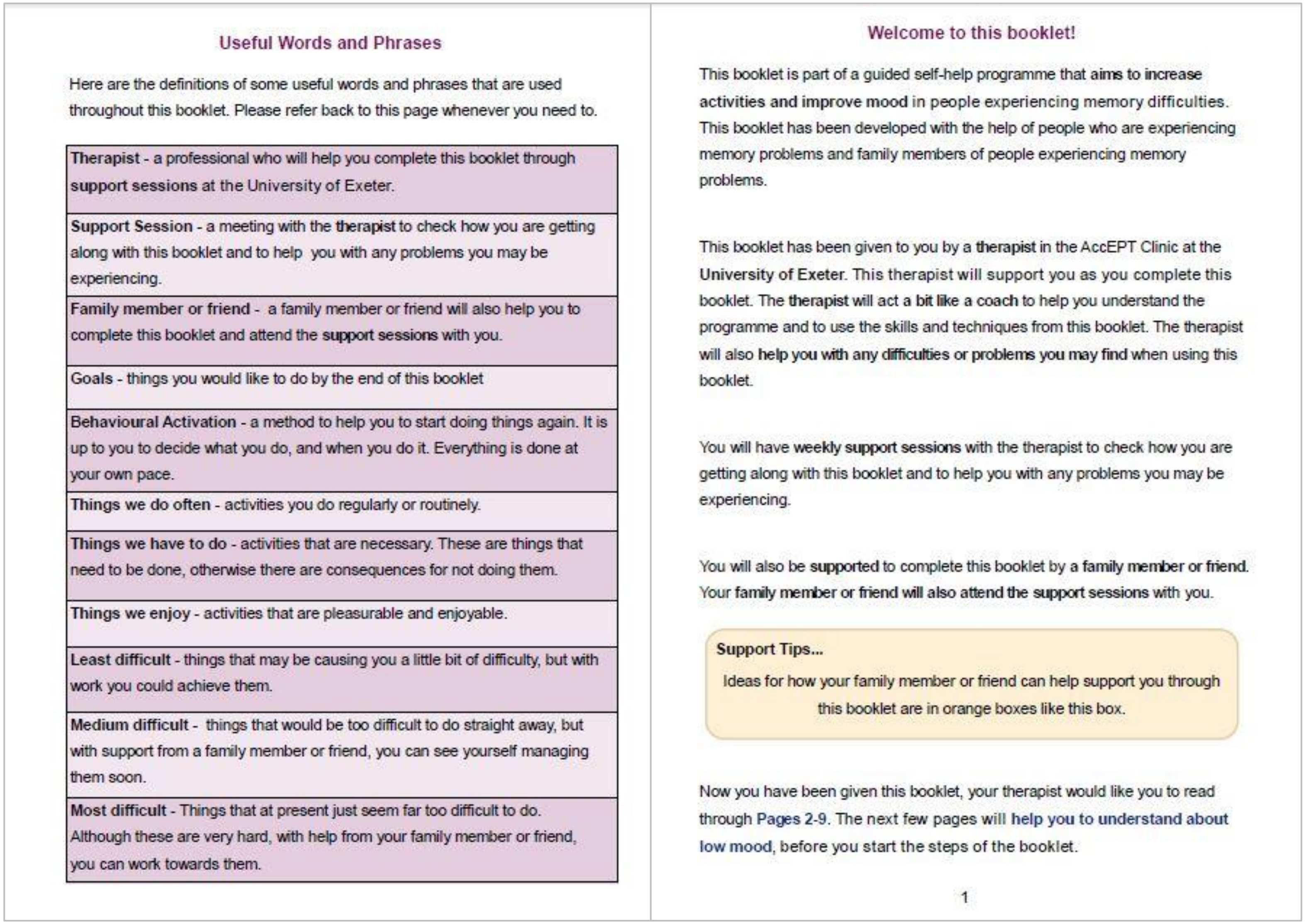
Note: * = M & SD reported for both active treatment conditions combined for all time points; BDI = Beck Depression Inventory; CES-D = Centre for Epidemiological Studies of Depression Scale; CNA = certified nurse assistant; CSDD = Cornell Scale for Depression in Dementia; DSM = Diagnostic and Statistical Manual; GDS = Geriatric Depression Scale; HRSD = Hamilton Rating Scale for Depression; M = mean; MDS-DRS = Minimum Data Set Depression Rating Scale; No. = number; SADS = Schedule for Affective Disorders and Schizophrenia; SADQ-H 21 = Stroke Aphasic Depression Questionnaire 21-item Hospital version; SCID = Structured Clinical Interview for DSM; SD = standard deviation; SE = standard error; VAMS = Visual Analogue Mood Scale.

Appendix 4.1 BEAMD Workbook (Version 1)



Live Well Every Day

A programme for people with memory problems



Useful Words and Phrases

Here are the definitions of some useful words and phrases that are used throughout this booklet. Please refer back to this page whenever you need to.

Therapist - a professional who will help you complete this booklet through **support sessions** at the University of Exeter.

Support Session - a meeting with the **therapist** to check how you are getting along with this booklet and to help you with any problems you may be experiencing.

Family member or friend - a family member or friend will also help you to complete this booklet and attend the **support sessions** with you.

Goals - things you would like to do by the end of this booklet

Behavioural Activation - a method to help you to start doing things again. It is up to you to decide what you do, and when you do it. Everything is done at your own pace.

Things we do often - activities you do regularly or routinely.

Things we have to do - activities that are necessary. These are things that need to be done, otherwise there are consequences for not doing them.

Things we enjoy - activities that are pleasurable and enjoyable.

Least difficult - things that may be causing you a little bit of difficulty, but with work you could achieve them.

Medium difficult - things that would be too difficult to do straight away, but with support from a family member or friend, you can see yourself managing them soon.

Most difficult - Things that at present just seem far too difficult to do. Although these are very hard, with help from your family member or friend, you can work towards them.

Welcome to this booklet!

This booklet is part of a guided self-help programme that **aims to increase activities and improve mood** in people experiencing memory difficulties. This booklet has been developed with the help of people who are experiencing memory problems and family members of people experiencing memory problems.

This booklet has been given to you by a **therapist** in the AccEPT Clinic at the **University of Exeter**. This therapist will support you as you complete this booklet. The **therapist** will act **a bit like a coach** to help you understand the programme and to use the skills and techniques from this booklet. The therapist will also **help you with any difficulties or problems you may find** when using this booklet.

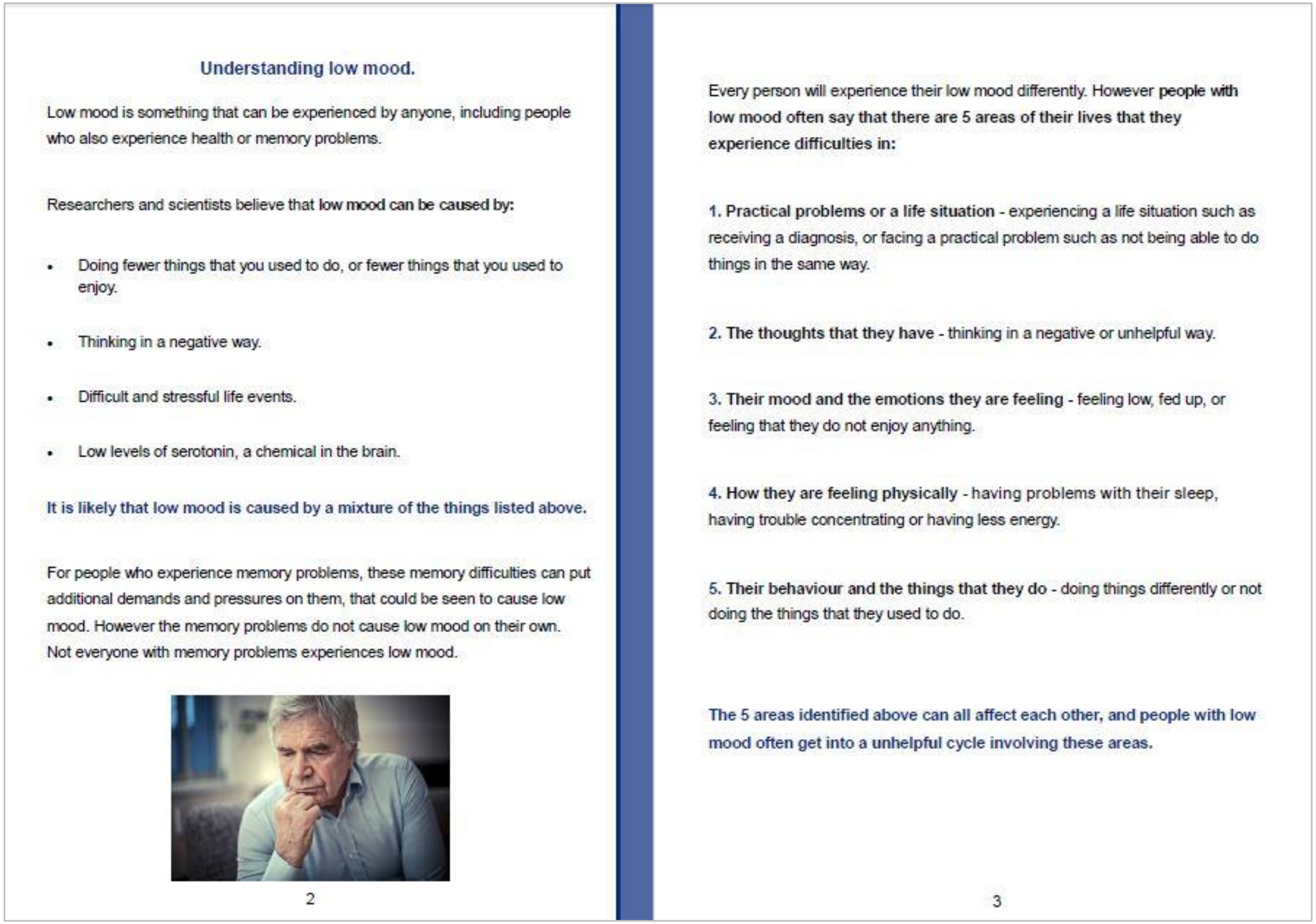
You will have **weekly support sessions** with the therapist to check how you are getting along with this booklet and to help you with any problems you may be experiencing.

You will also be **supported** to complete this booklet by a **family member or friend**. Your **family member or friend will also attend the support sessions** with you.

Support Tips...

Ideas for how your family member or friend can help support you through this booklet are in orange boxes like this box.

Now you have been given this booklet, your therapist would like you to read through Pages 2-9. The next few pages will **help you to understand about low mood**, before you start the steps of the booklet.



Understanding low mood.

Low mood is something that can be experienced by anyone, including people who also experience health or memory problems.

Researchers and scientists believe that **low mood can be caused by:**

- Doing fewer things that you used to do, or fewer things that you used to enjoy.
- Thinking in a negative way.
- Difficult and stressful life events.
- Low levels of serotonin, a chemical in the brain.

It is likely that low mood is caused by a mixture of the things listed above.

For people who experience memory problems, these memory difficulties can put additional demands and pressures on them, that could be seen to cause low mood. However the memory problems do not cause low mood on their own. Not everyone with memory problems experiences low mood.

Every person will experience their low mood differently. However **people with low mood often say that there are 5 areas of their lives that they experience difficulties in:**

1. Practical problems or a life situation - experiencing a life situation such as receiving a diagnosis, or facing a practical problem such as not being able to do things in the same way.

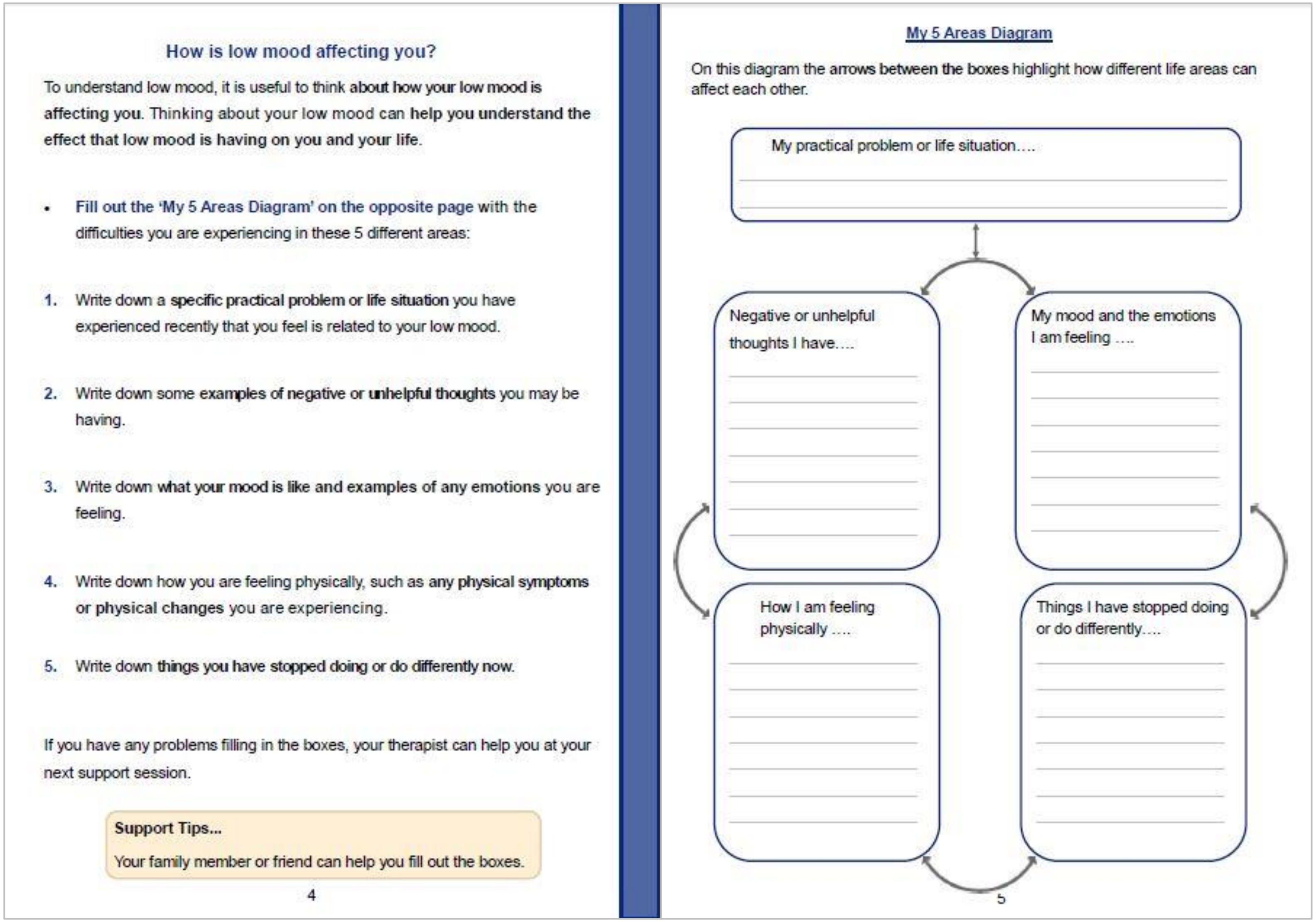
2. The thoughts that they have - thinking in a negative or unhelpful way.

3. Their mood and the emotions they are feeling - feeling low, fed up, or feeling that they do not enjoy anything.

4. How they are feeling physically - having problems with their sleep, having trouble concentrating or having less energy.

5. Their behaviour and the things that they do - doing things differently or not doing the things that they used to do.

The 5 areas identified above can all affect each other, and people with low mood often get into a unhelpful cycle involving these areas.



How is low mood affecting you?

To understand low mood, it is useful to think **about how your low mood is affecting you**. Thinking about your low mood can **help you understand the effect that low mood is having on you and your life**.

- **Fill out the 'My 5 Areas Diagram' on the opposite page** with the difficulties you are experiencing in these 5 different areas:

1. Write down a **specific practical problem or life situation** you have experienced recently that you feel is related to your low mood.
2. Write down some **examples of negative or unhelpful thoughts** you may be having.
3. Write down **what your mood is like and examples of any emotions** you are feeling.
4. Write down how you are feeling physically, such as **any physical symptoms or physical changes** you are experiencing.
5. Write down **things you have stopped doing or do differently now**.

If you have any problems filling in the boxes, your therapist can help you at your next support session.

Support Tips...

Your family member or friend can help you fill out the boxes.

My 5 Areas Diagram

On this diagram the **arrows between the boxes** highlight how different life areas can affect each other.

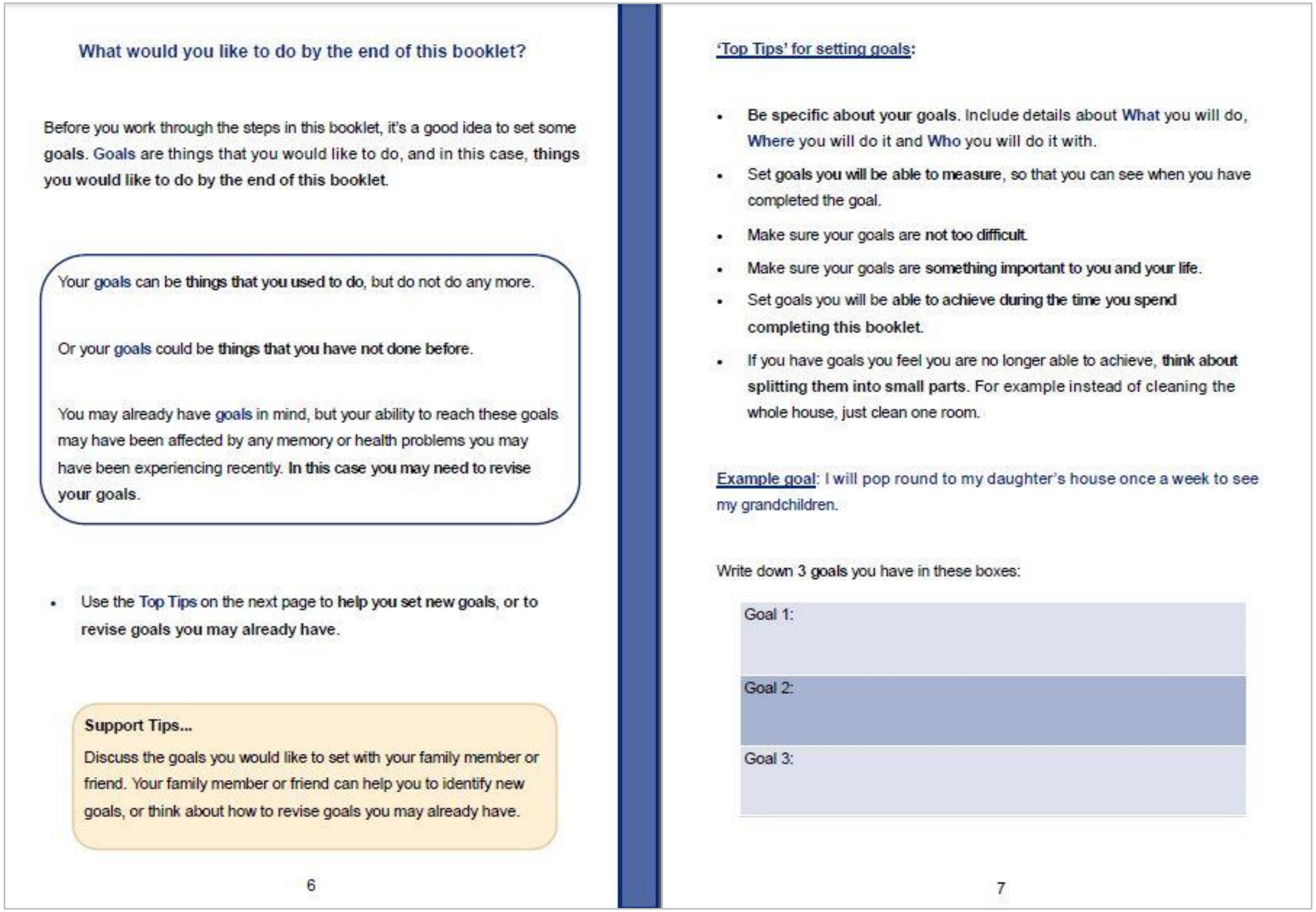
My practical problem or life situation....

Negative or unhelpful thoughts I have....

My mood and the emotions I am feeling ....

How I am feeling physically ....

Things I have stopped doing or do differently....



What would you like to do by the end of this booklet?

Before you work through the steps in this booklet, it's a good idea to set some goals. Goals are things that you would like to do, and in this case, **things you would like to do by the end of this booklet.**

Your goals can be **things that you used to do**, but do not do any more.

Or your goals could be **things that you have not done before.**

You may already have goals in mind, but your ability to reach these goals may have been affected by any memory or health problems you may have been experiencing recently. **In this case you may need to revise your goals.**

- Use the Top Tips on the next page to **help you set new goals, or to revise goals you may already have.**

Support Tips...

Discuss the goals you would like to set with your family member or friend. Your family member or friend can help you to identify new goals, or think about how to revise goals you may already have.

'Top Tips' for setting goals:

- **Be specific about your goals.** Include details about **What** you will do, **Where** you will do it and **Who** you will do it with.
- Set goals **you will be able to measure**, so that you can see when you have completed the goal.
- Make sure your goals are **not too difficult.**
- Make sure your goals are **something important to you and your life.**
- Set goals you will be **able to achieve during the time you spend completing this booklet.**
- If you have goals you feel you are no longer able to achieve, **think about splitting them into small parts.** For example instead of cleaning the whole house, just clean one room.

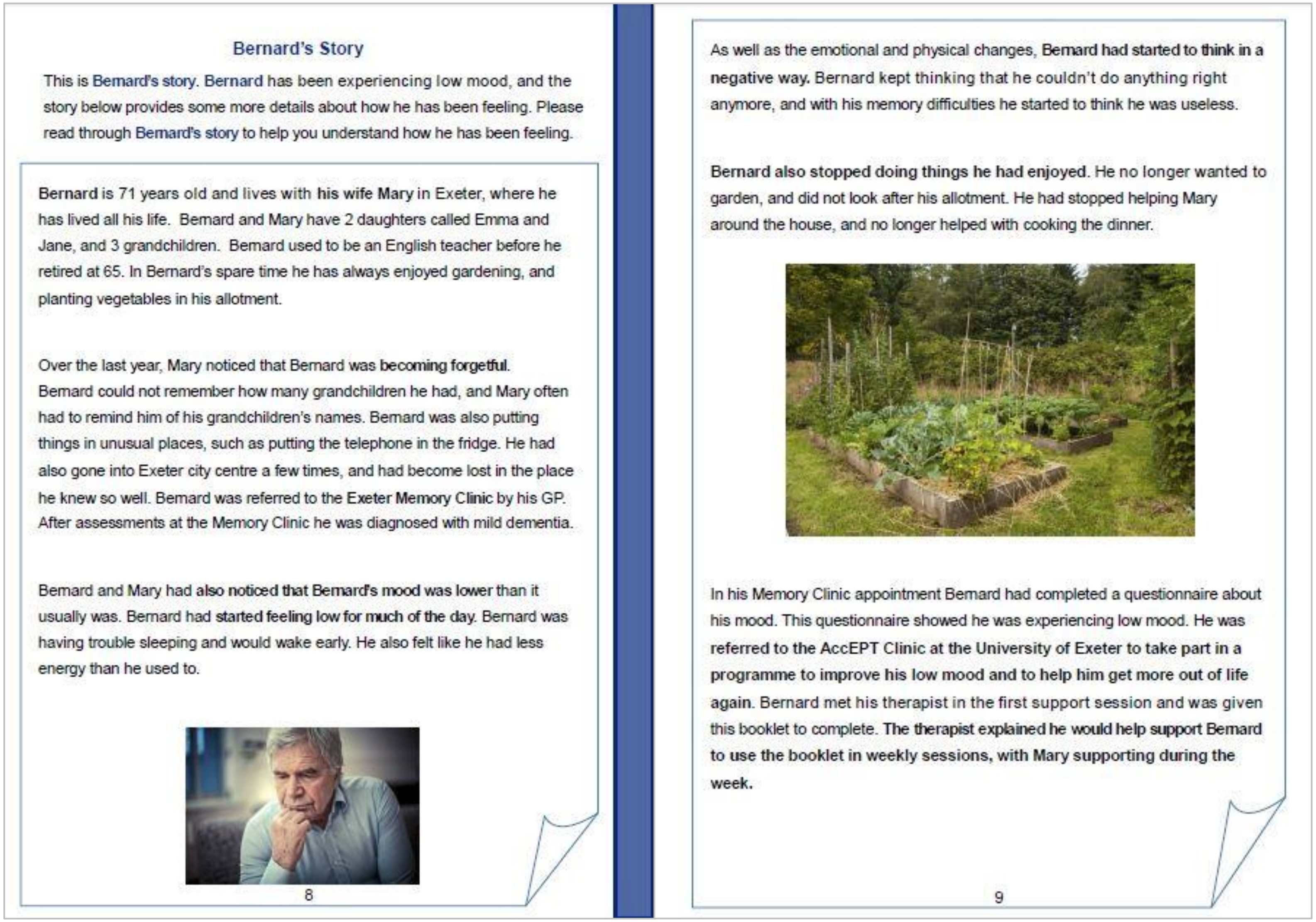
Example goal: I will pop round to my daughter's house once a week to see my grandchildren.

Write down 3 **goals** you have in these boxes:

Goal 1:

Goal 2:

Goal 3:



Bernard's Story

This is Bernard's story. Bernard has been experiencing low mood, and the story below provides some more details about how he has been feeling. Please read through Bernard's story to help you understand how he has been feeling.

Bernard is 71 years old and lives with **his wife Mary** in Exeter, where he has lived all his life. Bernard and Mary have 2 daughters called Emma and Jane, and 3 grandchildren. Bernard used to be an English teacher before he retired at 65. In Bernard's spare time he has always enjoyed gardening, and planting vegetables in his allotment.

Over the last year, Mary noticed that Bernard was **becoming forgetful.** Bernard could not remember how many grandchildren he had, and Mary often had to remind him of his grandchildren's names. Bernard was also putting things in unusual places, such as putting the telephone in the fridge. He had also gone into Exeter city centre a few times, and had become lost in the place he knew so well. Bernard was referred to the **Exeter Memory Clinic** by his GP. After assessments at the Memory Clinic he was diagnosed with mild dementia.

Bernard and Mary had **also noticed that Bernard's mood was lower** than it usually was. Bernard had **started feeling low for much of the day.** Bernard was having trouble sleeping and would wake early. He also felt like he had less energy than he used to.

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As well as the emotional and physical changes, **Bernard had started to think in a negative way.** Bernard kept thinking that he couldn't do anything right anymore, and with his memory difficulties he started to think he was useless.

Bernard also stopped doing things he had enjoyed. He no longer wanted to garden, and did not look after his allotment. He had stopped helping Mary around the house, and no longer helped with cooking the dinner.

In his Memory Clinic appointment Bernard had completed a questionnaire about his mood. This questionnaire showed he was experiencing low mood. He was **referred to the AccEPT Clinic at the University of Exeter to take part in a programme to improve his low mood and to help him get more out of life again.** Bernard met his therapist in the first support session and was given this booklet to complete. **The therapist explained he would help support Bernard to use the booklet in weekly sessions, with Mary supporting during the week.**

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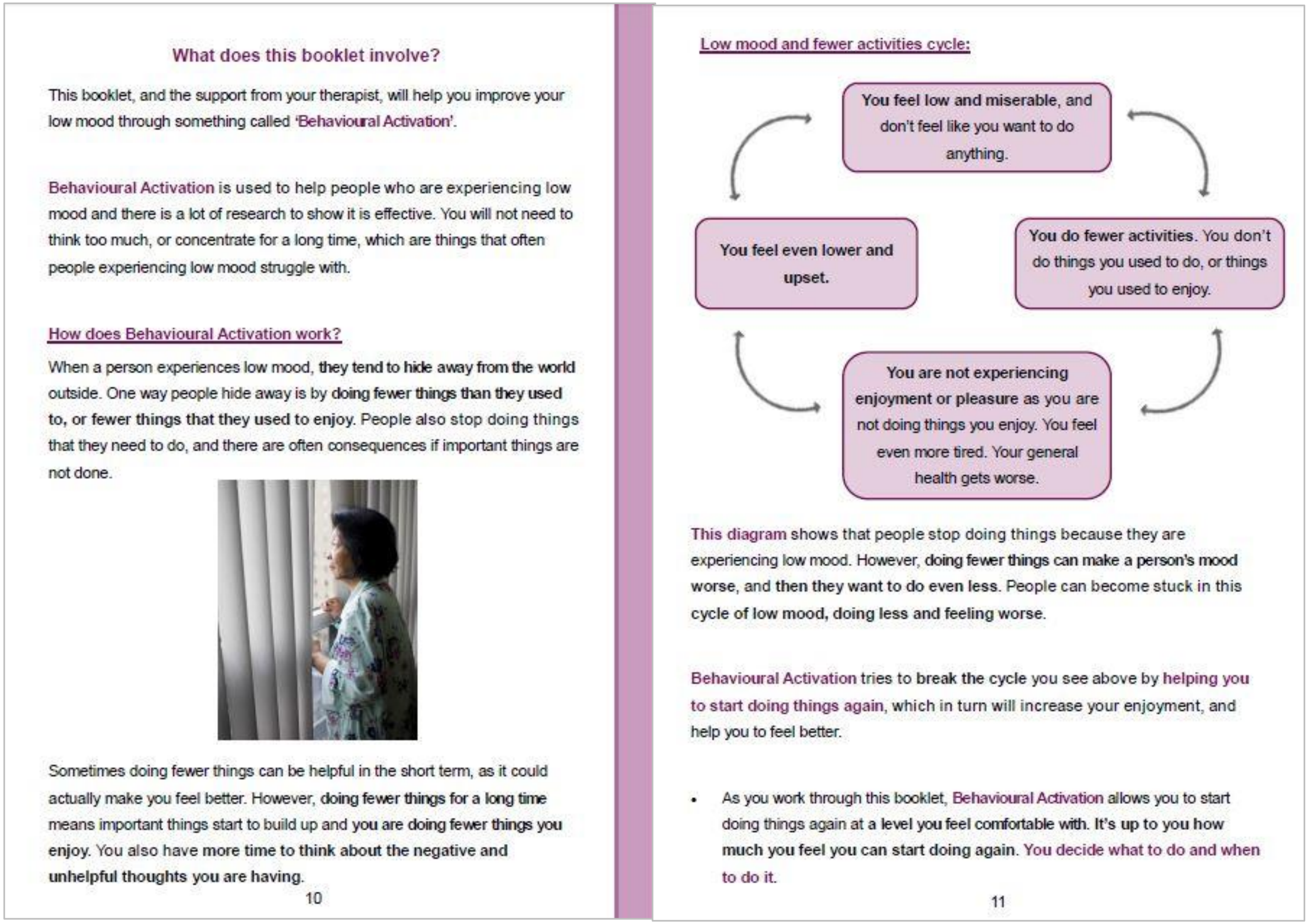


What does this booklet involve?

This booklet, and the support from your therapist, will help you improve your low mood through something called 'Behavioural Activation'.

Behavioural Activation is used to help people who are experiencing low mood and there is a lot of research to show it is effective. You will not need to think too much, or concentrate for a long time, which are things that often people experiencing low mood struggle with.

How does Behavioural Activation work?

When a person experiences low mood, **they tend to hide away from the world** outside. One way people hide away is by **doing fewer things than they used to, or fewer things that they used to enjoy.** People also stop doing things that they need to do, and there are often consequences if important things are not done.

Sometimes doing fewer things can be helpful in the short term, as it could actually make you feel better. However, **doing fewer things for a long time** means important things start to build up and **you are doing fewer things you enjoy.** You also have **more time to think about the negative and unhelpful thoughts you are having.**

Low mood and fewer activities cycle:

You feel low and miserable, and don't feel like you want to do anything.

You do fewer activities. You don't do things you used to do, or things you used to enjoy.

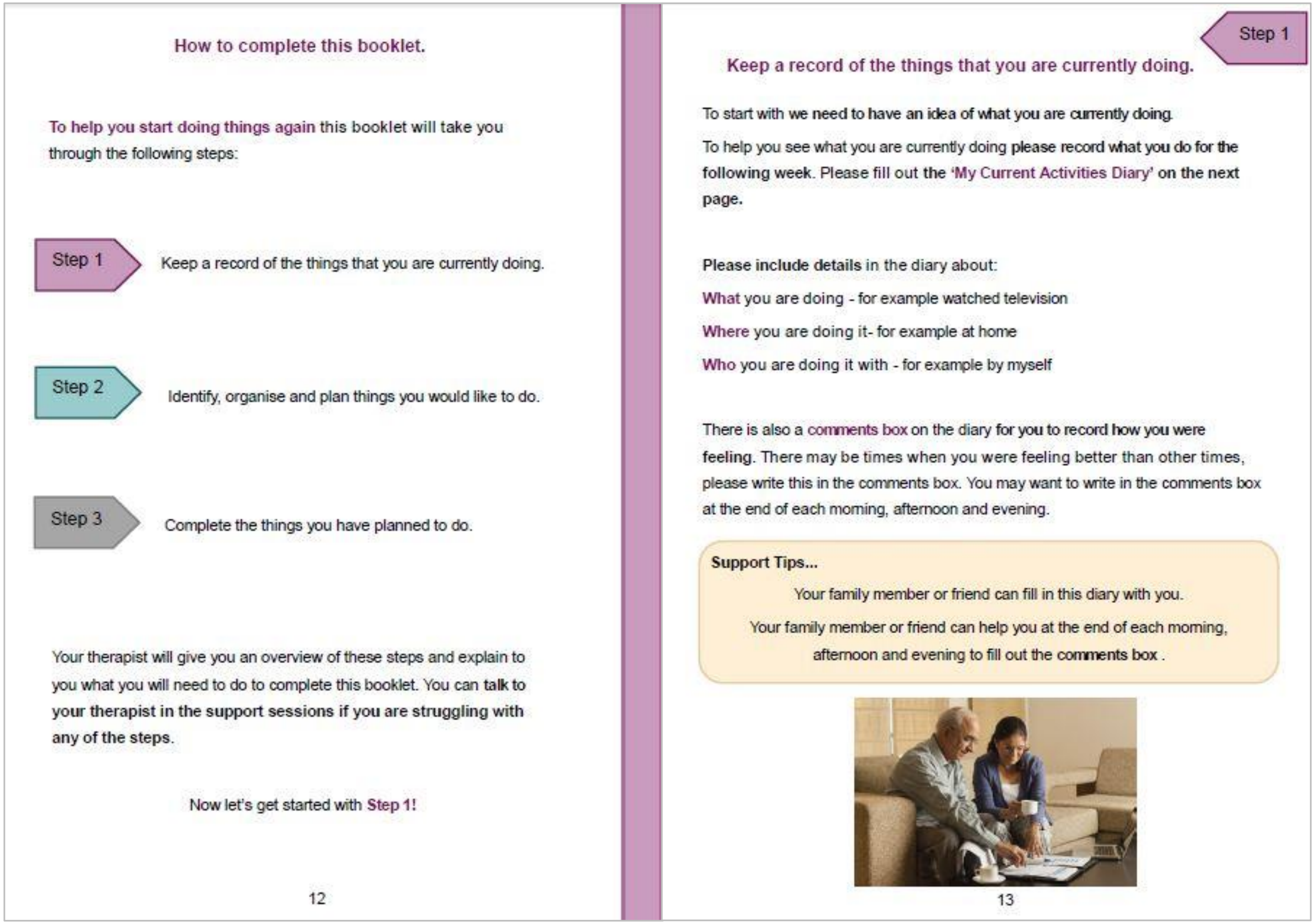
You are not experiencing enjoyment or pleasure as you are not doing things you enjoy. You feel even more tired. Your general health gets worse.

You feel even lower and upset.

This diagram shows that people stop doing things because they are experiencing low mood. However, **doing fewer things can make a person's mood worse**, and **then they want to do even less.** People can become stuck in this **cycle of low mood, doing less and feeling worse.**

Behavioural Activation tries to **break the cycle** you see above by **helping you to start doing things again**, which in turn will increase your enjoyment, and help you to feel better.

- As you work through this booklet, Behavioural Activation allows you to start doing things again at a **level you feel comfortable with. It's up to you how much you feel you can start doing again. You decide what to do and when to do it.**



How to complete this booklet.

To help you start doing things again this booklet will take you through the following steps:

Step 1 Keep a record of the things that you are currently doing.

Step 2 Identify, organise and plan things you would like to do.

Step 3 Complete the things you have planned to do.

Your therapist will give you an overview of these steps and explain to you what you will need to do to complete this booklet. You can **talk to your therapist in the support sessions if you are struggling with any of the steps.**

Now let's get started with **Step 1!**

Step 1

Keep a record of the things that you are currently doing.

To start with **we need to have an idea of what you are currently doing.**

To help you see what you are currently doing **please record what you do for the following week.** Please fill out the **'My Current Activities Diary' on the next page.**

Please include details in the diary about:

What you are doing - for example watched television

Where you are doing it- for example at home

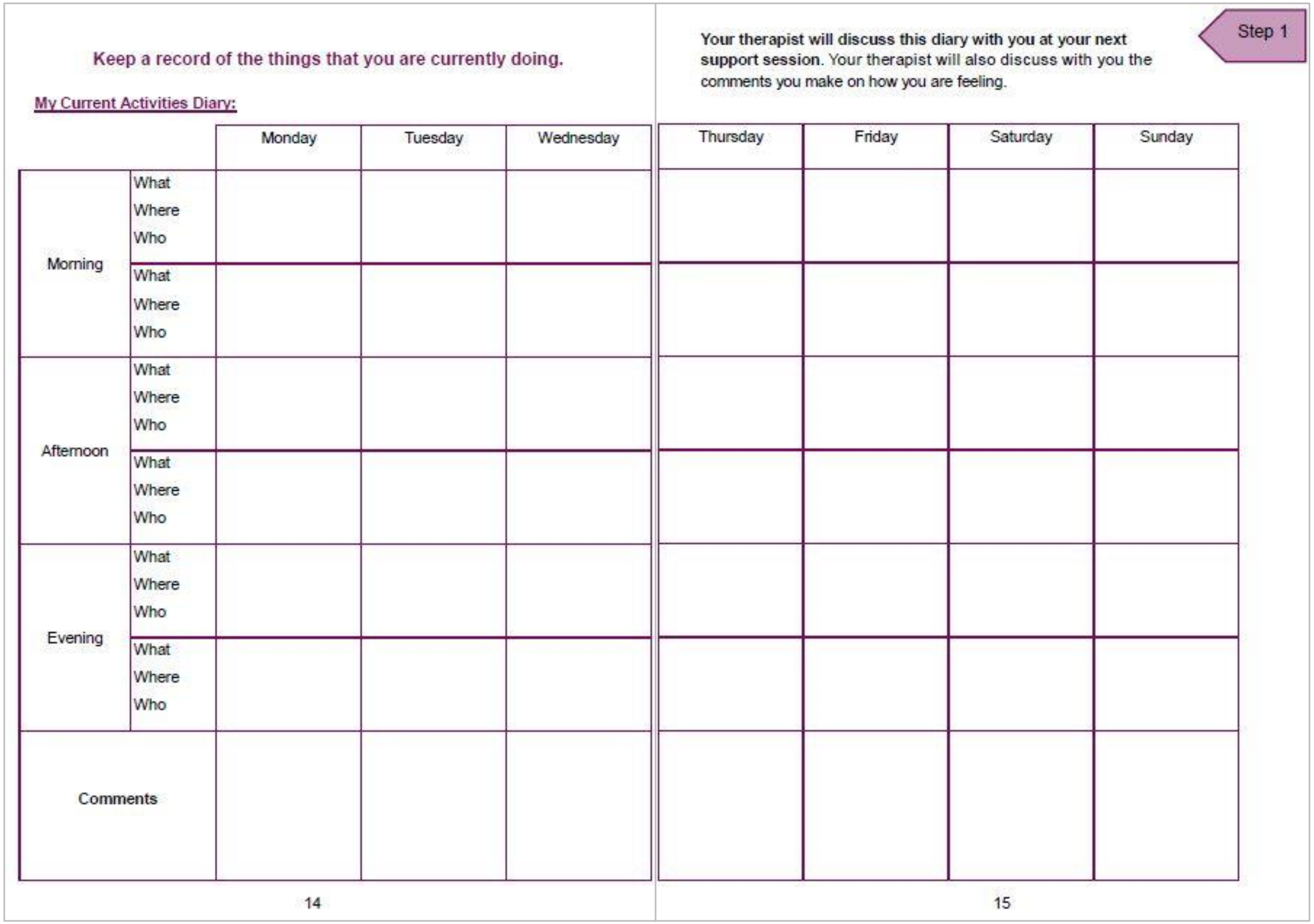
Who you are doing it with - for example by myself

There is also a **comments box** on the diary **for you to record how you were feeling.** There may be times when you were feeling better than other times, please write this in the comments box. You may want to write in the comments box at the end of each morning, afternoon and evening.

Support Tips...

Your family member or friend can fill in this diary with you.

Your family member or friend can help you at the end of each morning, afternoon and evening to fill out the **comments box** .



Step 1

Keep a record of the things that you are currently doing.

Your therapist will discuss this diary with you at your next support session. Your therapist will also discuss with you the comments you make on how you are feeling.

My Current Activities Diary:

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	What Where Who							
	What Where Who							
Afternoon	What Where Who							
	What Where Who							
Evening	What Where Who							
	What Where Who							
Comments								

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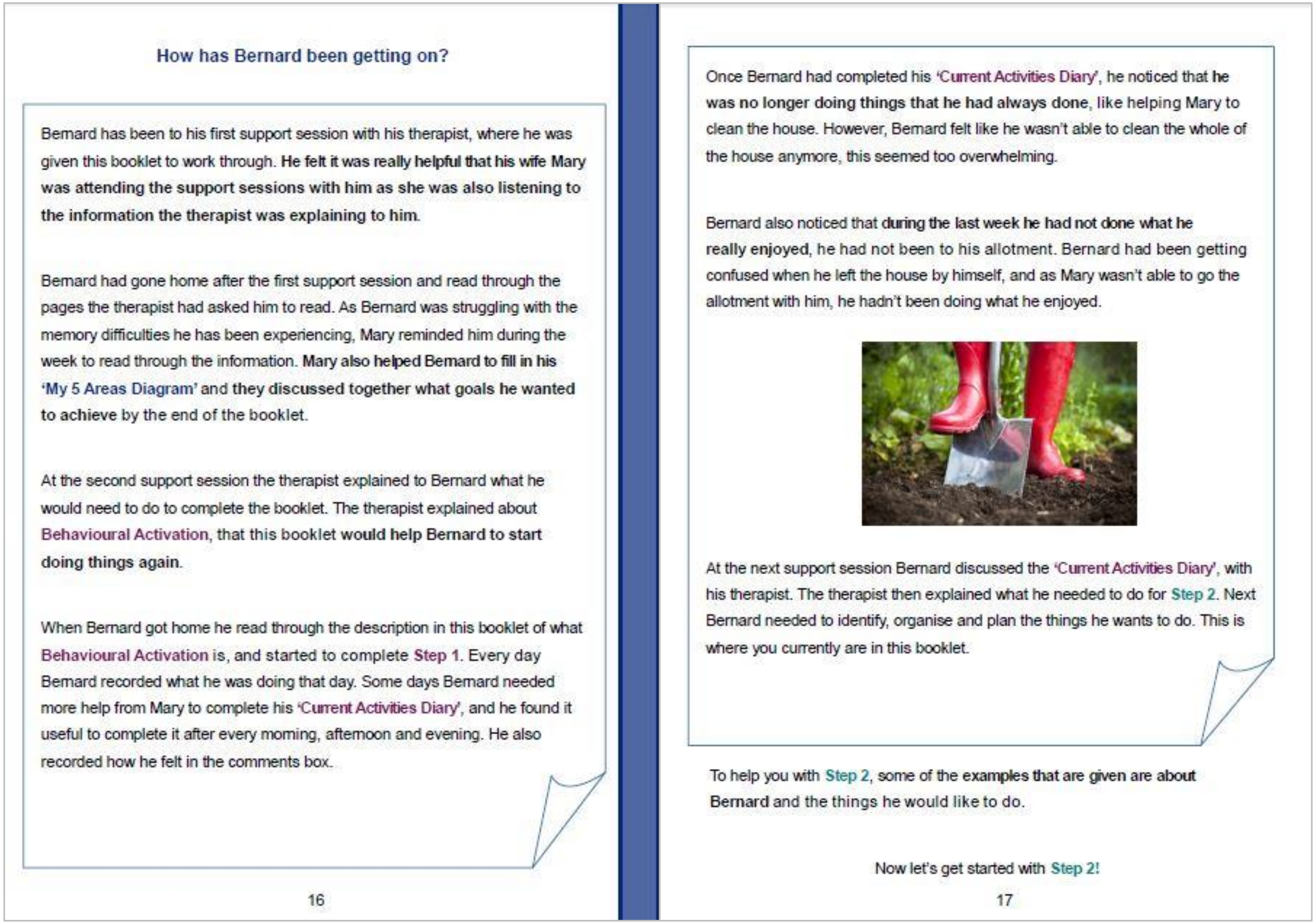

How has Bernard been getting on?

Bernard has been to his first support session with his therapist, where he was given this booklet to work through. **He felt it was really helpful that his wife Mary was attending the support sessions with him as she was also listening to the information the therapist was explaining to him.**

Bernard had gone home after the first support session and read through the pages the therapist had asked him to read. As Bernard was struggling with the memory difficulties he has been experiencing, Mary reminded him during the week to read through the information. **Mary also helped Bernard to fill in his 'My 5 Areas Diagram' and they discussed together what goals he wanted to achieve** by the end of the booklet.

At the second support session the therapist explained to Bernard what he would need to do to complete the booklet. The therapist explained about Behavioural Activation, that this booklet **would help Bernard to start doing things again.**

When Bernard got home he read through the description in this booklet of what Behavioural Activation is, and started to complete Step 1. Every day Bernard recorded what he was doing that day. Some days Bernard needed more help from Mary to complete his 'Current Activities Diary', and he found it useful to complete it after every morning, afternoon and evening. He also recorded how he felt in the comments box.

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Once Bernard had completed his 'Current Activities Diary', he noticed that **he was no longer doing things that he had always done**, like helping Mary to clean the house. However, Bernard felt like he wasn't able to clean the whole of the house anymore, this seemed too overwhelming.

Bernard also noticed that **during the last week he had not done what he really enjoyed**, he had not been to his allotment. Bernard had been getting confused when he left the house by himself, and as Mary wasn't able to go the allotment with him, he hadn't been doing what he enjoyed.

At the next support session Bernard discussed the 'Current Activities Diary', with his therapist. The therapist then explained what he needed to do for Step 2. Next Bernard needed to identify, organise and plan the things he wants to do. This is where you currently are in this booklet.

To help you with Step 2, some of the **examples that are given are about Bernard** and the things he would like to do.

Now let's get started with Step 2!

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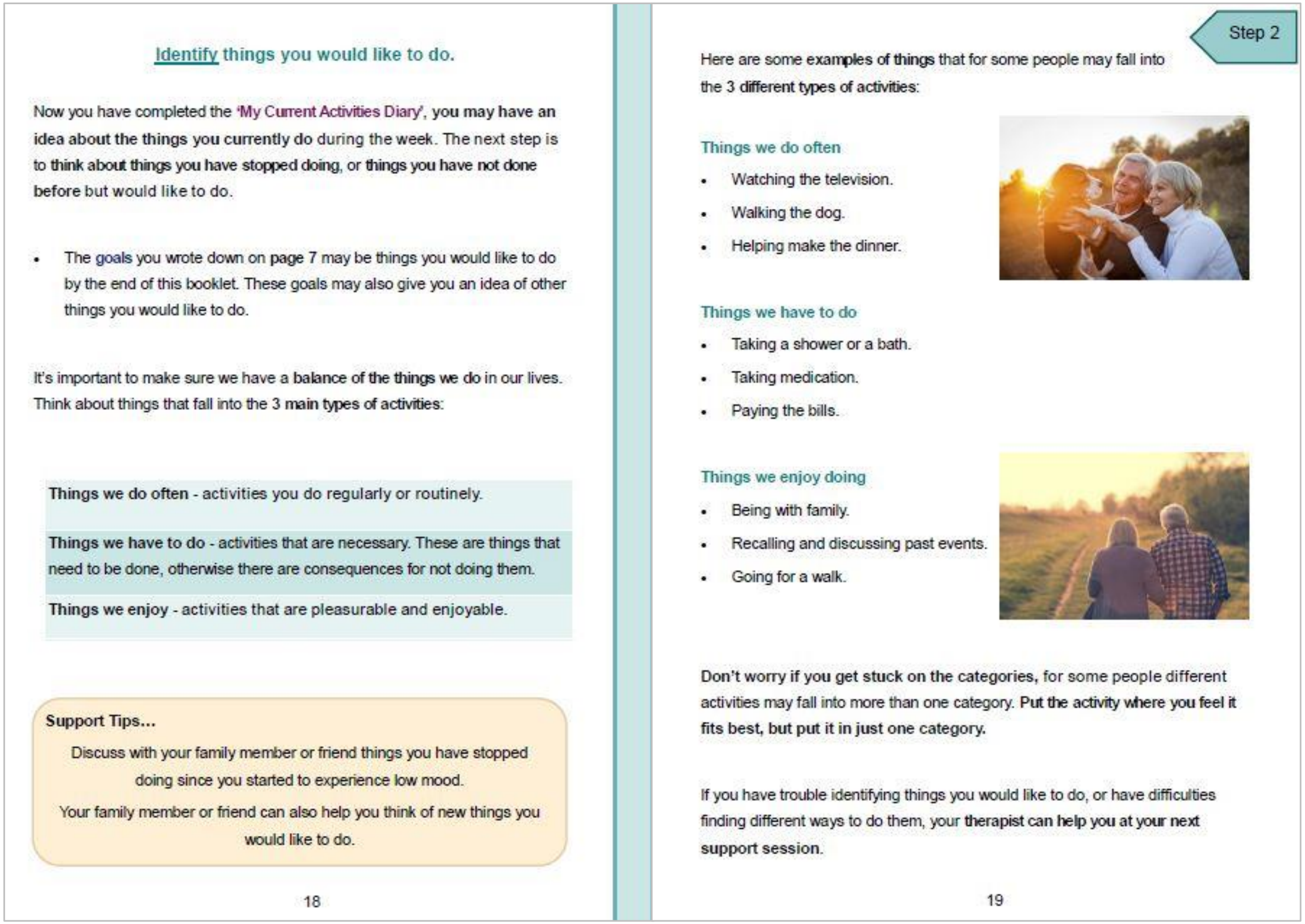


Identify things you would like to do.

Now you have completed the **'My Current Activities Diary'**, **you may have an idea about the things you currently do** during the week. The next step is to **think about things you have stopped doing**, or **things you have not done before** but would like to do.

- The **goals** you wrote down on page 7 may be things you would like to do by the end of this booklet. These goals may also give you an idea of other things you would like to do.

It's important to make sure we have a **balance of the things we do** in our lives. Think about things that fall into the **3 main types of activities**:

Things we do often - activities you do regularly or routinely.

Things we have to do - activities that are necessary. These are things that need to be done, otherwise there are consequences for not doing them.

Things we enjoy - activities that are pleasurable and enjoyable.

Support Tips…

Discuss with your family member or friend things you have stopped doing since you started to experience low mood.

Your family member or friend can also help you think of new things you would like to do.

Here are some **examples of things** that for some people may fall into the **3 different types of activities**:

Things we do often

- Watching the television.
- Walking the dog.
- Helping make the dinner.

Things we have to do

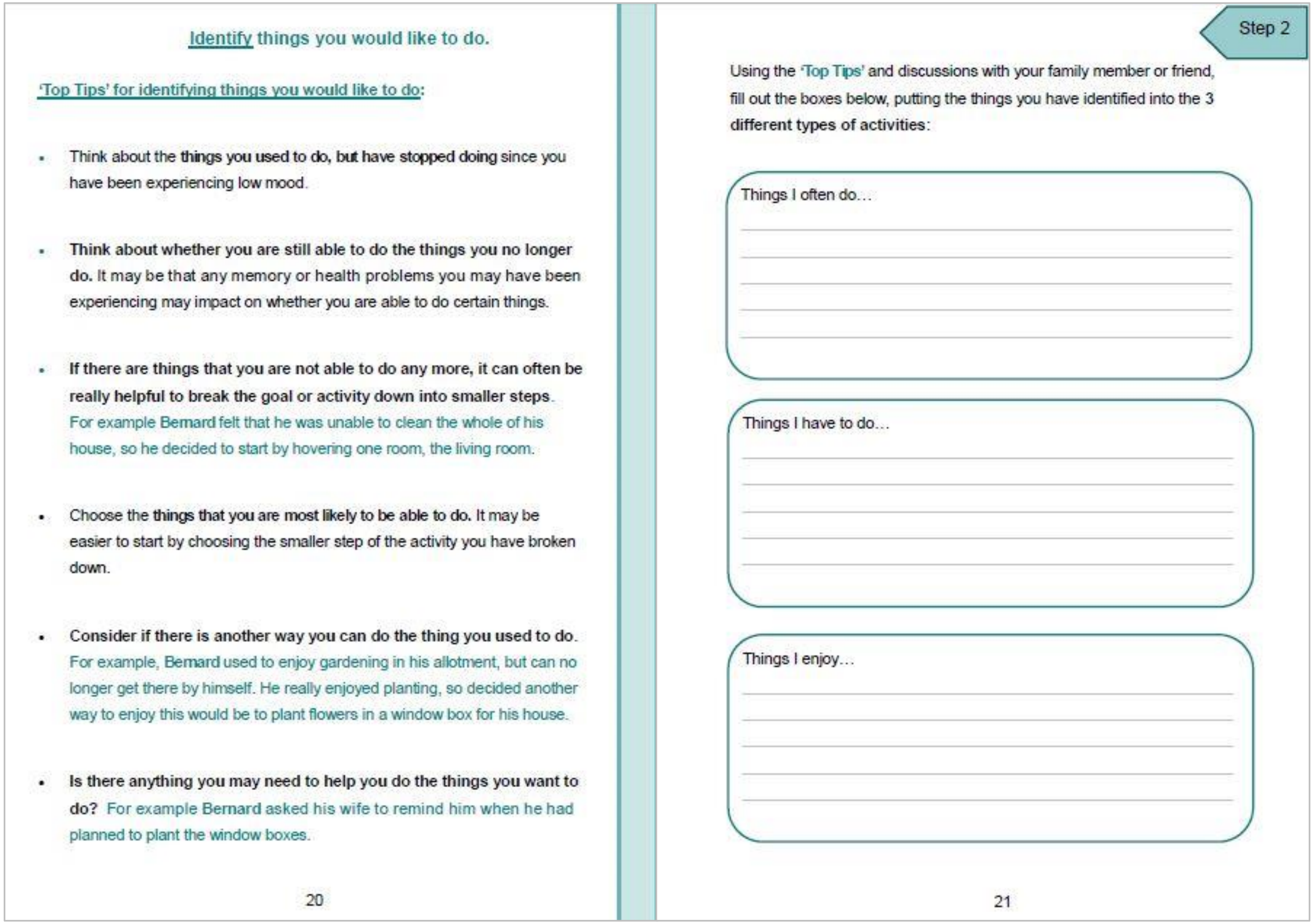
- Taking a shower or a bath.
- Taking medication.
- Paying the bills.

Things we enjoy doing

- Being with family.
- Recalling and discussing past events.
- Going for a walk.

Don't worry if you get stuck on the categories, for some people different activities may fall into more than one category. **Put the activity where you feel it fits best, but put it in just one category.**

If you have trouble identifying things you would like to do, or have difficulties finding different ways to do them, your **therapist can help you at your next support session.**



Identify things you would like to do.

'Top Tips' for identifying things you would like to do:

- Think about the **things you used to do, but have stopped doing** since you have been experiencing low mood.
- **Think about whether you are still able to do the things you no longer do.** It may be that any memory or health problems you may have been experiencing may impact on whether you are able to do certain things.
- **If there are things that you are not able to do any more, it can often be really helpful to break the goal or activity down into smaller steps**. For example Bernard felt that he was unable to clean the whole of his house, so he decided to start by hovering one room, the living room.
- Choose the **things that you are most likely to be able to do.** It may be easier to start by choosing the smaller step of the activity you have broken down.
- **Consider if there is another way you can do the thing you used to do.** For example, Bernard used to enjoy gardening in his allotment, but can no longer get there by himself. He really enjoyed planting, so decided another way to enjoy this would be to plant flowers in a window box for his house.
- **Is there anything you may need to help you do the things you want to do?** For example Bernard asked his wife to remind him when he had planned to plant the window boxes.

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Step 2

Using the 'Top Tips' and discussions with your family member or friend, fill out the boxes below, putting the things you have identified into the 3 **different types of activities**:

Things I often do…

Things I have to do…

Things I enjoy…

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Step 2

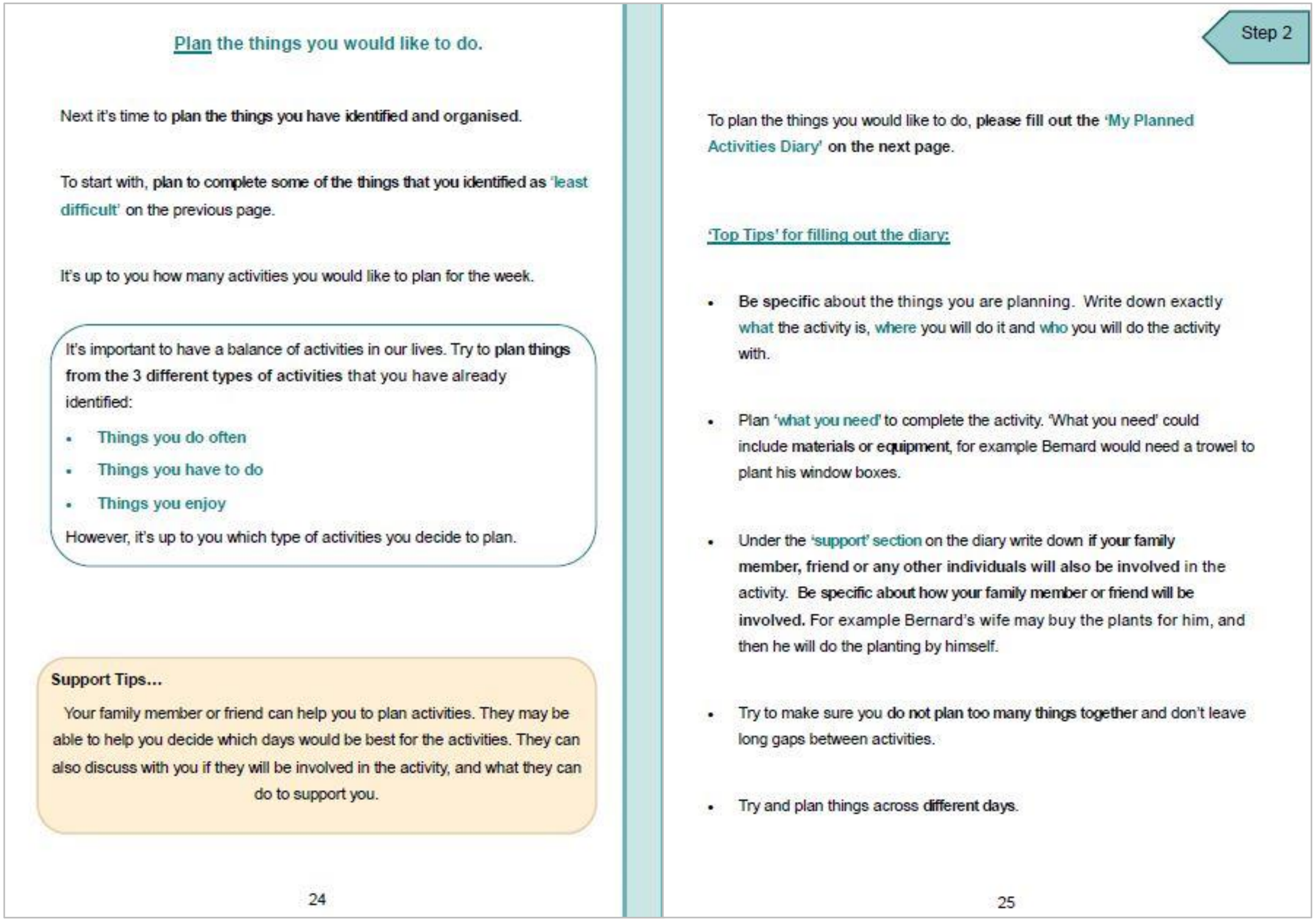
Organise the things you would like to do.

Now let's put the **things you have identified** into an **order of how difficult they are to complete**. To put the activities into an order, **think about how difficult they would be to complete in the next day or two**. Please fill out the boxes below:

Least difficult: things that may be causing you a little bit of difficulty, but with work you could achieve them.

Medium difficult: things that would be too difficult to do straight away, but with support from a family member or friend, you can see yourself managing them soon.

Most difficult: Things that at present just seem far too difficult to do. Although these are very hard, with help from your family member or friend, you can work towards them.



Plan the things you would like to do.

Next it's time to **plan the things you have identified and organised**.

To start with, **plan to complete some of the things that you identified as** 'least difficult' on the previous page.

It's up to you how many activities you would like to plan for the week.

It's important to have a balance of activities in our lives. Try to **plan things from the 3 different types of activities** that you have already identified:

- Things you do often
- Things you have to do
- Things you enjoy

However, it's up to you which type of activities you decide to plan.

Support Tips…

Your family member or friend can help you to plan activities. They may be able to help you decide which days would be best for the activities. They can also discuss with you if they will be involved in the activity, and what they can do to support you.

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Step 2

To plan the things you would like to do, **please fill out the** 'My Planned Activities Diary' **on the next page**.

'Top Tips' for filling out the diary:

- **Be specific** about the things you are planning. Write down exactly what the activity is, where you will do it and who you will do the activity with.
- Plan 'what you need' to complete the activity. 'What you need' could include **materials or equipment**, for example Bernard would need a trowel to plant his window boxes.
- Under the 'support' section on the diary write down **if your family member, friend or any other individuals will also be involved** in the activity. **Be specific about how your family member or friend will be involved.** For example Bernard's wife may buy the plants for him, and then he will do the planting by himself.
- Try to make sure you **do not plan too many things together** and don't leave long gaps between activities.
- Try and plan things across **different days**.

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My Planned Activities Diary:

Step 2

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	What Where Who What I need Support							
	What Where Who What I need Support							
Afternoon	What Where Who What I need Support							
	What Where Who What I need Support							
Evening	What Where Who What I need Support							
	What Where Who What I need Support							
Comments								

26

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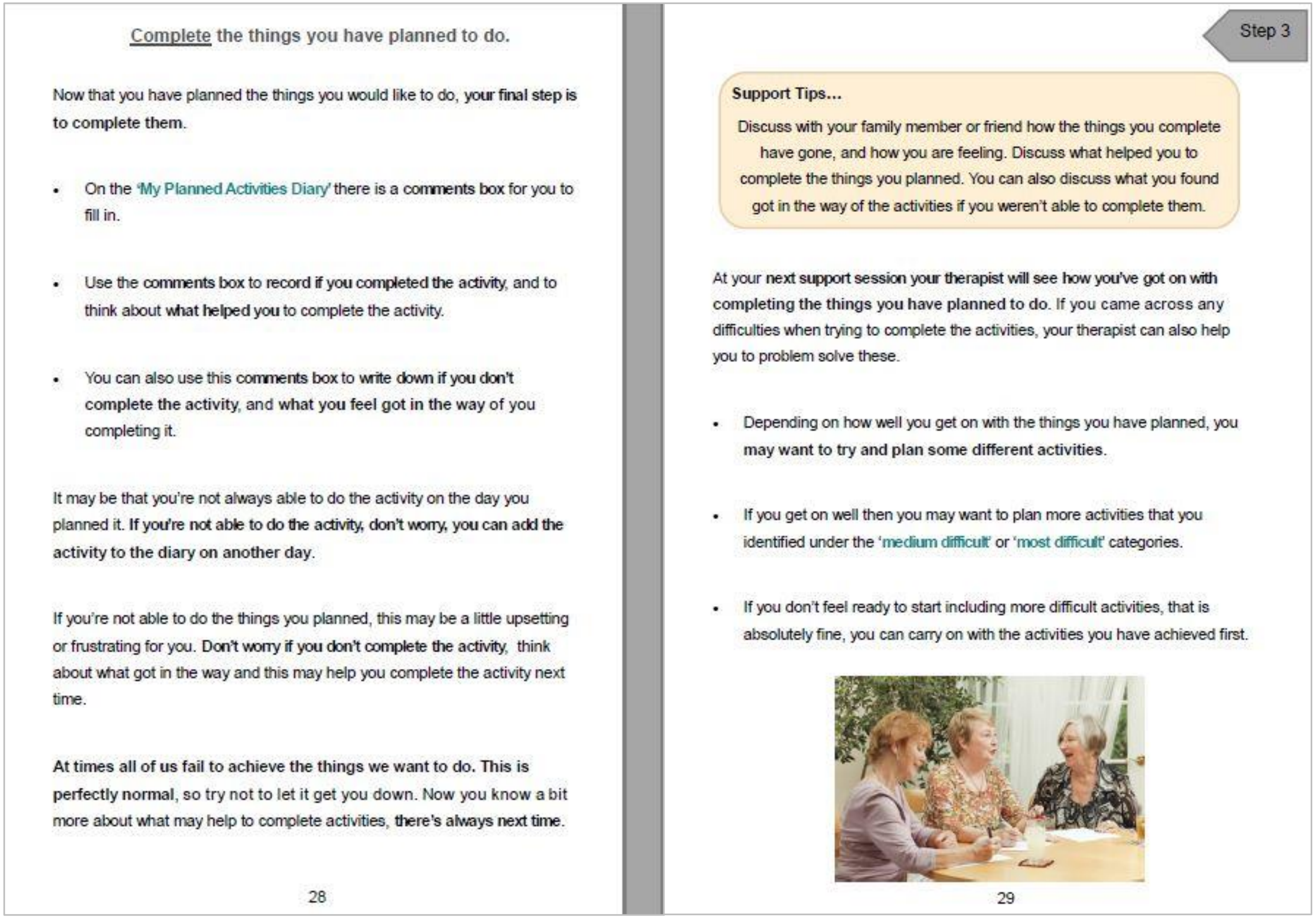

Complete the things you have planned to do.

Now that you have planned the things you would like to do, **your final step is to complete them.**

- On the 'My Planned Activities Diary' there is a **comments box** for you to fill in.
- Use the **comments box** to **record if you completed the activity**, and to think about **what helped you** to complete the activity.
- You can also use this **comments box** to **write down if you don't complete the activity**, and **what you feel got in the way** of you completing it.

It may be that you're not always able to do the activity on the day you planned it. **If you're not able to do the activity, don't worry, you can add the activity to the diary on another day.**

If you're not able to do the things you planned, this may be a little upsetting or frustrating for you. **Don't worry if you don't complete the activity**, think about what got in the way and this may help you complete the activity next time.

At times all of us fail to achieve the things we want to do. This is perfectly normal, so try not to let it get you down. Now you know a bit more about what may help to complete activities, **there's always next time.**

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Step 3

Support Tips…

Discuss with your family member or friend how the things you complete have gone, and how you are feeling. Discuss what helped you to complete the things you planned. You can also discuss what you found got in the way of the activities if you weren't able to complete them.

At your **next support session your therapist will see how you've got on with completing the things you have planned to do.** If you came across any difficulties when trying to complete the activities, your therapist can also help you to problem solve these.

- Depending on how well you get on with the things you have planned, you **may want to try and plan some different activities.**
- If you get on well then you may want to plan more activities that you identified under the 'medium difficult' or 'most difficult' categories.
- If you don't feel ready to start including more difficult activities, that is absolutely fine, you can carry on with the activities you have achieved first.

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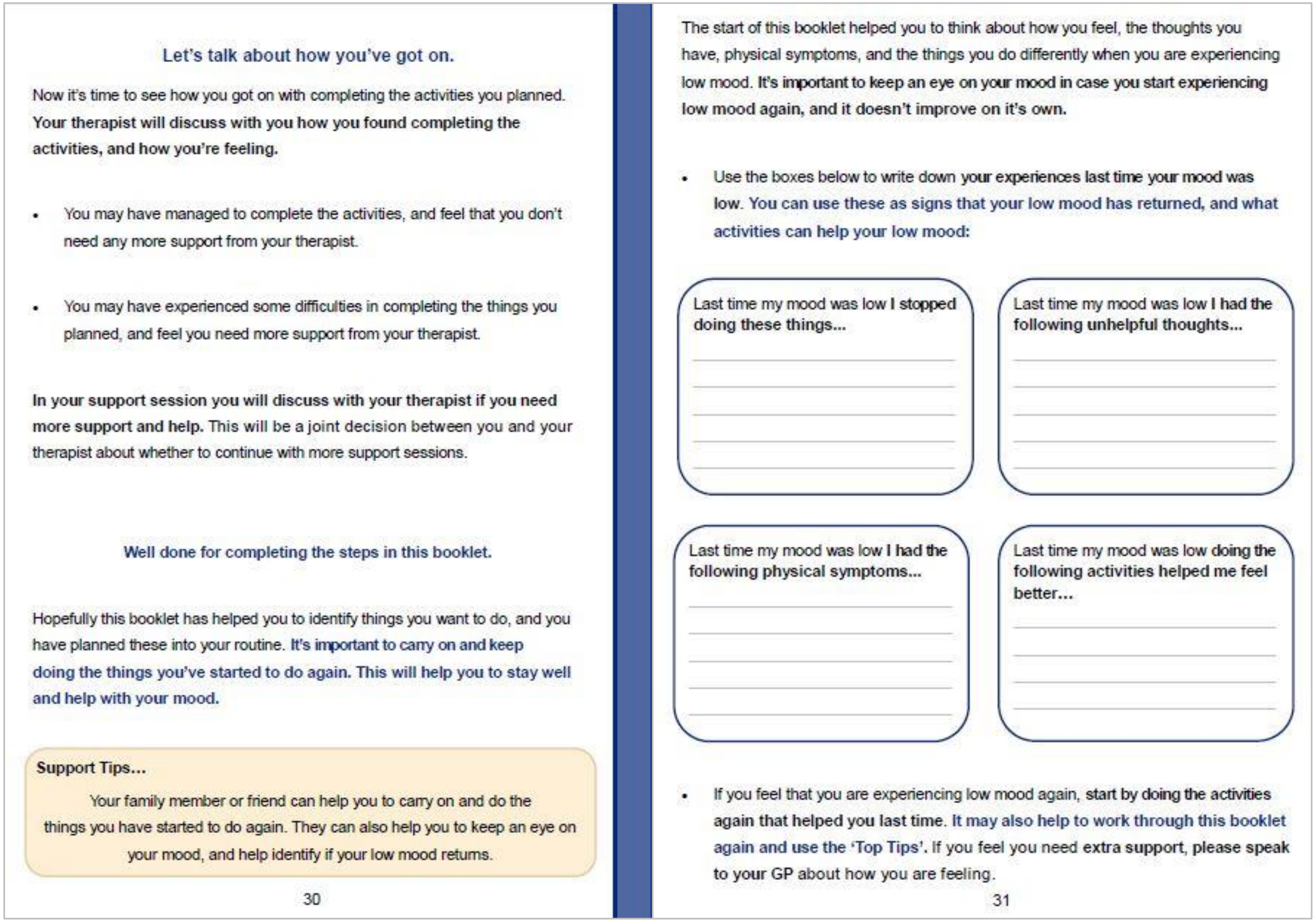

Let's talk about how you've got on.

Now it's time to see how you got on with completing the activities you planned. **Your therapist will discuss with you how you found completing the activities, and how you're feeling.**

- You may have managed to complete the activities, and feel that you don't need any more support from your therapist.
- You may have experienced some difficulties in completing the things you planned, and feel you need more support from your therapist.

In your support session you will discuss with your therapist if you need more support and help. This will be a joint decision between you and your therapist about whether to continue with more support sessions.

Well done for completing the steps in this booklet.

Hopefully this booklet has helped you to identify things you want to do, and you have planned these into your routine. **It's important to carry on and keep doing the things you've started to do again. This will help you to stay well and help with your mood.**

Support Tips…

Your family member or friend can help you to carry on and do the things you have started to do again. They can also help you to keep an eye on your mood, and help identify if your low mood returns.

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The start of this booklet helped you to think about how you feel, the thoughts you have, physical symptoms, and the things you do differently when you are experiencing low mood. **It's important to keep an eye on your mood in case you start experiencing low mood again, and it doesn't improve on it's own.**

- Use the boxes below to write down **your experiences last time your mood was low. You can use these as signs that your low mood has returned, and what activities can help your low mood:**

Last time my mood was low **I stopped doing these things…**

Last time my mood was low **I had the following unhelpful thoughts…**

Last time my mood was low **I had the following physical symptoms…**

Last time my mood was low **doing the following activities helped me feel better…**

- If you feel that you are experiencing low mood again, **start by doing the activities again that helped you last time. It may also help to work through this booklet again and use the 'Top Tips'.** If you feel you need **extra support, please speak to your GP** about how you are feeling.

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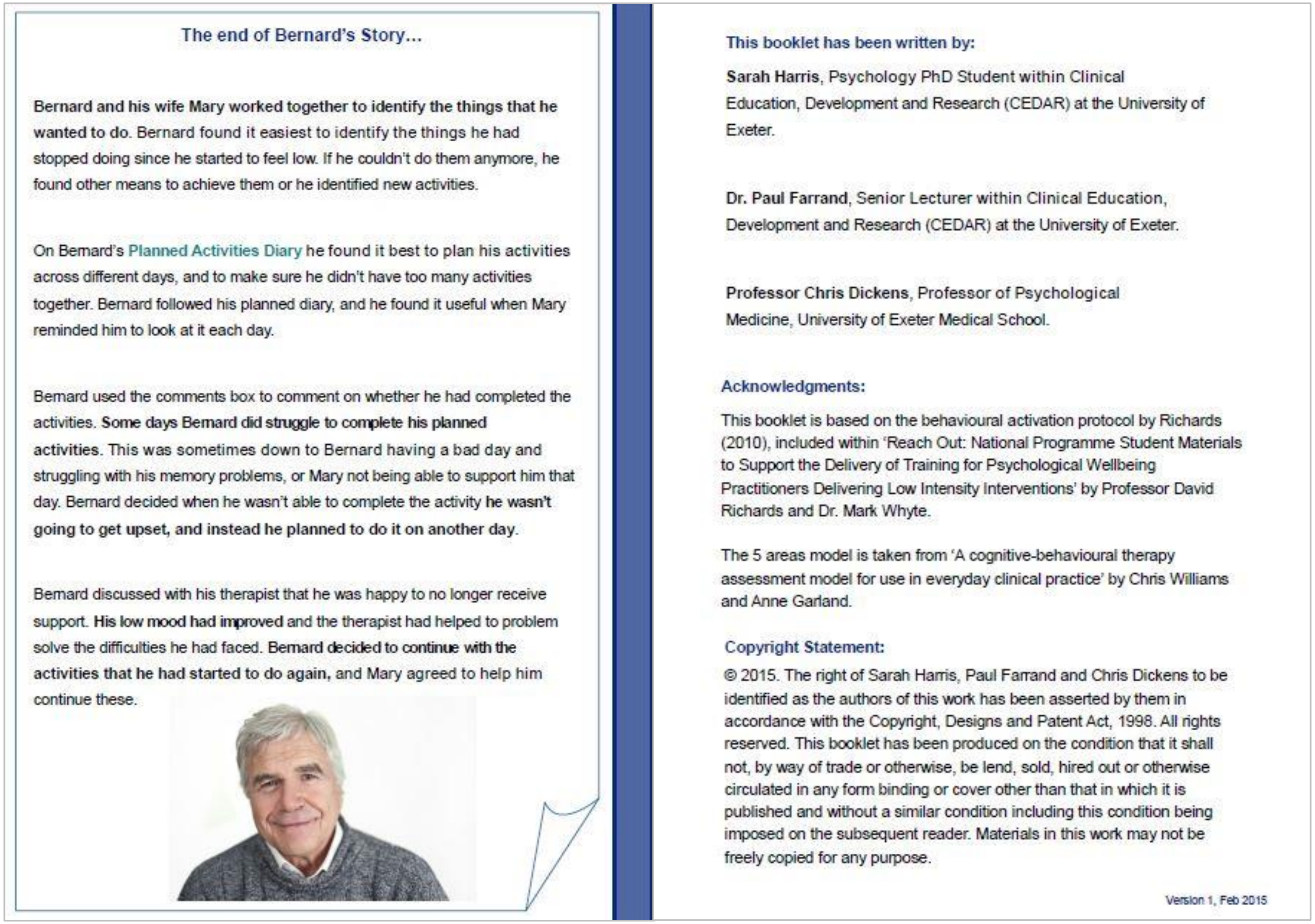

The end of Bernard's Story…

Bernard and his wife Mary worked together to identify the things that he wanted to do. Bernard found it easiest to identify the things he had stopped doing since he started to feel low. If he couldn't do them anymore, he found other means to achieve them or he identified new activities.

On Bernard's Planned Activities Diary he found it best to plan his activities across different days, and to make sure he didn't have too many activities together. Bernard followed his planned diary, and he found it useful when Mary reminded him to look at it each day.

Bernard used the comments box to comment on whether he had completed the activities. **Some days Bernard did struggle to complete his planned activities.** This was sometimes down to Bernard having a bad day and struggling with his memory problems, or Mary not being able to support him that day. Bernard decided when he wasn't able to complete the activity **he wasn't going to get upset, and instead he planned to do it on another day.**

Bernard discussed with his therapist that he was happy to no longer receive support. **His low mood had improved** and the therapist had helped to problem solve the difficulties he had faced. **Bernard decided to continue with the activities that he had started to do again,** and Mary agreed to help him continue these.

This booklet has been written by:

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Professor Chris Dickens, Professor of Psychological Medicine, University of Exeter Medical School.

Acknowledgments:

This booklet is based on the behavioural activation protocol by Richards (2010), included within 'Reach Out: National Programme Student Materials to Support the Delivery of Training for Psychological Wellbeing Practitioners Delivering Low Intensity Interventions' by Professor David Richards and Dr. Mark Whyte.

The 5 areas model is taken from 'A cognitive-behavioural therapy assessment model for use in everyday clinical practice' by Chris Williams and Anne Garland.

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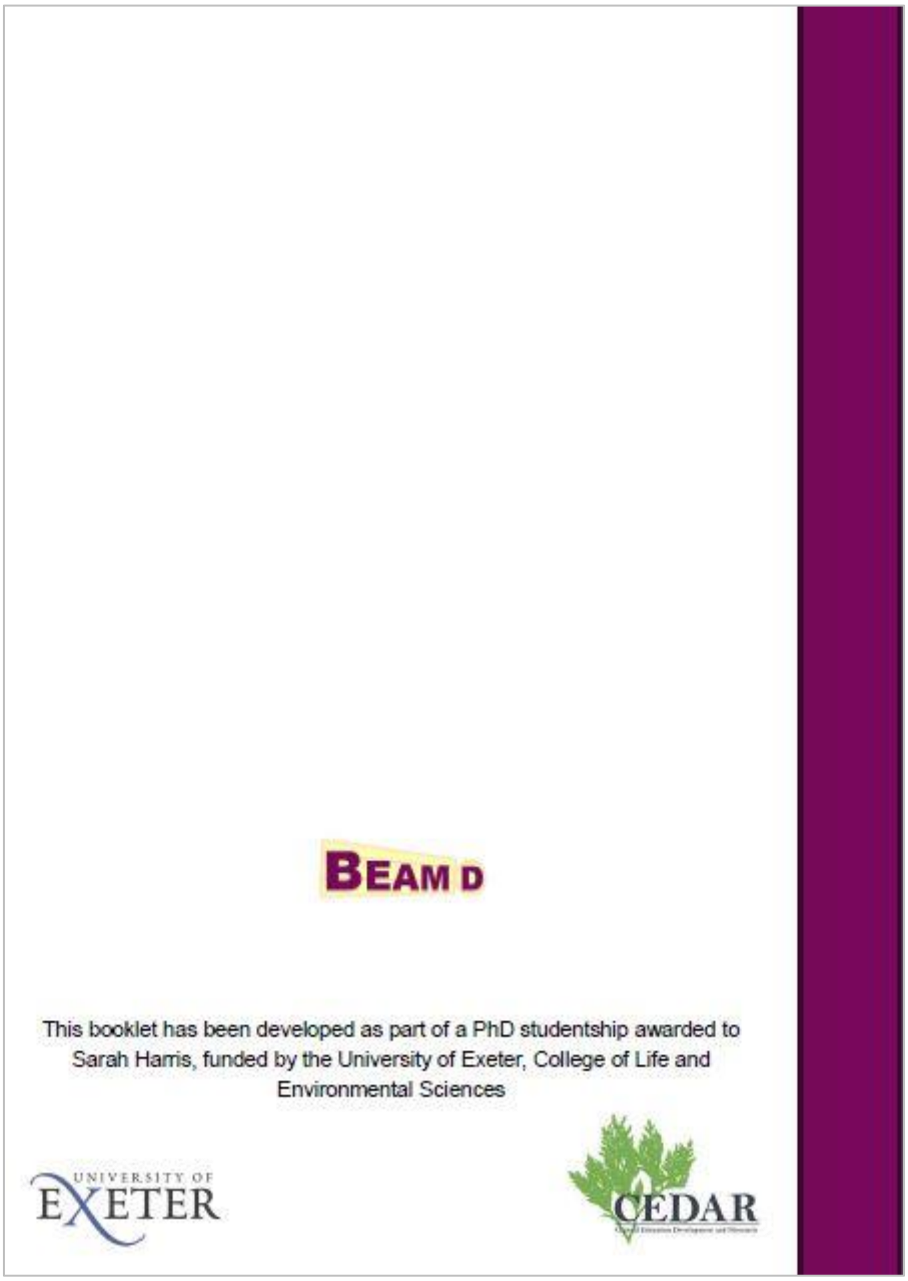

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This booklet has been developed as part of a PhD studentship awarded to Sarah Harris, funded by the University of Exeter, College of Life and Environmental Sciences

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Appendix 4.2 Overview of Support Session Content

Session	Session Content
Assessment Session	• Discuss agenda for the session. • Discuss why the person with dementia has come to the programme. • Complete geriatric depression scale-15. • Assess risk. • Establish if the person with dementia is being supported by anyone else (for example the community mental health team). • Discuss and agree with the dyad (person with dementia and carer) how much the carer will be involved and what they will do to support the programme and person with dementia. • Discuss the Five Areas™ of depression, a provisional diagnosis (of low mood) and problem statement. • Other important information (medication review). • Provide information about low mood. • Give the workbook to the person with dementia and explain how support sessions will work. Page 1 of the workbook provides an overview of the programme. To be completed for the next support session: • Read pages 2-7 about low mood and goal setting. • Read ‘Bernard’s Story’ on pages 8-9. • Complete Five Areas™ diagram on page 5, and goals on page 7.
Session 2	• Discuss agenda for the session. • Complete geriatric depression scale-15. • Assess risk. • Review problem statement. • Recap of what has been completed since the assessment session.

	• Review the Five Areas™ diagram and goals. • Provide rationale for BA verbally and show the rationale for BA on pages 10-11 of the workbook. • Provide an overview of the steps involved in the programme (page 12 of the workbook). • Show the 'My Current Activities Diary' (step 1) on pages 14-15 of the workbook. To be completed for the next support session: • Record current activities for the week. • Read Bernard's Story on pages 16-17.
Session 3	• Discuss agenda for the session. • Complete geriatric depression scale-15. • Assess risk. • Review problem statement. • Talk through 'My Current Activities Diary' and discuss what activities the person with dementia has done and how they have been feeling. Comment on the amount and type of activities. Link to low mood and doing fewer activities. • Go through steps 2 and 3 (pages 18-29). Start the person with dementia identifying activities. Explain how to organise and plan the activities. To be completed for the next support session: • Identify, organise, plan and complete activities.
Session 4	• Discuss agenda for the session. • Complete geriatric depression scale-15. • Assess risk. • Review problem statement. • Review how the person with dementia has been getting along with the planned activities. • If the person with dementia is struggling, help to problem solve. • Discuss with the person with dementia whether more support is needed.

	• Clinical decision about whether the person with dementia is improving.
	• If needed, continue support sessions and continue planning and completing activities. In each subsequent session discuss agenda, complete geriatric depression scale-15, assess risk, review problem statement, review progress with planned activities and help to problem solve if the person with dementia is struggling. • If support sessions continue, the final session will be the 12th session- discuss relapse prevention, low mood warning signs (page 31) and discharge.
	• If the person with dementia is doing well and does not need any more help, discharge to their GP. • Discuss relapse prevention and low mood warning signs (page 31).

Note: Page numbers correspond with workbook V1; BA = behavioural activation; GP = general practitioner.

Appendix 4.3 Study Two Interview Schedule

“Thank you very much for agreeing to be interviewed as part of the development process for a low intensity guided self-help programme which we are developing as part of my PhD at the University of Exeter. The aim of the programme is to improve low mood in individuals with dementia. Firstly I would like to ask you some general questions about low mood and current services, before I ask you more specific questions about the programme itself…”

Questions	Prompts
Could you please tell me a little bit about how you felt when you had low mood? Can you please tell me a little bit about how your family member felt when they had low mood?	Lack of interest in things? Feeling sad/depressed/hopeless? Trouble with sleep? Tiredness/lack of energy? Changes in appetite? Trouble concentrating? Etc.
Notes:	
When you were experiencing low mood, did you find you (your family member) were (was) able to carry on doing activities you (they) previously did?	Fewer activities which you (they) used to enjoy? Fewer routine or necessary activities?
Notes:	
Where you (they) offered any help for your low mood?	Any particular services? Who offered help? Did you (they) speak to your GP about how you felt?
Notes:	
Do you think something should be offered to help with low mood in individuals with dementia?	If yes – what do you think would help?
Notes:	

“As part of my research I am developing a programme to help with low mood in dementia. The programme is based on an intervention called behavioural activation, which aims to increase activities across three areas of a person’s life to gain balance and to improve mood.

This programme is guided self-help, which means there is weekly contact with a therapist to support the programme. The therapist acts a bit like a coach to help the individual understand the programme and to use the skills and techniques from the workbook. There will be up to 12 support sessions, that are up to 40 minutes in length, but the session number and length is agreed in collaboration with the person receiving the programme. The number of support sessions is dependent on how long the individual takes to complete the workbook.”

Questions	Prompts
What do you think would be any benefits of having the programme supported by a therapist?	Expert knowledge? Guidance? Help problem solve?
Notes:	
Do you think there are any barriers or problems with having the programme supported by a therapist?	Time/length of sessions? Getting to see the therapist?
Notes:	

“This programme involves a workbook that is completed at home. In the support sessions the therapist checks how the individual is getting along with the self-help materials and helps with any problems they may be experiencing. In the workbook the individual will identify, schedule and complete activities. An informal carer will also help the individual through the programme. The informal carer will also attend the support sessions with the individual and will help them complete the workbook. The informal carer may be involved in identifying activities, helping to schedule them and also helping to complete them.”

Questions	Prompts
What should the informal carer be referred to in the workbook/support sessions?	Family member/friend?
Notes:	

Are there any benefits to involving an informal carer in attending the support sessions and helping to complete the workbook?	If so – what? Helping to get to support session? Helping to remember/also will learn the rationale? Will an informal carer be beneficial for any memory problems? Helping to identify activities? Help to complete activities?
Notes:	
Are there any barriers or problems which may be faced involving an informal carer in supporting the programme?	Time? Commitment?
Notes:	
In your opinion, what sort of things would the informal carer help to complete in the workbook?	Identifying? Scheduling? Completing? Remembering the rationale?
Notes:	
What do you think of the term ‘therapist’? Are there any benefits/barriers to the use of this term?	What other term would you use? Coach? Practitioner?
Notes:	

“Here is a draft of the programme workbook. I would like you to have a look through the workbook and then I will ask you some questions about it”

Questions	Prompts
What are your initial impressions of the layout of the workbook?	Amount of information? Layout? Colour? White spaces? Glossary?

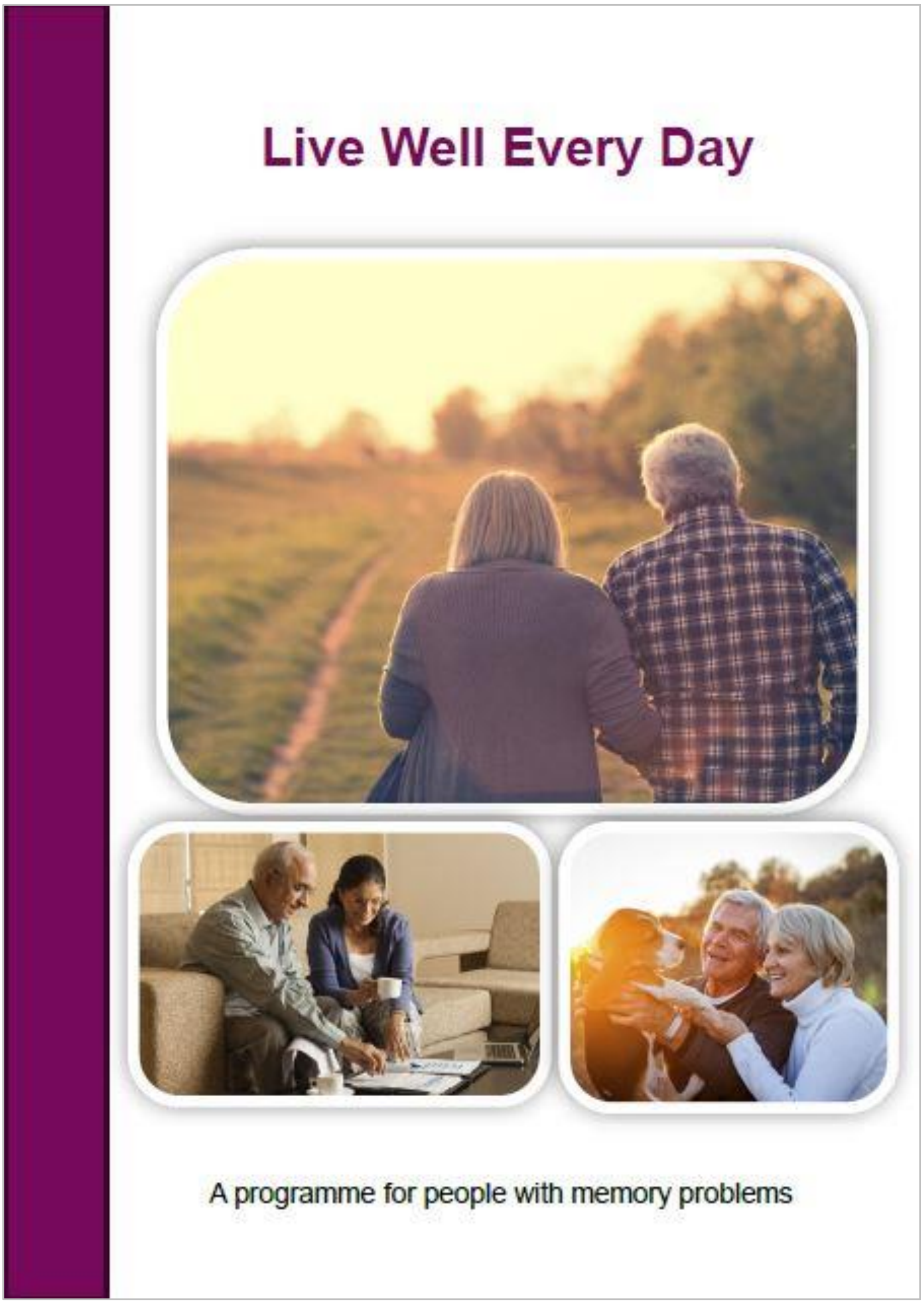
	Photographs or illustrations? Illustrations if they have a relevant context?
Notes:	
What are your initial impressions about the worksheets that need to be completed?	Look? Layout?
Notes:	
What do you think about providing a list of potential activities which are suitable for individuals with dementia?	Will it help to identify activities?
Notes:	
What do you think of the steps that are provided to help schedule activities?	Is there anything else that would help someone with dementia to identify, schedule and complete activities? Any techniques to aid memory problems?
Notes:	
What are your thoughts on the informal carer information sections?	Important? Right information? Have separately?
Notes:	

Do you think the format and layout are suitable for people with dementia?	If yes – why? If no – why?
Notes:	
What do you think of the case studies?	Should they be presented in a separate booklet? Included in the same workbook? The idea that some of the worksheet are completed?
Notes:	
Are there any changes you would make to the programme workbook? To the delivery of the programme?	Ideas about length and amount of sessions? Involvement of informal carer? Other support that may be needed?
Notes:	
The acronym used in the information sheets and consent forms for the next study is ‘BEAMD’ – behavioural activation for mood in dementia. What do you think of this acronym?	Use of an acronym in general? Use of the term dementia in the acronym?
Notes:	

“Thank you for your help today. I would just like to summarise a few of the main points which you made today…….

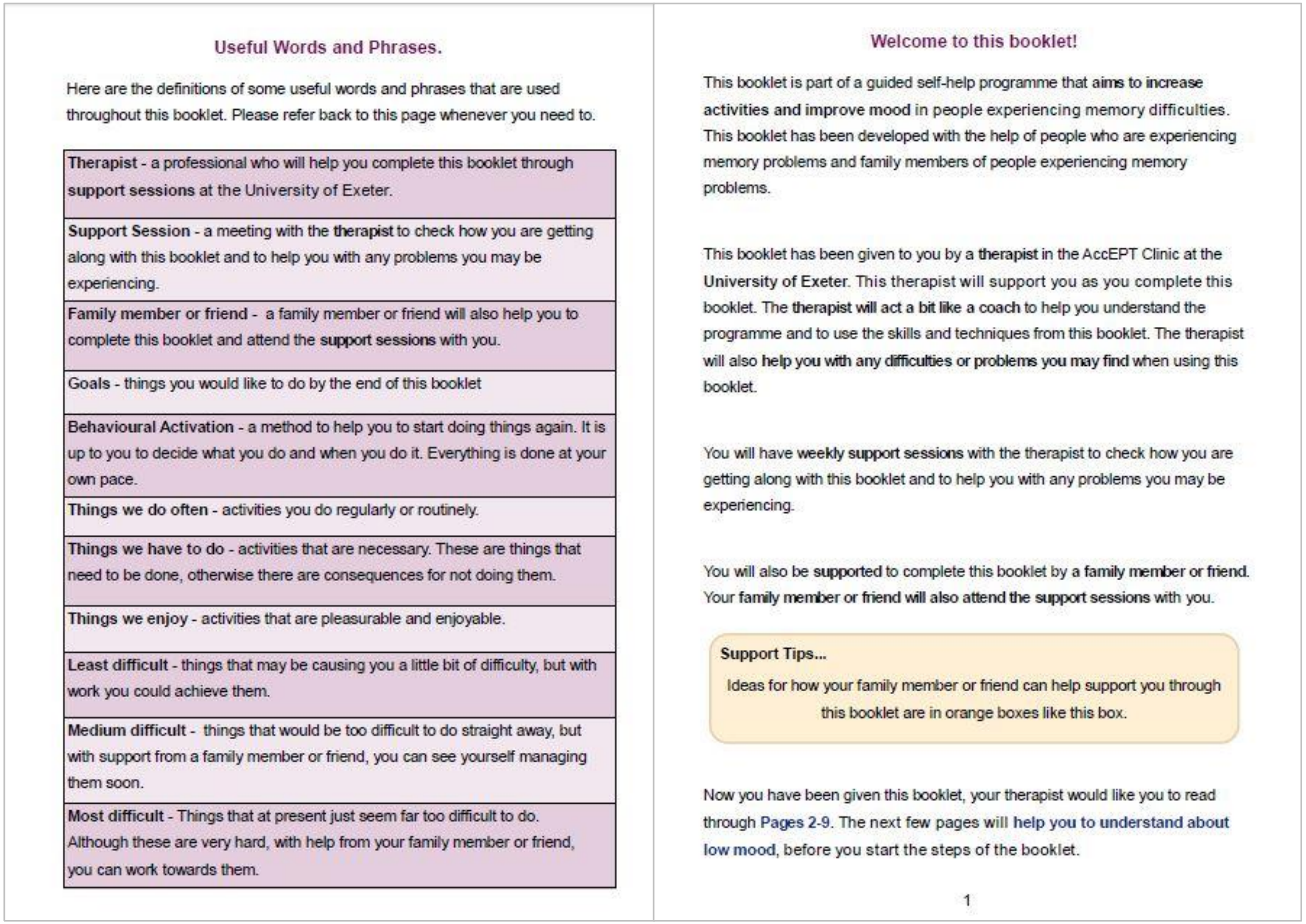
The purpose of the interviews with individuals with dementia and carers is to identify and adaptations or alterations which may be needed to the programme or the workbook to ensure that it is suitable for individuals with dementia. Any alterations which are highlighted in theses interviews will be made to the programme before we investigate uncertainties around the acceptability and feasibility of the programme. Thank you once again.”

Appendix 4.4 BEAMD Workbook (Version 1.1)



Live Well Every Day

A programme for people with memory problems



Useful Words and Phrases.

Here are the definitions of some useful words and phrases that are used throughout this booklet. Please refer back to this page whenever you need to.

Therapist - a professional who will help you complete this booklet through **support sessions** at the University of Exeter.

Support Session - a meeting with the **therapist** to check how you are getting along with this booklet and to help you with any problems you may be experiencing.

Family member or friend - a family member or friend will also help you to complete this booklet and attend the **support sessions** with you.

Goals - things you would like to do by the end of this booklet

Behavioural Activation - a method to help you to start doing things again. It is up to you to decide what you do and when you do it. Everything is done at your own pace.

Things we do often - activities you do regularly or routinely.

Things we have to do - activities that are necessary. These are things that need to be done, otherwise there are consequences for not doing them.

Things we enjoy - activities that are pleasurable and enjoyable.

Least difficult - things that may be causing you a little bit of difficulty, but with work you could achieve them.

Medium difficult - things that would be too difficult to do straight away, but with support from a family member or friend, you can see yourself managing them soon.

Most difficult - Things that at present just seem far too difficult to do. Although these are very hard, with help from your family member or friend, you can work towards them.

Welcome to this booklet!

This booklet is part of a guided self-help programme that **aims to increase activities and improve mood** in people experiencing memory difficulties. This booklet has been developed with the help of people who are experiencing memory problems and family members of people experiencing memory problems.

This booklet has been given to you by a **therapist** in the AccEPT Clinic at the **University of Exeter**. This therapist will support you as you complete this booklet. The **therapist will act a bit like a coach** to help you understand the programme and to use the skills and techniques from this booklet. The therapist will also **help you with any difficulties or problems you may find** when using this booklet.

You will have **weekly support sessions** with the therapist to check how you are getting along with this booklet and to help you with any problems you may be experiencing.

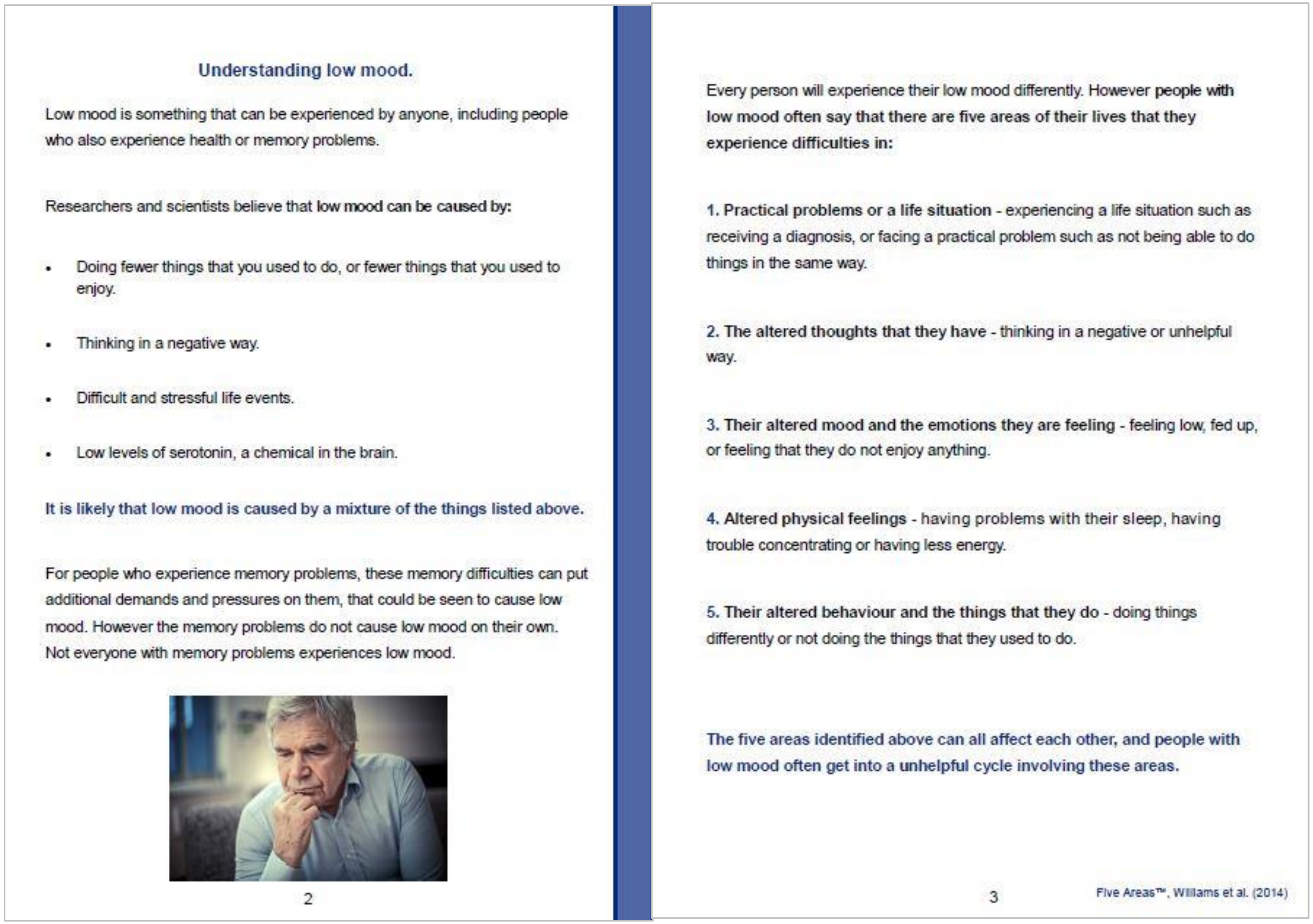
You will also be **supported** to complete this booklet by **a family member or friend**. Your **family member or friend will also attend the support sessions** with you.

Support Tips...

Ideas for how your family member or friend can help support you through this booklet are in orange boxes like this box.

Now you have been given this booklet, your therapist would like you to read through **Pages 2-9**. The next few pages will **help you to understand about low mood**, before you start the steps of the booklet.

1



Understanding low mood.

Low mood is something that can be experienced by anyone, including people who also experience health or memory problems.

Researchers and scientists believe that **low mood can be caused by:**

- Doing fewer things that you used to do, or fewer things that you used to enjoy.
- Thinking in a negative way.
- Difficult and stressful life events.
- Low levels of serotonin, a chemical in the brain.

It is likely that low mood is caused by a mixture of the things listed above.

For people who experience memory problems, these memory difficulties can put additional demands and pressures on them, that could be seen to cause low mood. However the memory problems do not cause low mood on their own. Not everyone with memory problems experiences low mood.

2

Every person will experience their low mood differently. However **people with low mood often say that there are five areas of their lives that they experience difficulties in:**

1. Practical problems or a life situation - experiencing a life situation such as receiving a diagnosis, or facing a practical problem such as not being able to do things in the same way.

2. The altered thoughts that they have - thinking in a negative or unhelpful way.

3. Their altered mood and the emotions they are feeling - feeling low, fed up, or feeling that they do not enjoy anything.

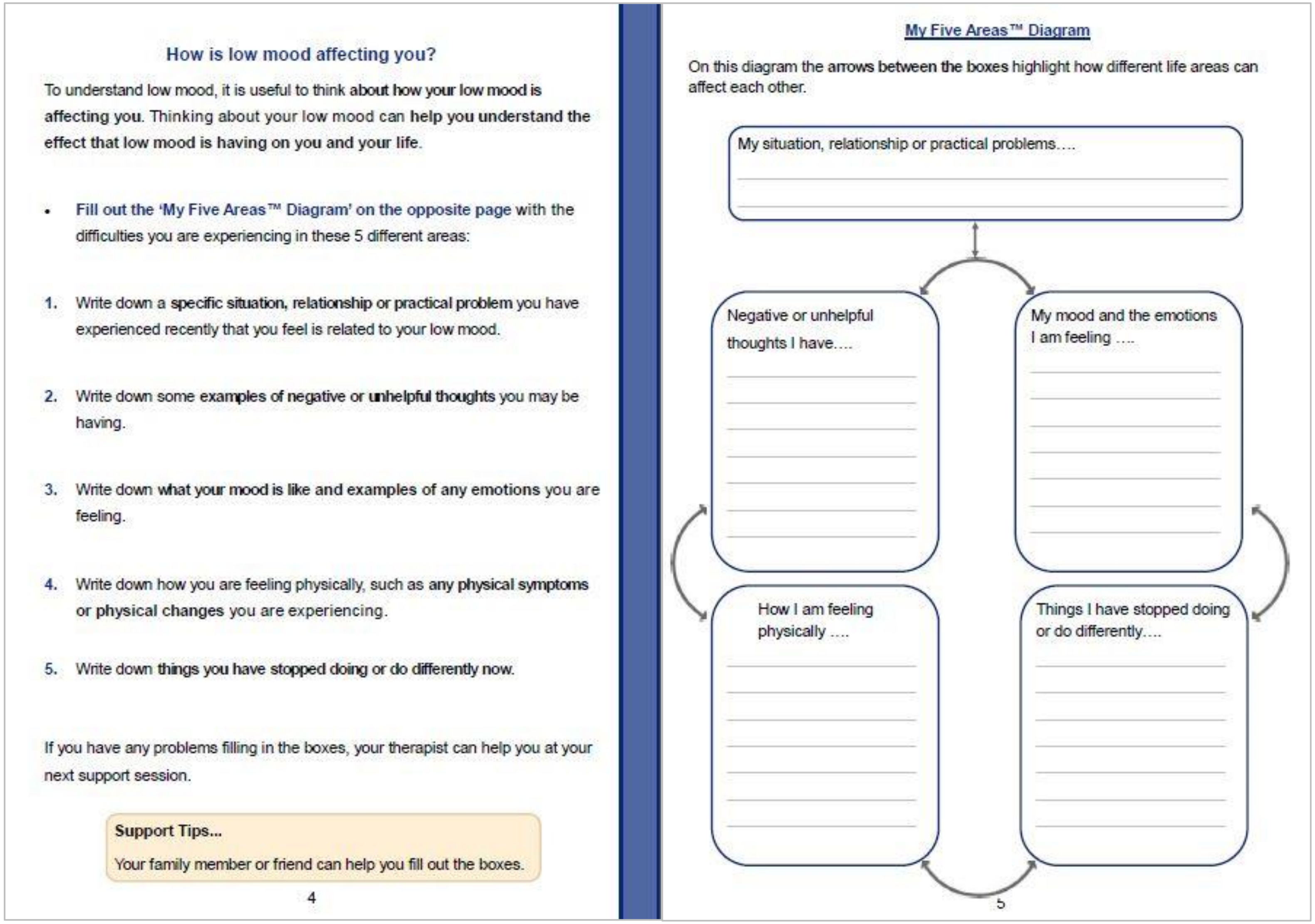
4. Altered physical feelings - having problems with their sleep, having trouble concentrating or having less energy.

5. Their altered behaviour and the things that they do - doing things differently or not doing the things that they used to do.

The five areas identified above can all affect each other, and people with low mood often get into a unhelpful cycle involving these areas.

3

Five Areas™, Williams et al. (2014)



How is low mood affecting you?

To understand low mood, it is useful to think **about how your low mood is affecting you**. Thinking about your low mood can **help you understand the effect that low mood is having on you and your life**.

- **Fill out the 'My Five Areas™ Diagram' on the opposite page** with the difficulties you are experiencing in these 5 different areas:

1. Write down a **specific situation, relationship or practical problem** you have experienced recently that you feel is related to your low mood.
2. Write down some **examples of negative or unhelpful thoughts** you may be having.
3. Write down **what your mood is like and examples of any emotions** you are feeling.
4. Write down how you are feeling physically, such as **any physical symptoms or physical changes** you are experiencing.
5. Write down **things you have stopped doing or do differently now**.

If you have any problems filling in the boxes, your therapist can help you at your next support session.

Support Tips...

Your family member or friend can help you fill out the boxes.

4

My Five Areas™ Diagram

On this diagram the **arrows between the boxes** highlight how different life areas can affect each other.

My situation, relationship or practical problems….

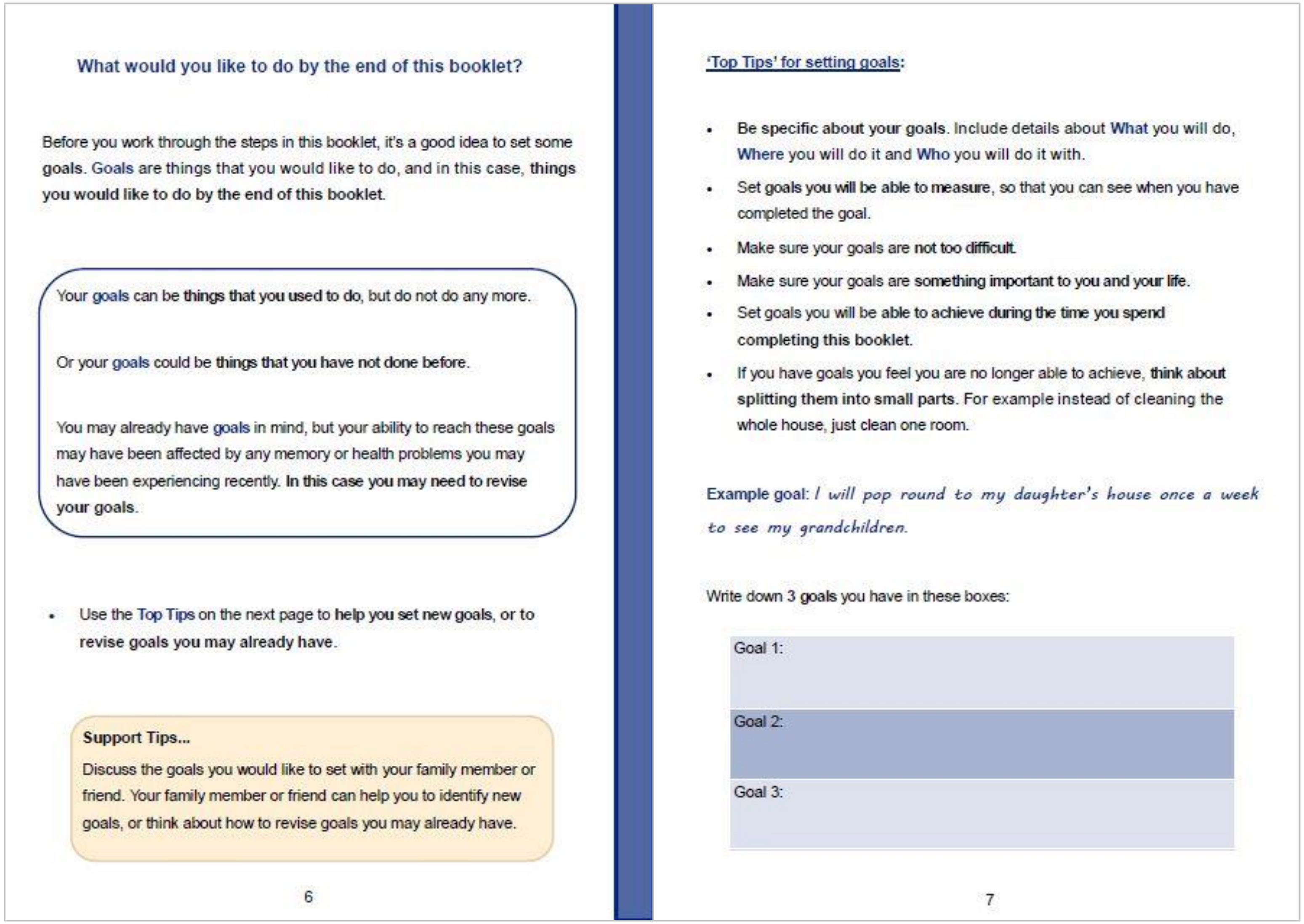
Negative or unhelpful thoughts I have….

My mood and the emotions I am feeling ….

How I am feeling physically ….

Things I have stopped doing or do differently….

5



What would you like to do by the end of this booklet?

Before you work through the steps in this booklet, it's a good idea to set some goals. **Goals** are things that you would like to do, and in this case, **things you would like to do by the end of this booklet**.

Your **goals** can be **things that you used to do**, but do not do any more.

Or your **goals** could be **things that you have not done before**.

You may already have **goals** in mind, but your ability to reach these goals may have been affected by any memory or health problems you may have been experiencing recently. **In this case you may need to revise your goals**.

- Use the **Top Tips** on the next page to **help you set new goals**, or to **revise goals you may already have**.

Support Tips...

Discuss the goals you would like to set with your family member or friend. Your family member or friend can help you to identify new goals, or think about how to revise goals you may already have.

6

'Top Tips' for setting goals:

- **Be specific about your goals**. Include details about **What** you will do, **Where** you will do it and **Who** you will do it with.
- **Set goals you will be able to measure**, so that you can see when you have completed the goal.
- Make sure your goals are **not too difficult**.
- Make sure your goals are **something important to you and your life**.
- Set goals you will be able to achieve **during the time you spend completing this booklet**.
- If you have goals you feel you are no longer able to achieve, **think about splitting them into small parts**. For example instead of cleaning the whole house, just clean one room.

Example goal: *I will pop round to my daughter's house once a week to see my grandchildren.*

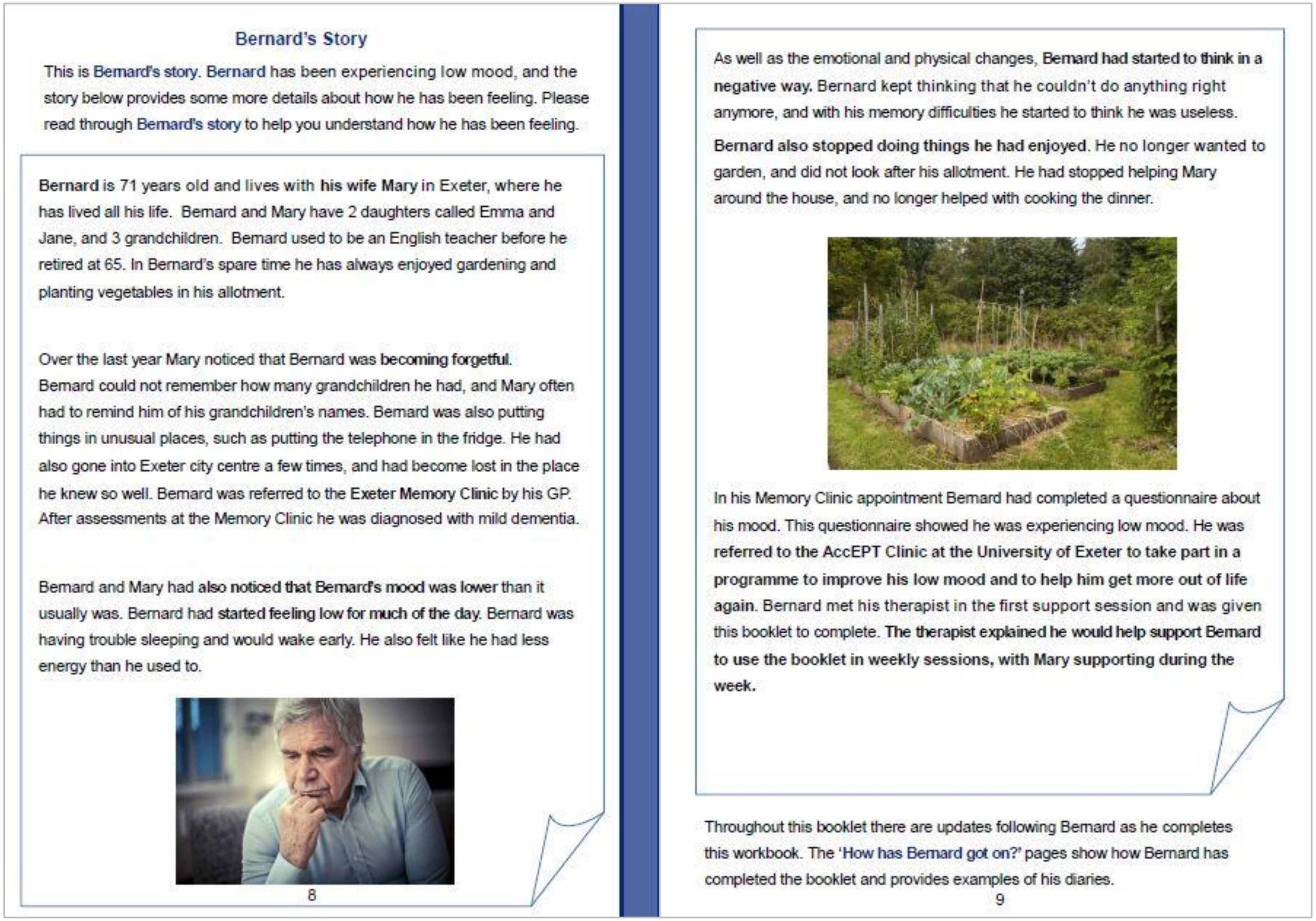
Write down 3 **goals** you have in these boxes:

Goal 1:

Goal 2:

Goal 3:

7



Bernard's Story

This is Bernard's story. Bernard has been experiencing low mood, and the story below provides some more details about how he has been feeling. Please read through Bernard's story to help you understand how he has been feeling.

Bernard is 71 years old and lives with **his wife Mary** in Exeter, where he has lived all his life. Bernard and Mary have 2 daughters called Emma and Jane, and 3 grandchildren. Bernard used to be an English teacher before he retired at 65. In Bernard's spare time he has always enjoyed gardening and planting vegetables in his allotment.

Over the last year Mary noticed that Bernard was **becoming forgetful.** Bernard could not remember how many grandchildren he had, and Mary often had to remind him of his grandchildren's names. Bernard was also putting things in unusual places, such as putting the telephone in the fridge. He had also gone into Exeter city centre a few times, and had become lost in the place he knew so well. Bernard was referred to the **Exeter Memory Clinic** by his GP. After assessments at the Memory Clinic he was diagnosed with mild dementia.

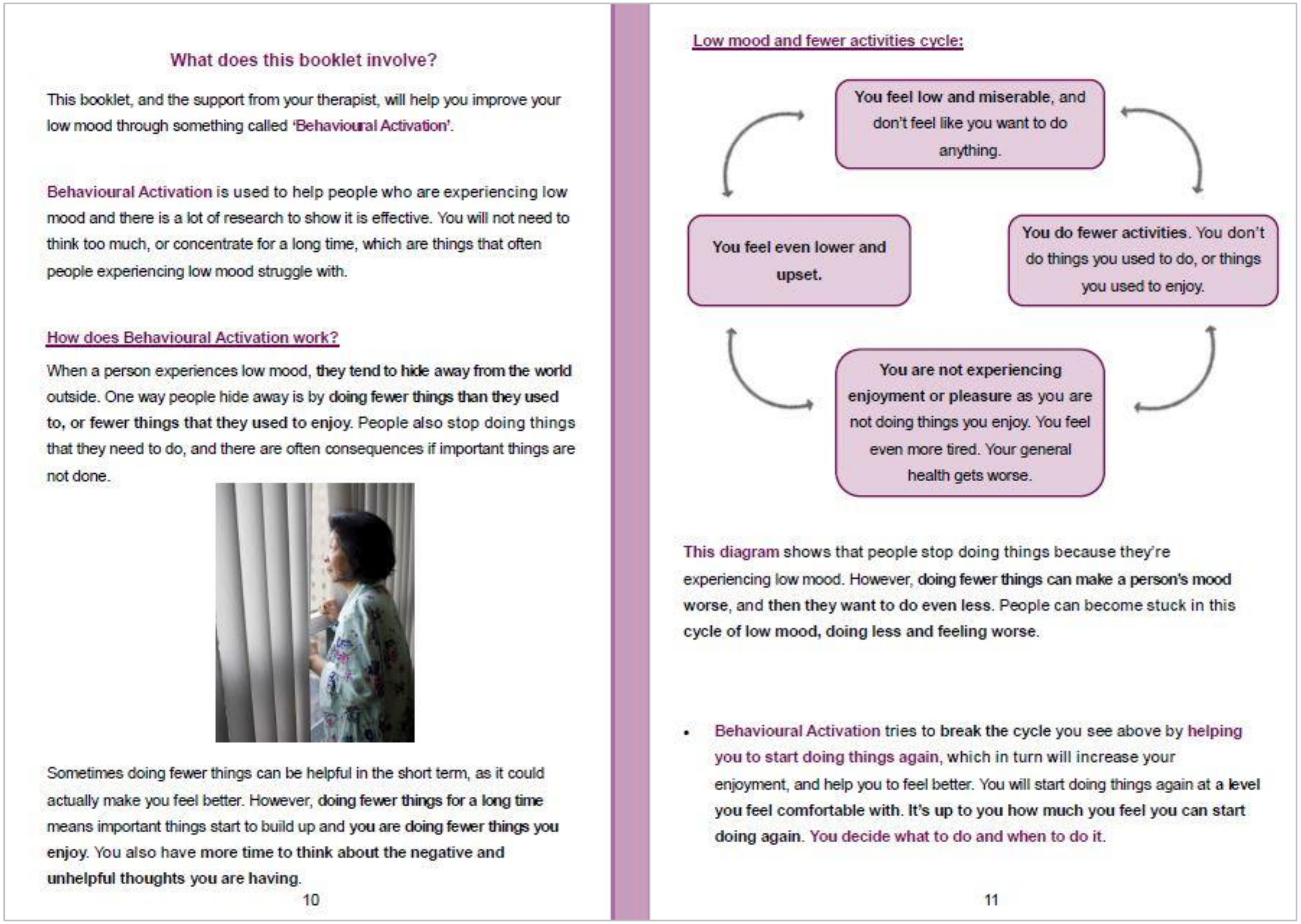
Bernard and Mary had **also noticed that Bernard's mood was lower** than it usually was. Bernard had **started feeling low for much of the day.** Bernard was having trouble sleeping and would wake early. He also felt like he had less energy than he used to.

As well as the emotional and physical changes, **Bernard had started to think in a negative way.** Bernard kept thinking that he couldn't do anything right anymore, and with his memory difficulties he started to think he was useless.

Bernard also stopped doing things he had enjoyed. He no longer wanted to garden, and did not look after his allotment. He had stopped helping Mary around the house, and no longer helped with cooking the dinner.

In his Memory Clinic appointment Bernard had completed a questionnaire about his mood. This questionnaire showed he was experiencing low mood. He was **referred to the AccEPT Clinic at the University of Exeter to take part in a programme to improve his low mood and to help him get more out of life again.** Bernard met his therapist in the first support session and was given this booklet to complete. **The therapist explained he would help support Bernard to use the booklet in weekly sessions, with Mary supporting during the week.**

Throughout this booklet there are updates following Bernard as he completes this workbook. The 'How has Bernard got on?' pages show how Bernard has completed the booklet and provides examples of his diaries.



What does this booklet involve?

This booklet, and the support from your therapist, will help you improve your low mood through something called 'Behavioural Activation'.

Behavioural Activation is used to help people who are experiencing low mood and there is a lot of research to show it is effective. You will not need to think too much, or concentrate for a long time, which are things that often people experiencing low mood struggle with.

How does Behavioural Activation work?

When a person experiences low mood, **they tend to hide away from the world** outside. One way people hide away is by **doing fewer things than they used to, or fewer things that they used to enjoy.** People also stop doing things that they need to do, and there are often consequences if important things are not done.

Sometimes doing fewer things can be helpful in the short term, as it could actually make you feel better. However, **doing fewer things for a long time** means important things start to build up and **you are doing fewer things you enjoy.** You also have **more time to think about the negative and unhelpful thoughts you are having.**

10

Low mood and fewer activities cycle:

You feel low and miserable, and don't feel like you want to do anything.

You do fewer activities. You don't do things you used to do, or things you used to enjoy.

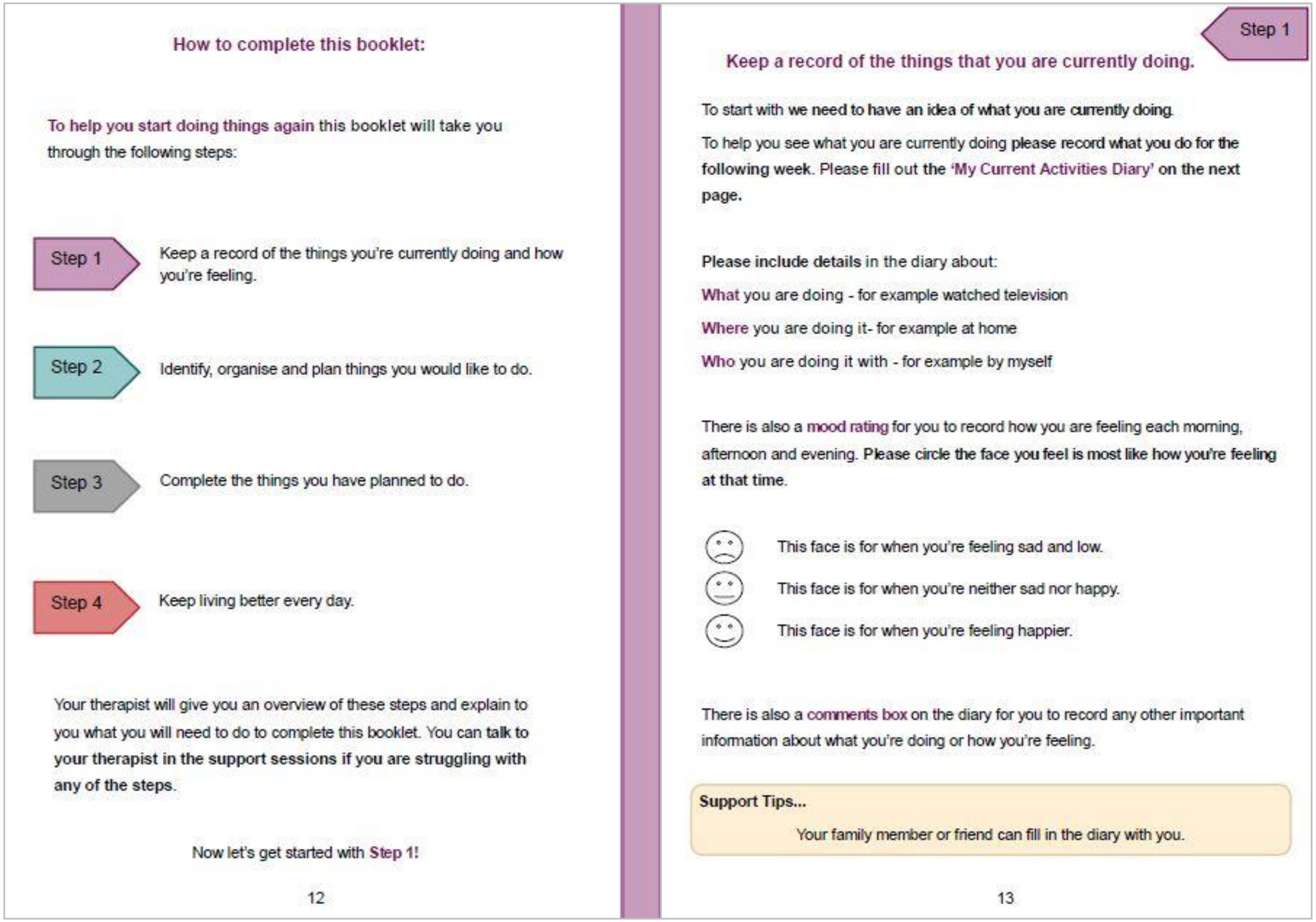
You are not experiencing enjoyment or pleasure as you are not doing things you enjoy. You feel even more tired. Your general health gets worse.

You feel even lower and upset.

This diagram shows that people stop doing things because they're experiencing low mood. However, **doing fewer things can make a person's mood worse,** and **then they want to do even less.** People can become stuck in this **cycle of low mood, doing less and feeling worse.**

- Behavioural Activation tries to **break the cycle** you see above by **helping you to start doing things again**, which in turn will increase your enjoyment, and help you to feel better. You will start doing things again at a **level you feel comfortable with. It's up to you how much you feel you can start doing again. You decide what to do and when to do it.**

11



How to complete this booklet:

To help you start doing things again this booklet will take you through the following steps:

Step 1	Keep a record of the things you're currently doing and how you're feeling.
Step 2	Identify, organise and plan things you would like to do.
Step 3	Complete the things you have planned to do.
Step 4	Keep living better every day.

Your therapist will give you an overview of these steps and explain to you what you will need to do to complete this booklet. You can talk to **your therapist in the support sessions if you are struggling with any of the steps.**

Now let's get started with **Step 1!**

Step 1

Keep a record of the things that you are currently doing.

To start with **we need to have an idea of what you are currently doing.**

To help you see what you are currently doing **please record what you do for the following week. Please fill out the 'My Current Activities Diary' on the next page.**

Please include details in the diary about:

What you are doing - for example watched television

Where you are doing it- for example at home

Who you are doing it with - for example by myself

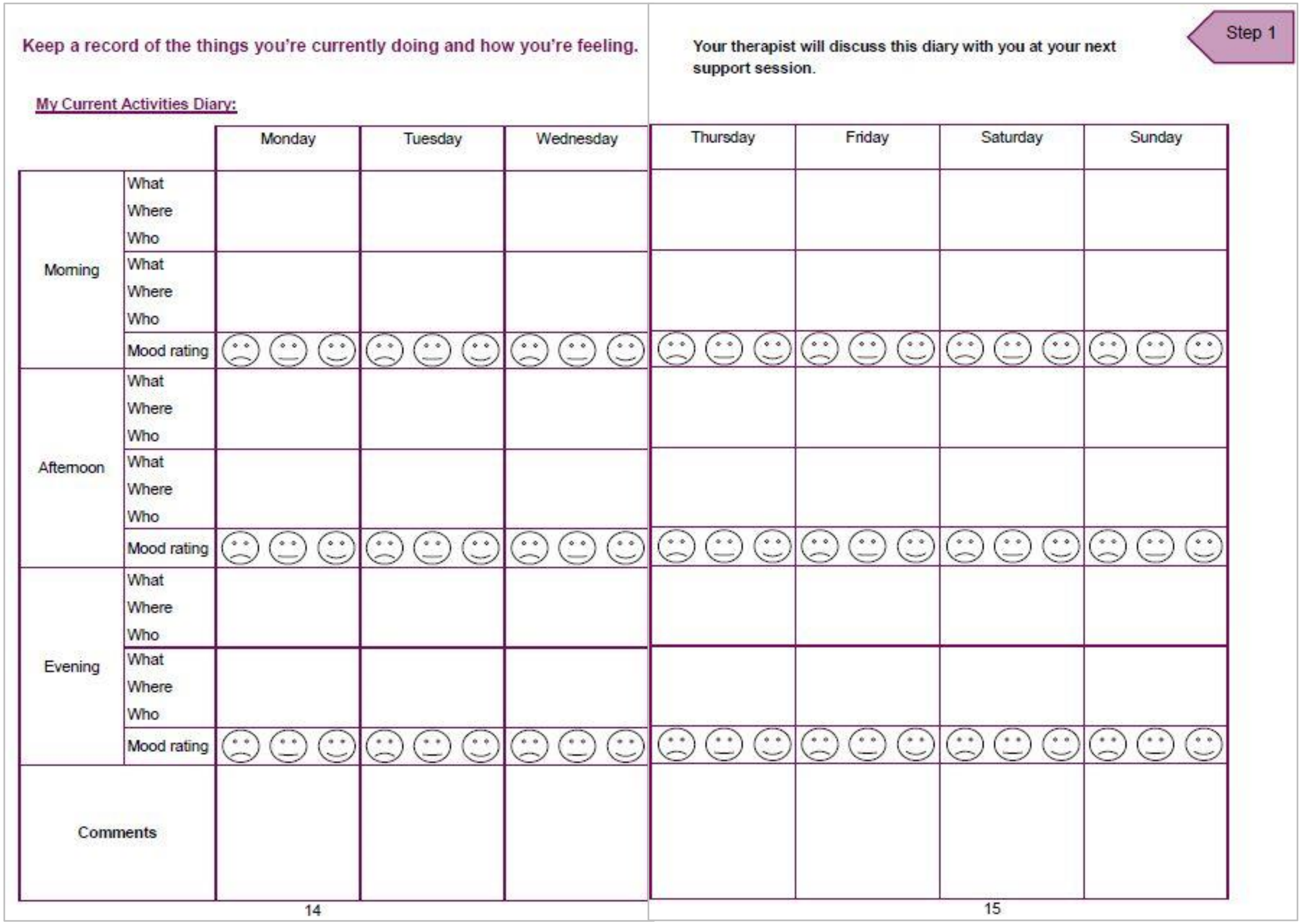
There is also a mood rating for you to record how you are feeling each morning, afternoon and evening. **Please circle the face you feel is most like how you're feeling at that time.**

☹	This face is for when you're feeling sad and low.
😐	This face is for when you're neither sad nor happy.
☺	This face is for when you're feeling happier.

There is also a comments box on the diary for you to record any other important information about what you're doing or how you're feeling.

Support Tips...

Your family member or friend can fill in the diary with you.



Keep a record of the things you're currently doing and how you're feeling.

Your therapist will discuss this diary with you at your next support session.

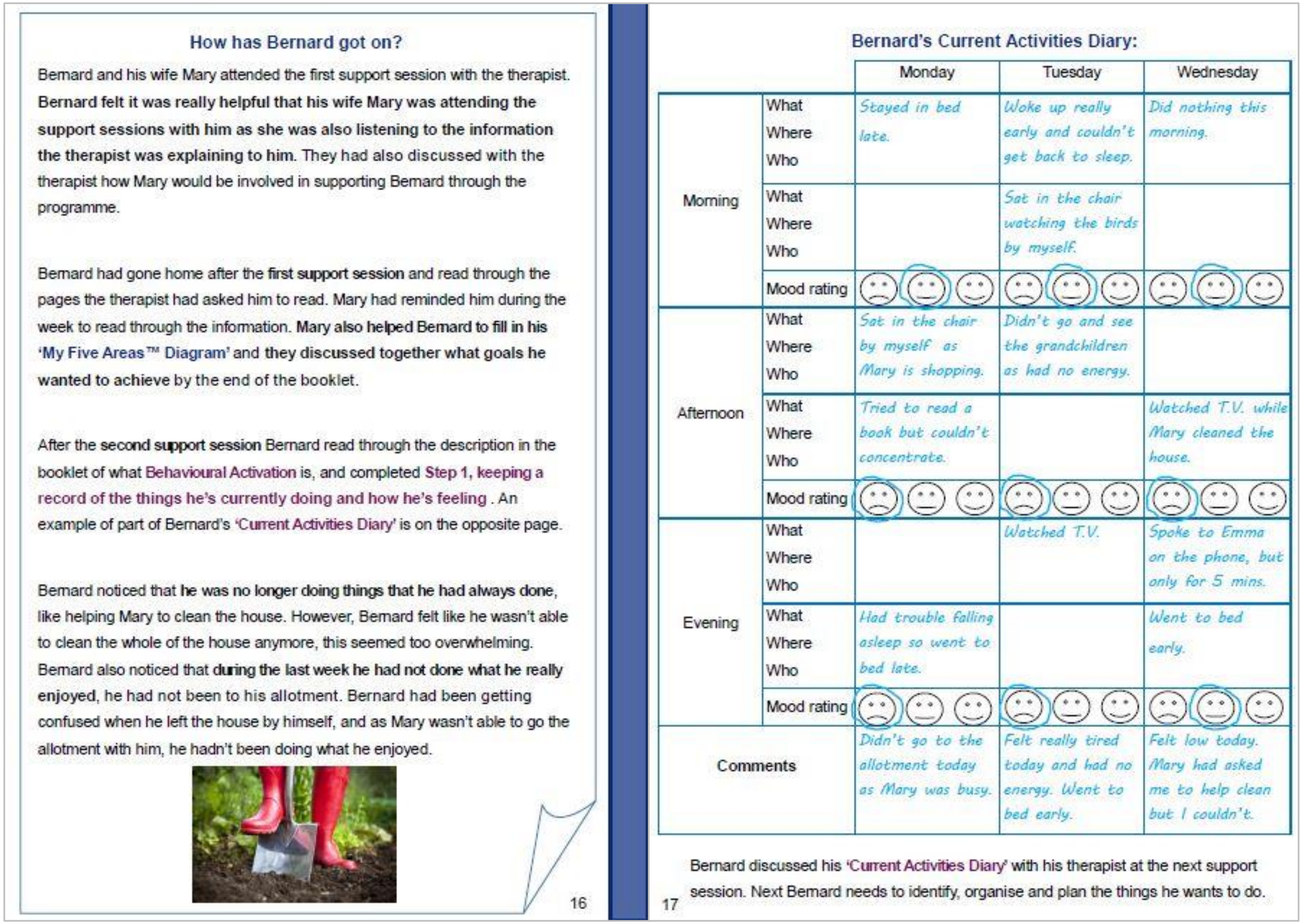
Step 1

My Current Activities Diary:

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	What Where Who							
	What Where Who							
	Mood rating	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺
Afternoon	What Where Who							
	What Where Who							
	Mood rating	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺
Evening	What Where Who							
	What Where Who							
	Mood rating	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺	☹ 😐 ☺
Comments								

14

15



How has Bernard got on?

Bernard and his wife Mary attended the first support session with the therapist. **Bernard felt it was really helpful that his wife Mary was attending the support sessions with him as she was also listening to the information the therapist was explaining to him.** They had also discussed with the therapist how Mary would be involved in supporting Bernard through the programme.

Bernard had gone home after the **first support session** and read through the pages the therapist had asked him to read. Mary had reminded him during the week to read through the information. **Mary also helped Bernard to fill in his 'My Five Areas™ Diagram' and they discussed together what goals he wanted to achieve** by the end of the booklet.

After the **second support session** Bernard read through the description in the booklet of what Behavioural Activation is, and completed **Step 1, keeping a record of the things he's currently doing and how he's feeling** . An example of part of Bernard's 'Current Activities Diary' is on the opposite page.

Bernard noticed that **he was no longer doing things that he had always done**, like helping Mary to clean the house. However, Bernard felt like he wasn't able to clean the whole of the house anymore, this seemed too overwhelming. Bernard also noticed that **during the last week he had not done what he really enjoyed**, he had not been to his allotment. Bernard had been getting confused when he left the house by himself, and as Mary wasn't able to go the allotment with him, he hadn't been doing what he enjoyed.

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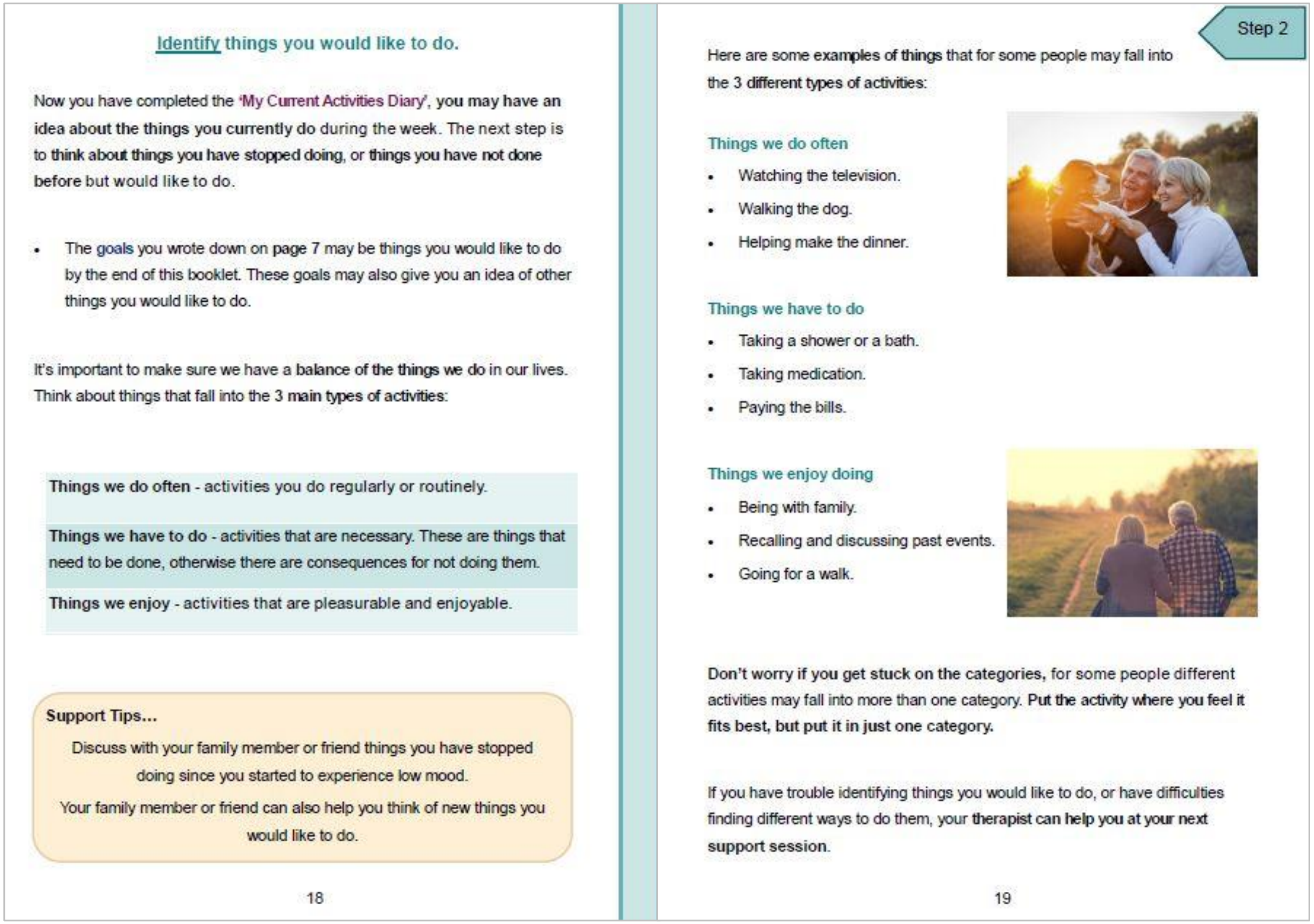
Bernard's Current Activities Diary:

		Monday	Tuesday	Wednesday
Morning	What Where Who	Stayed in bed late.	Woke up really early and couldn't get back to sleep.	Did nothing this morning.
	What Where Who		Sat in the chair watching the birds by myself.	
	Mood rating	☹ [✓ 😐] ☺	☹ [✓ 😐] ☺	☹ [✓ 😐] ☺
Afternoon	What Where Who	Sat in the chair by myself as Mary is shopping.	Didn't go and see the grandchildren as had no energy.	
	What Where Who	Tried to read a book but couldn't concentrate.		Watched T.V. while Mary cleaned the house.
	Mood rating	[✓ ☹] 😐 ☺	[✓ ☹] 😐 ☺	[✓ ☹] 😐 ☺
Evening	What Where Who		Watched T.V.	Spoke to Emma on the phone, but only for 5 mins.
	What Where Who	Had trouble falling asleep so went to bed late.		Went to bed early.
	Mood rating	[✓ ☹] 😐 ☺	[✓ ☹] 😐 ☺	☹ [✓ 😐] ☺
Comments		Didn't go to the allotment today as Mary was busy.	Felt really tired today and had no energy. Went to bed early.	Felt low today. Mary had asked me to help clean but I couldn't.

Bernard discussed his 'Current Activities Diary' with his therapist at the next support session. Next Bernard needs to identify, organise and plan the things he wants to do.

17



Identify things you would like to do.

Now you have completed the 'My Current Activities Diary', **you may have an idea about the things you currently do** during the week. The next step is to **think about things you have stopped doing**, or **things you have not done before** but would like to do.

- The goals you wrote down on page 7 may be things you would like to do by the end of this booklet. These goals may also give you an idea of other things you would like to do.

It's important to make sure we have a **balance of the things we do** in our lives. Think about things that fall into the **3 main types of activities**:

Things we do often - activities you do regularly or routinely.

Things we have to do - activities that are necessary. These are things that need to be done, otherwise there are consequences for not doing them.

Things we enjoy - activities that are pleasurable and enjoyable.

Support Tips…

Discuss with your family member or friend things you have stopped doing since you started to experience low mood.

Your family member or friend can also help you think of new things you would like to do.

Step 2

Here are some **examples of things** that for some people may fall into the **3 different types of activities**:

Things we do often

- Watching the television.
- Walking the dog.
- Helping make the dinner.

Things we have to do

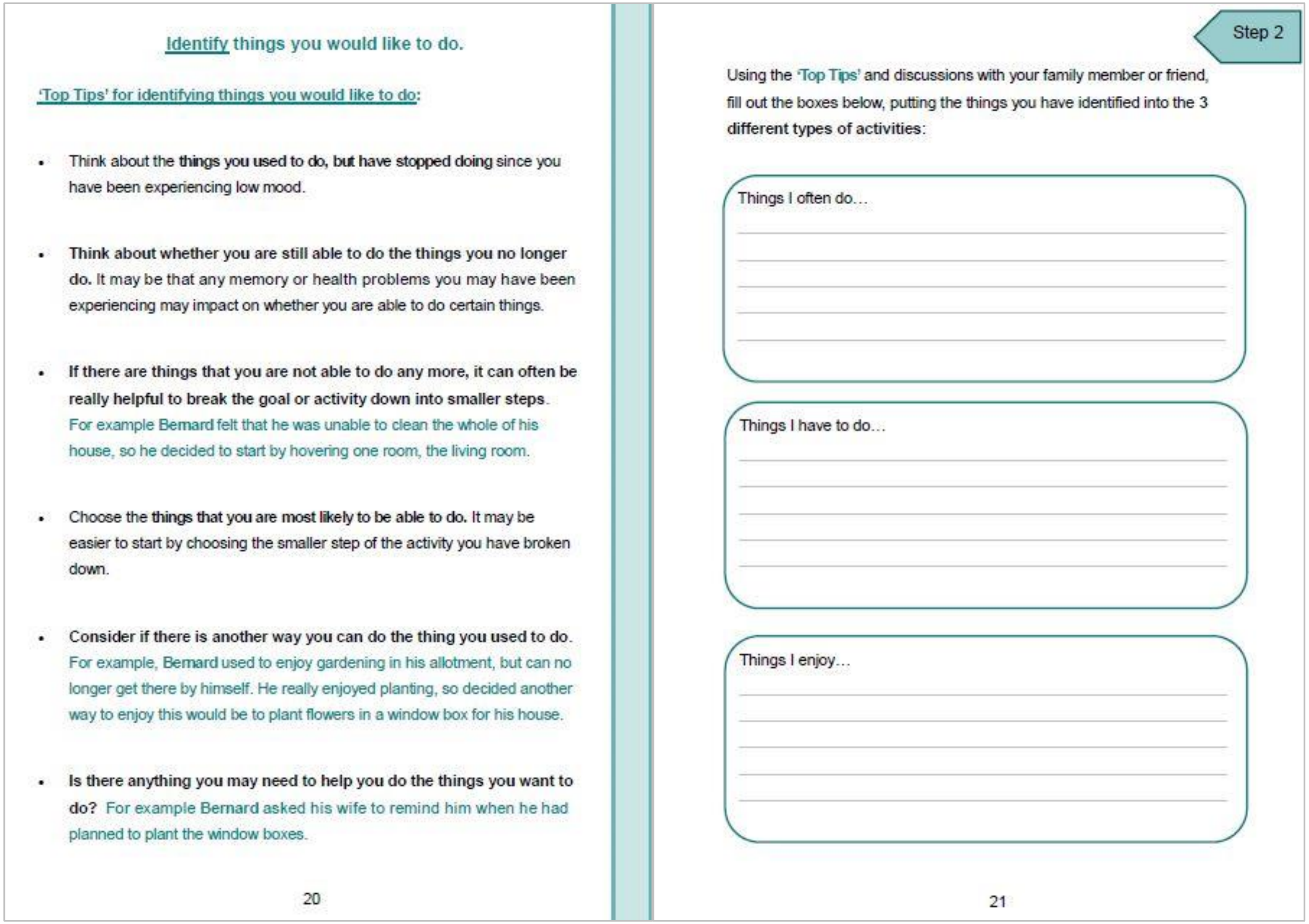
- Taking a shower or a bath.
- Taking medication.
- Paying the bills.

Things we enjoy doing

- Being with family.
- Recalling and discussing past events.
- Going for a walk.

Don't worry if you get stuck on the categories, for some people different activities may fall into more than one category. **Put the activity where you feel it fits best, but put it in just one category.**

If you have trouble identifying things you would like to do, or have difficulties finding different ways to do them, your **therapist can help you at your next support session**.



Identify things you would like to do.

'Top Tips' for identifying things you would like to do:

- Think about the **things you used to do, but have stopped doing** since you have been experiencing low mood.
- **Think about whether you are still able to do the things you no longer do.** It may be that any memory or health problems you may have been experiencing may impact on whether you are able to do certain things.
- **If there are things that you are not able to do any more, it can often be really helpful to break the goal or activity down into smaller steps**. For example Bernard felt that he was unable to clean the whole of his house, so he decided to start by hovering one room, the living room.
- Choose the **things that you are most likely to be able to do.** It may be easier to start by choosing the smaller step of the activity you have broken down.
- **Consider if there is another way you can do the thing you used to do**. For example, Bernard used to enjoy gardening in his allotment, but can no longer get there by himself. He really enjoyed planting, so decided another way to enjoy this would be to plant flowers in a window box for his house.
- **Is there anything you may need to help you do the things you want to do?** For example Bernard asked his wife to remind him when he had planned to plant the window boxes.

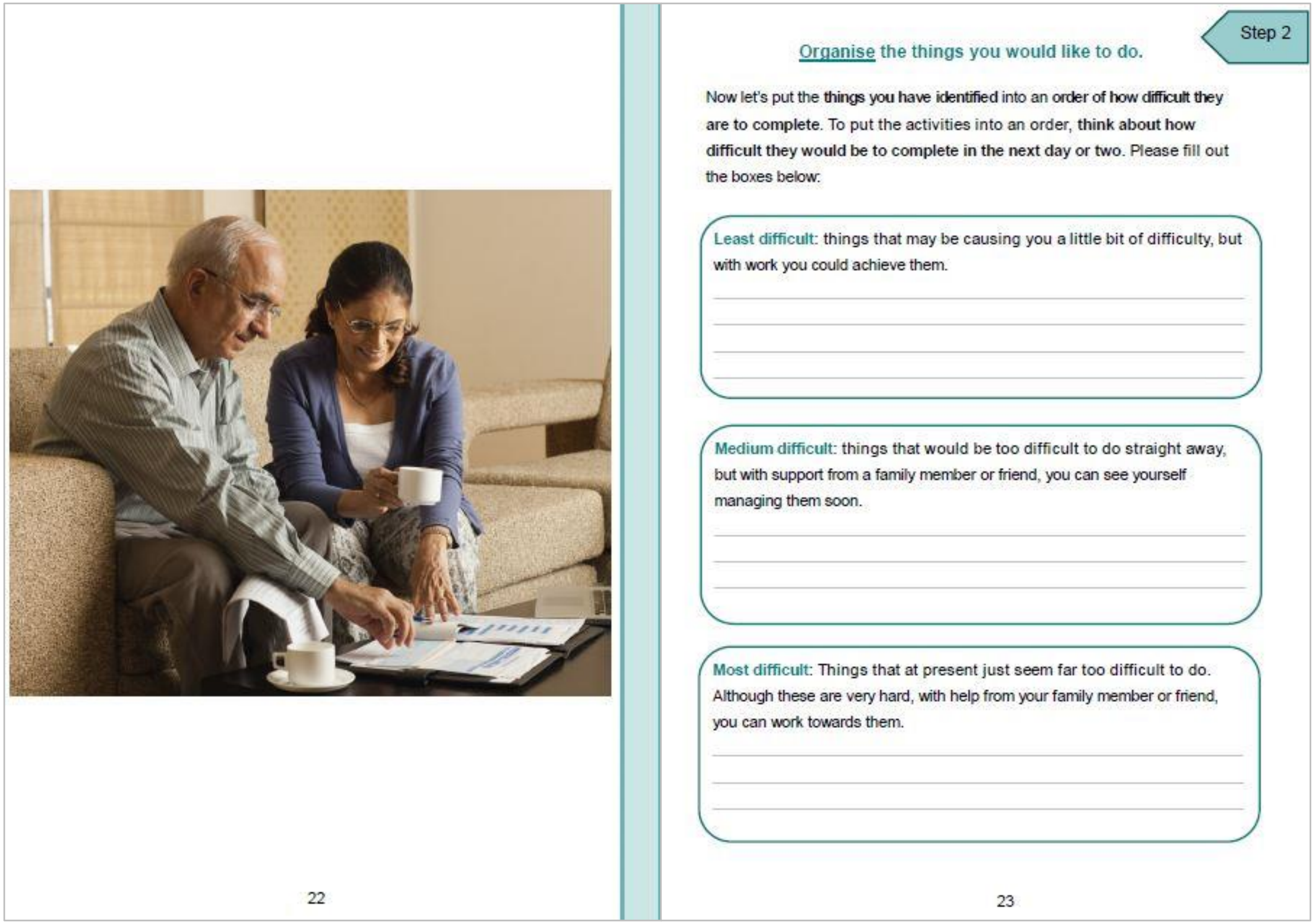
Step 2

Using the 'Top Tips' and discussions with your family member or friend, fill out the boxes below, putting the things you have identified into the 3 **different types of activities**:

Things I often do…

Things I have to do…

Things I enjoy…



Step 2

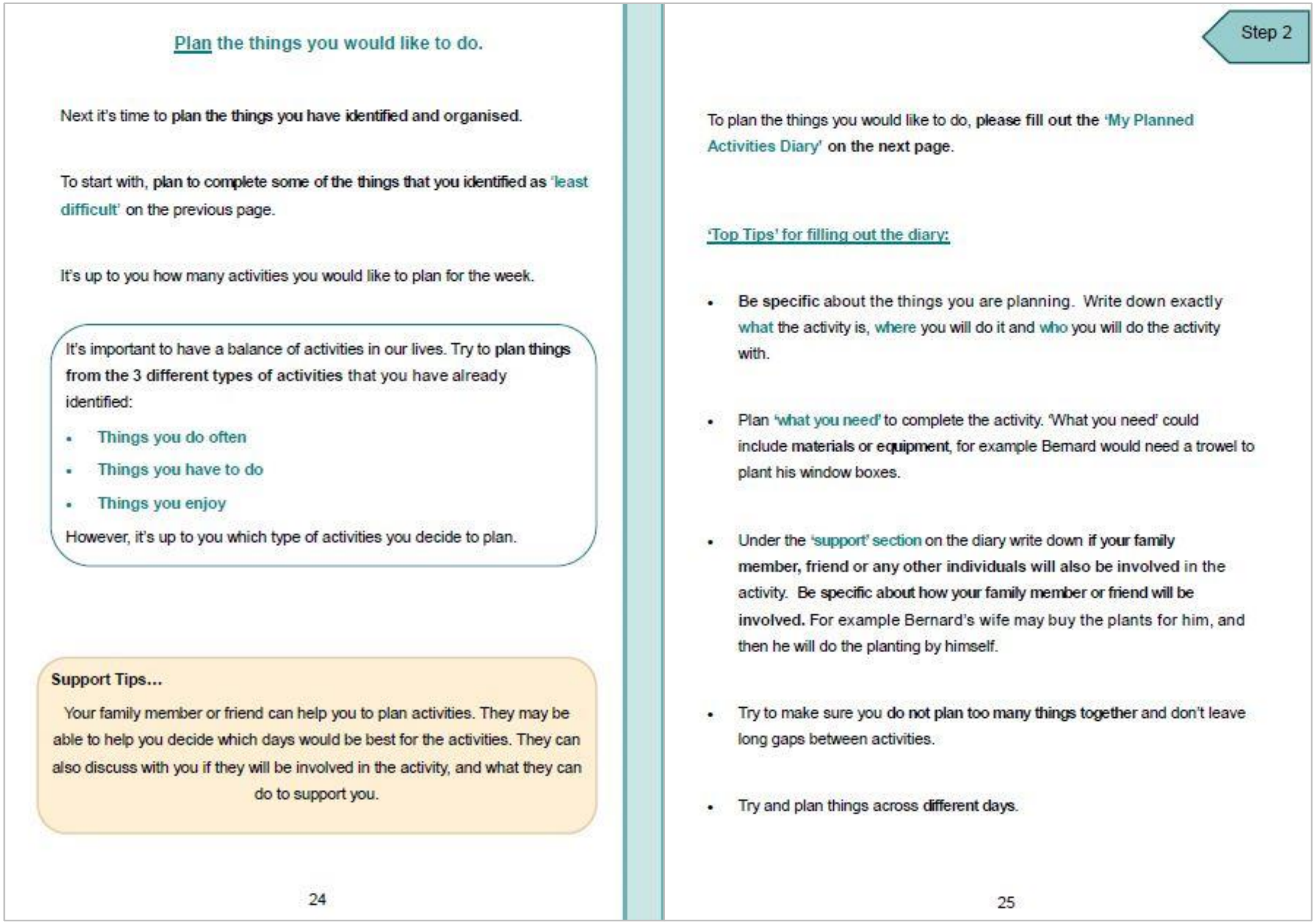
Organise the things you would like to do.

Now let's put the **things you have identified** into an **order of how difficult they are to complete**. To put the activities into an order, **think about how difficult they would be to complete in the next day or two.** Please fill out the boxes below:

Least difficult: things that may be causing you a little bit of difficulty, but with work you could achieve them.

Medium difficult: things that would be too difficult to do straight away, but with support from a family member or friend, you can see yourself managing them soon.

Most difficult: Things that at present just seem far too difficult to do. Although these are very hard, with help from your family member or friend, you can work towards them.



Plan the things you would like to do.

Next it's time to **plan the things you have identified and organised.**

To start with, **plan to complete some of the things that you identified as** 'least difficult' on the previous page.

It's up to you how many activities you would like to plan for the week.

It's important to have a balance of activities in our lives. Try to **plan things from the 3 different types of activities** that you have already identified:

- Things you do often
- Things you have to do
- Things you enjoy

However, it's up to you which type of activities you decide to plan.

Support Tips…

Your family member or friend can help you to plan activities. They may be able to help you decide which days would be best for the activities. They can also discuss with you if they will be involved in the activity, and what they can do to support you.

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Step 2

To plan the things you would like to do, **please fill out the** 'My Planned Activities Diary' **on the next page.**

'Top Tips' for filling out the diary:

- **Be specific** about the things you are planning. Write down exactly what the activity is, where you will do it and who you will do the activity with.
- Plan 'what you need' to complete the activity. 'What you need' could include **materials or equipment**, for example Bernard would need a trowel to plant his window boxes.
- Under the 'support' section on the diary write down **if your family member, friend or any other individuals will also be involved** in the activity. **Be specific about how your family member or friend will be involved.** For example Bernard's wife may buy the plants for him, and then he will do the planting by himself.
- Try to make sure you **do not plan too many things together** and don't leave long gaps between activities.
- Try and plan things across **different days.**

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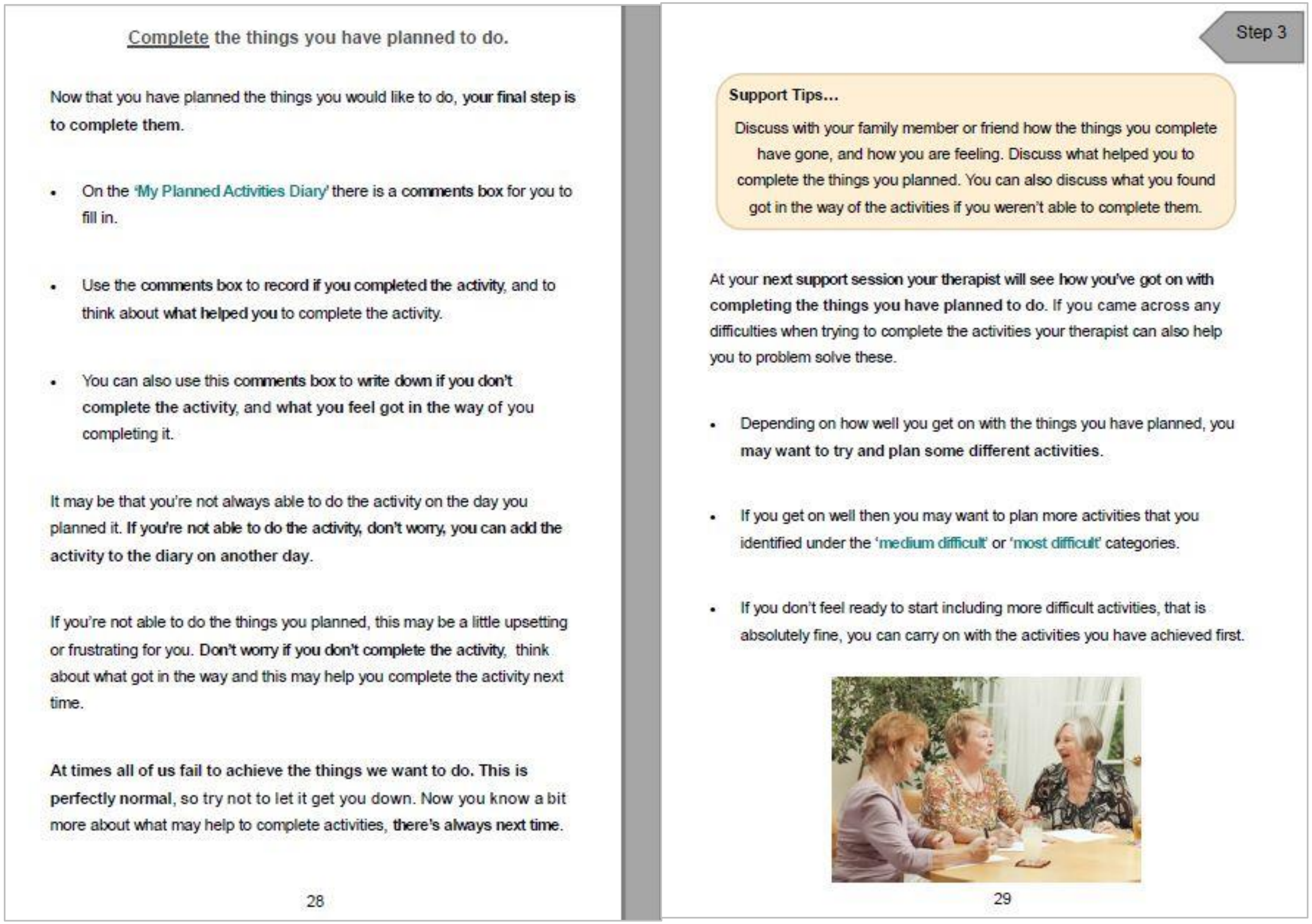
My Planned Activities Diary:

Step 2

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	What Where Who What I need Support							
	What Where Who What I need Support							
Afternoon	What Where Who What I need Support							
	What Where Who What I need Support							
Evening	What Where Who What I need Support							
	What Where Who What I need Support							
Comments								



Complete the things you have planned to do.

Now that you have planned the things you would like to do, **your final step is to complete them.**

- On the 'My Planned Activities Diary' there is a **comments box** for you to fill in.
- Use the **comments box** to record **if you completed the activity**, and to think about **what helped you** to complete the activity.
- You can also use this **comments box** to **write down if you don't complete the activity**, and **what you feel got in the way** of you completing it.

It may be that you're not always able to do the activity on the day you planned it. **If you're not able to do the activity, don't worry, you can add the activity to the diary on another day.**

If you're not able to do the things you planned, this may be a little upsetting or frustrating for you. **Don't worry if you don't complete the activity**, think about what got in the way and this may help you complete the activity next time.

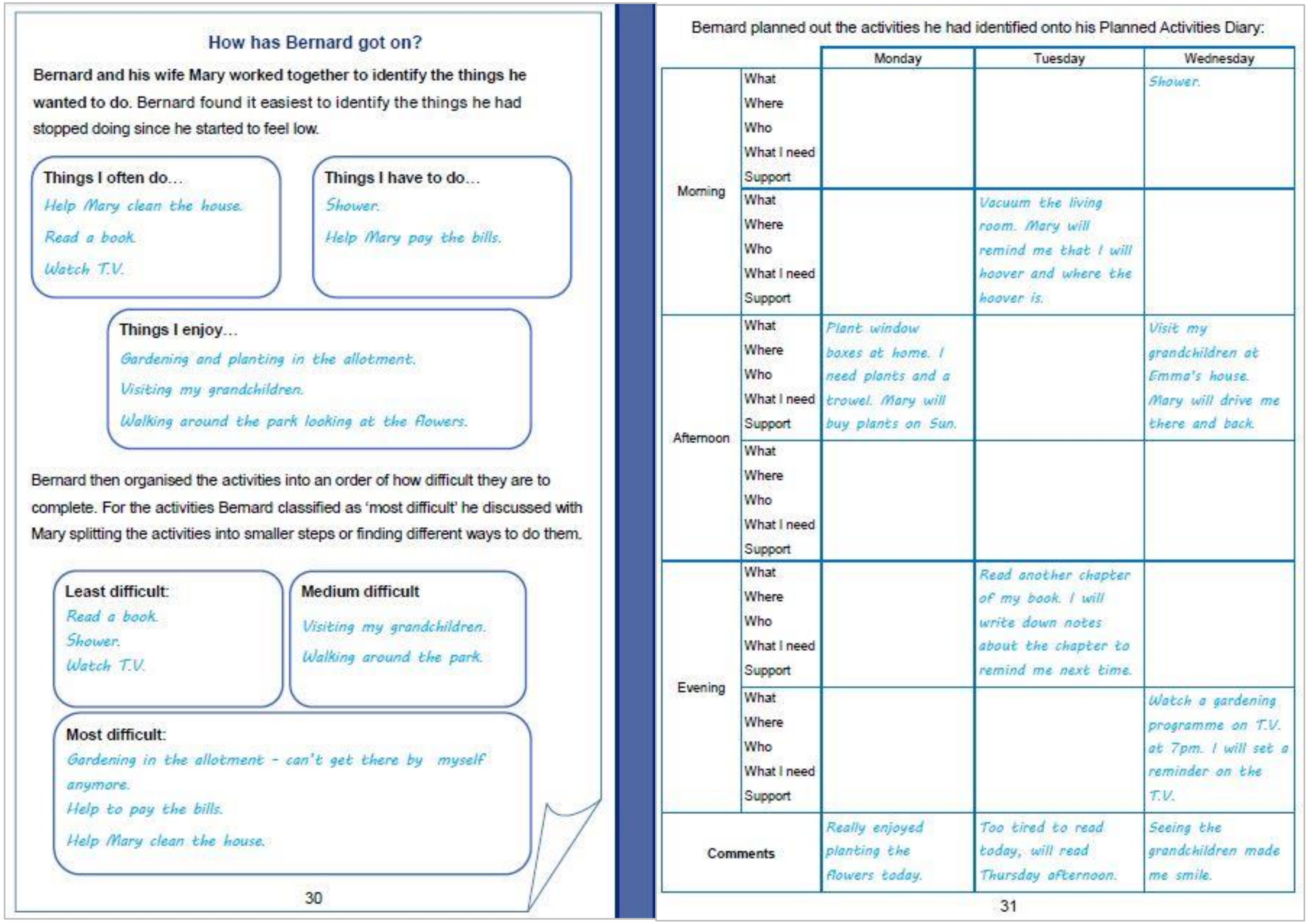
At times all of us fail to achieve the things we want to do. This is perfectly normal, so try not to let it get you down. Now you know a bit more about what may help to complete activities, **there's always next time.**

Support Tips…

Discuss with your family member or friend how the things you complete have gone, and how you are feeling. Discuss what helped you to complete the things you planned. You can also discuss what you found got in the way of the activities if you weren't able to complete them.

At your **next support session your therapist will see how you've got on with completing the things you have planned to do.** If you came across any difficulties when trying to complete the activities your therapist can also help you to problem solve these.

- Depending on how well you get on with the things you have planned, you **may want to try and plan some different activities.**
- If you get on well then you may want to plan more activities that you identified under the 'medium difficult' or 'most difficult' categories.
- If you don't feel ready to start including more difficult activities, that is absolutely fine, you can carry on with the activities you have achieved first.



How has Bernard got on?

Bernard and his wife Mary worked together to identify the things he wanted to do. Bernard found it easiest to identify the things he had stopped doing since he started to feel low.

Things I often do…
Help Mary clean the house.
Read a book.
Watch T.V.

Things I have to do…
Shower.
Help Mary pay the bills.

Things I enjoy…
Gardening and planting in the allotment.
Visiting my grandchildren.
Walking around the park looking at the flowers.

Bernard then organised the activities into an order of how difficult they are to complete. For the activities Bernard classified as 'most difficult' he discussed with Mary splitting the activities into smaller steps or finding different ways to do them.

Least difficult:
Read a book.
Shower.
Watch T.V.

Medium difficult
Visiting my grandchildren.
Walking around the park.

Most difficult:
Gardening in the allotment - can't get there by myself anymore.
Help to pay the bills.
Help Mary clean the house.

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Bernard planned out the activities he had identified onto his Planned Activities Diary:

		Monday	Tuesday	Wednesday
Morning	What Where Who What I need Support			Shower.
	What Where Who What I need Support		Vacuum the living room. Mary will remind me that I will hoover and where the hoover is.	
Afternoon	What Where Who What I need Support	Plant window boxes at home. I need plants and a trowel. Mary will buy plants on Sun.		Visit my grandchildren at Emma's house. Mary will drive me there and back.
	What Where Who What I need Support			
Evening	What Where Who What I need Support		Read another chapter of my book. I will write down notes about the chapter to remind me next time.	
	What Where Who What I need Support			Watch a gardening programme on T.V. at 7pm. I will set a reminder on the T.V.
Comments		Really enjoyed planting the flowers today.	Too tired to read today, will read Thursday afternoon.	Seeing the grandchildren made me smile.

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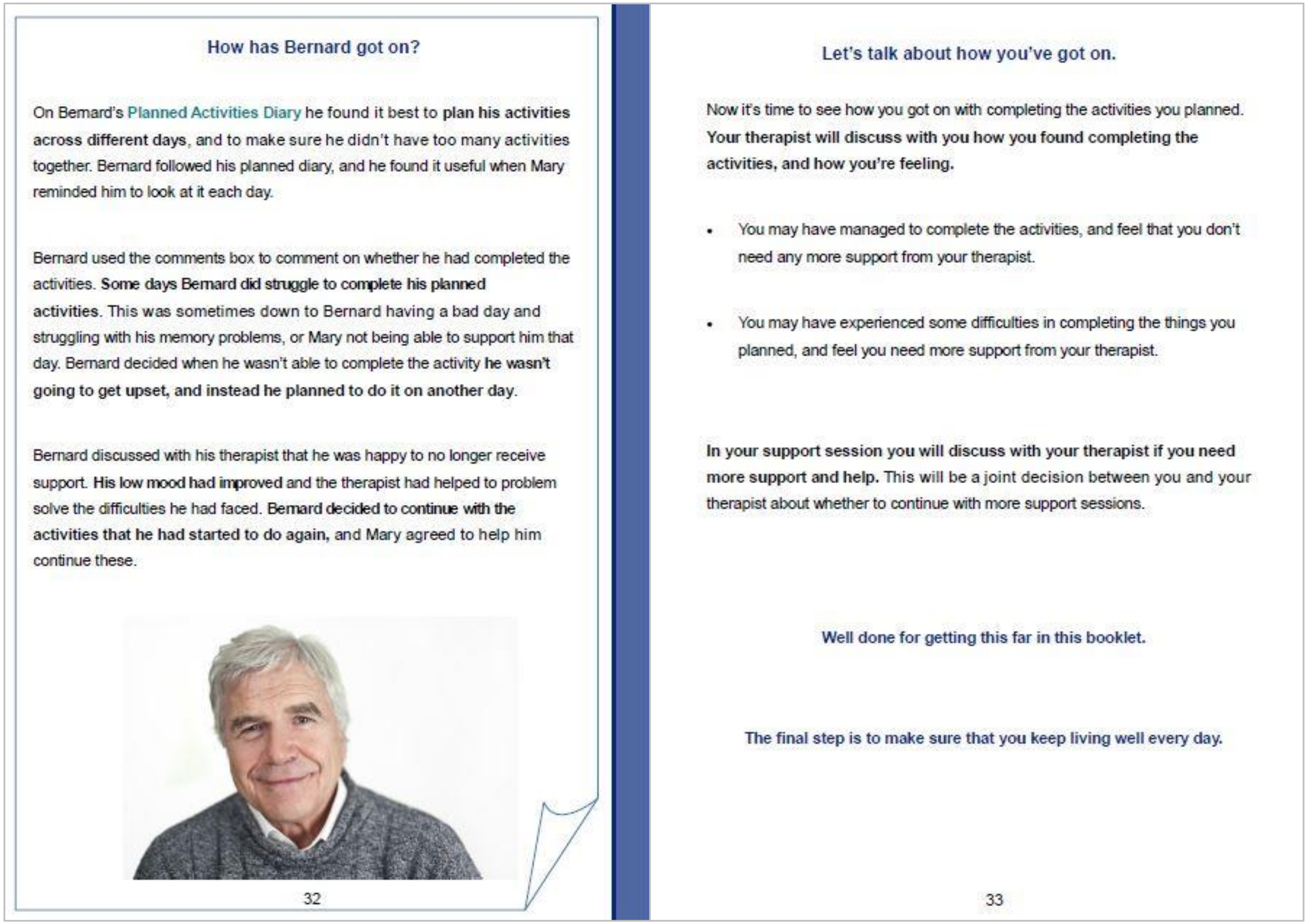

How has Bernard got on?

On Bernard's Planned Activities Diary he found it best to **plan his activities across different days**, and to make sure he didn't have too many activities together. Bernard followed his planned diary, and he found it useful when Mary reminded him to look at it each day.

Bernard used the comments box to comment on whether he had completed the activities. **Some days Bernard did struggle to complete his planned activities**. This was sometimes down to Bernard having a bad day and struggling with his memory problems, or Mary not being able to support him that day. Bernard decided when he wasn't able to complete the activity **he wasn't going to get upset, and instead he planned to do it on another day**.

Bernard discussed with his therapist that he was happy to no longer receive support. **His low mood had improved** and the therapist had helped to problem solve the difficulties he had faced. **Bernard decided to continue with the activities that he had started to do again,** and Mary agreed to help him continue these.

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Let's talk about how you've got on.

Now it's time to see how you got on with completing the activities you planned. **Your therapist will discuss with you how you found completing the activities, and how you're feeling.**

- You may have managed to complete the activities, and feel that you don't need any more support from your therapist.
- You may have experienced some difficulties in completing the things you planned, and feel you need more support from your therapist.

In your support session you will discuss with your therapist if you need more support and help. This will be a joint decision between you and your therapist about whether to continue with more support sessions.

Well done for getting this far in this booklet.

The final step is to make sure that you keep living well every day.

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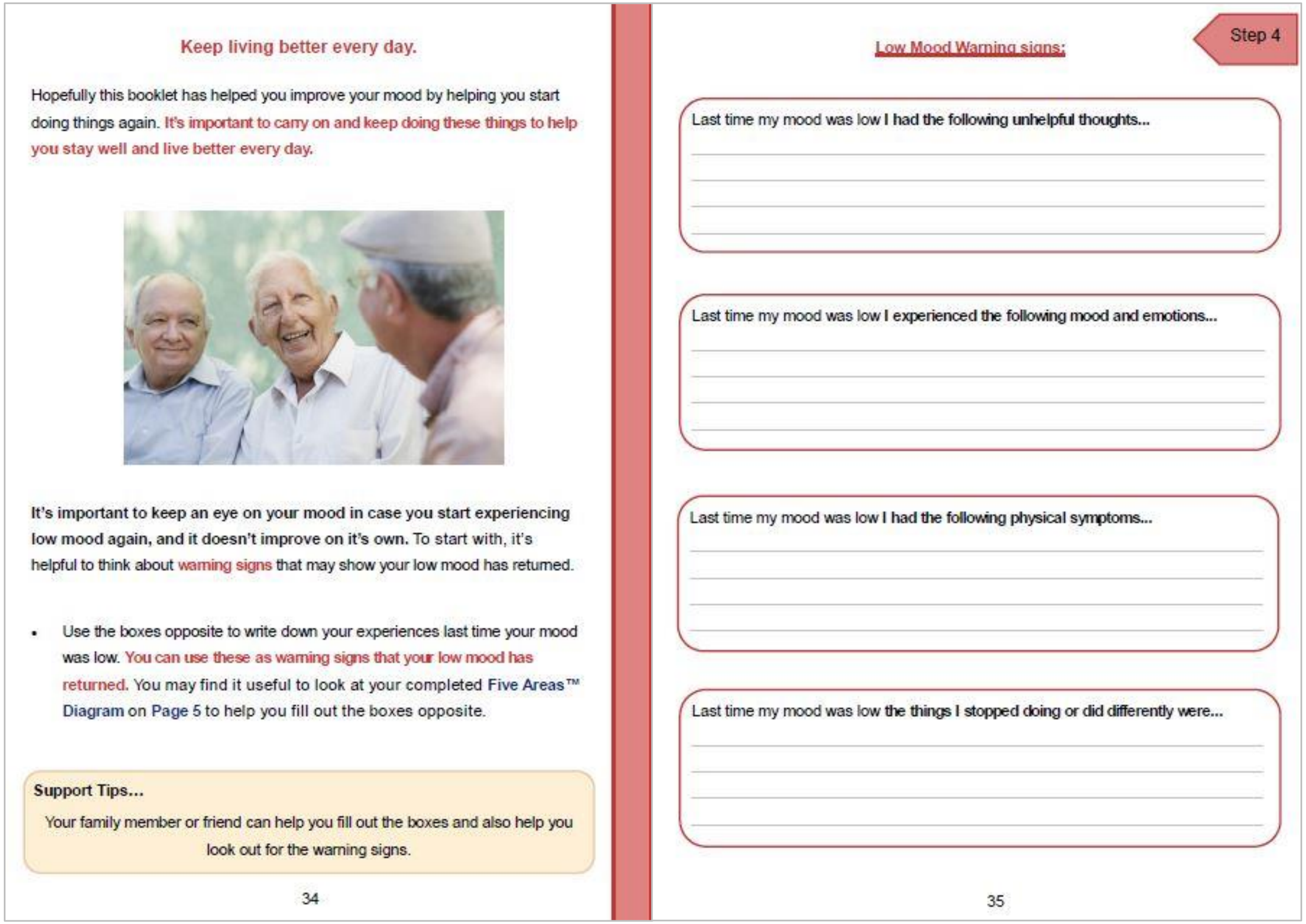


Keep living better every day.

Hopefully this booklet has helped you improve your mood by helping you start doing things again. **It's important to carry on and keep doing these things to help you stay well and live better every day.**

It's important to keep an eye on your mood in case you start experiencing low mood again, and it doesn't improve on it's own. To start with, it's helpful to think about warning signs that may show your low mood has returned.

- Use the boxes opposite to write down your experiences last time your mood was low. **You can use these as warning signs that your low mood has returned.** You may find it useful to look at your completed **Five Areas™ Diagram** on **Page 5** to help you fill out the boxes opposite.

Support Tips…

Your family member or friend can help you fill out the boxes and also help you look out for the warning signs.

Step 4

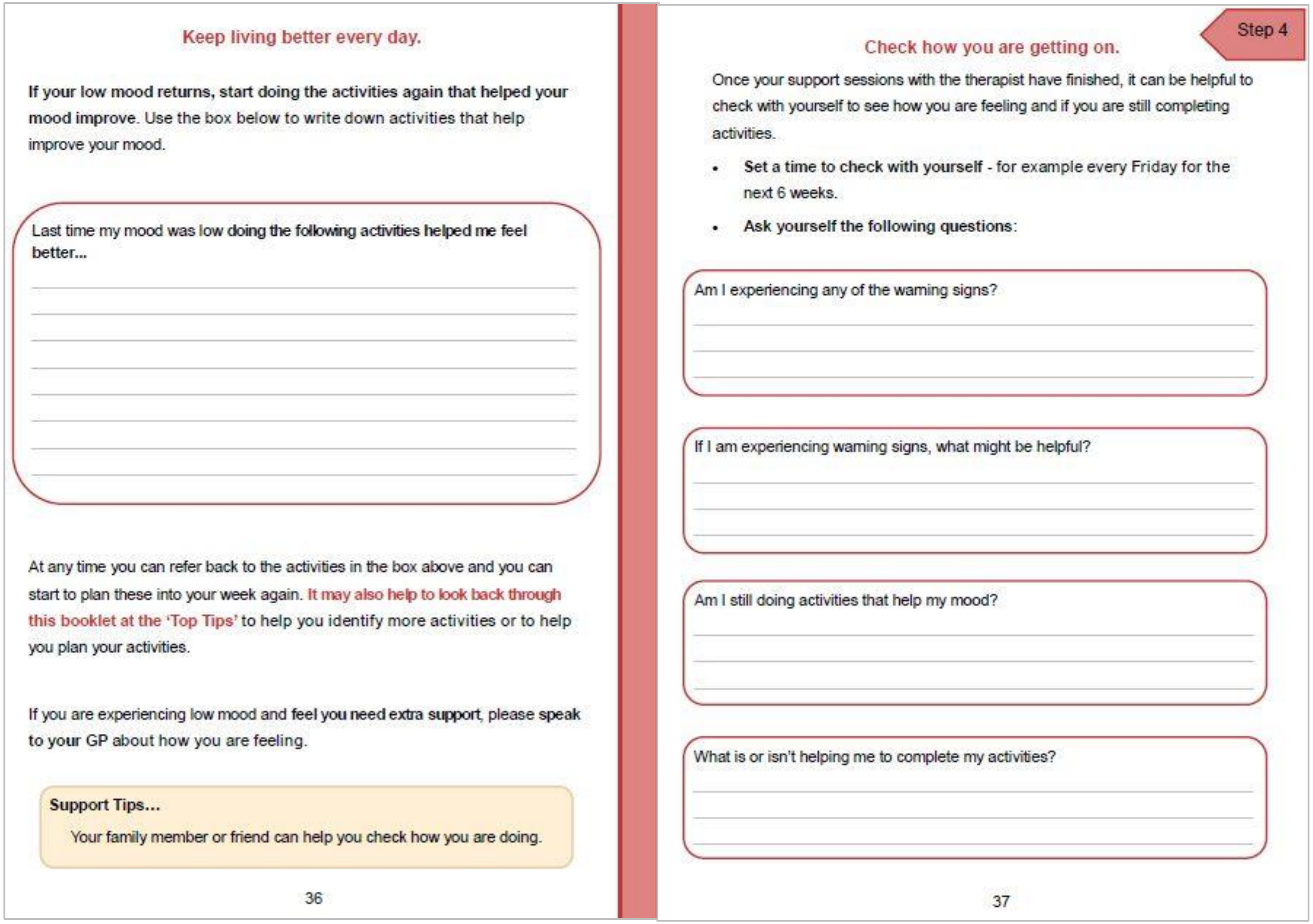
Low Mood Warning signs:

Last time my mood was low **I had the following unhelpful thoughts...**

Last time my mood was low **I experienced the following mood and emotions...**

Last time my mood was low **I had the following physical symptoms...**

Last time my mood was low **the things I stopped doing or did differently were...**



Keep living better every day.

If your low mood returns, start doing the activities again that helped your mood improve. Use the box below to write down activities that help improve your mood.

Last time my mood was low **doing the following activities helped me feel better...**

At any time you can refer back to the activities in the box above and you can start to plan these into your week again. **It may also help to look back through this booklet at the 'Top Tips'** to help you identify more activities or to help you plan your activities.

If you are experiencing low mood and **feel you need extra support**, please **speak to your GP** about how you are feeling.

Support Tips…

Your family member or friend can help you check how you are doing.

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Step 4

Check how you are getting on.

Once your support sessions with the therapist have finished, it can be helpful to check with yourself to see how you are feeling and if you are still completing activities.

- **Set a time to check with yourself** - for example every Friday for the next 6 weeks.
- **Ask yourself the following questions**:

Am I experiencing any of the warning signs?

If I am experiencing warning signs, what might be helpful?

Am I still doing activities that help my mood?

What is or isn't helping me to complete my activities?

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This booklet has been written by:

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The Five Areas™ Model is taken from Overcoming depression and low mood booklet series by Dr Chris Williams (Five Areas Limited, 2014) and is used with kind permission of Dr Chris Williams and Five Areas Limited.

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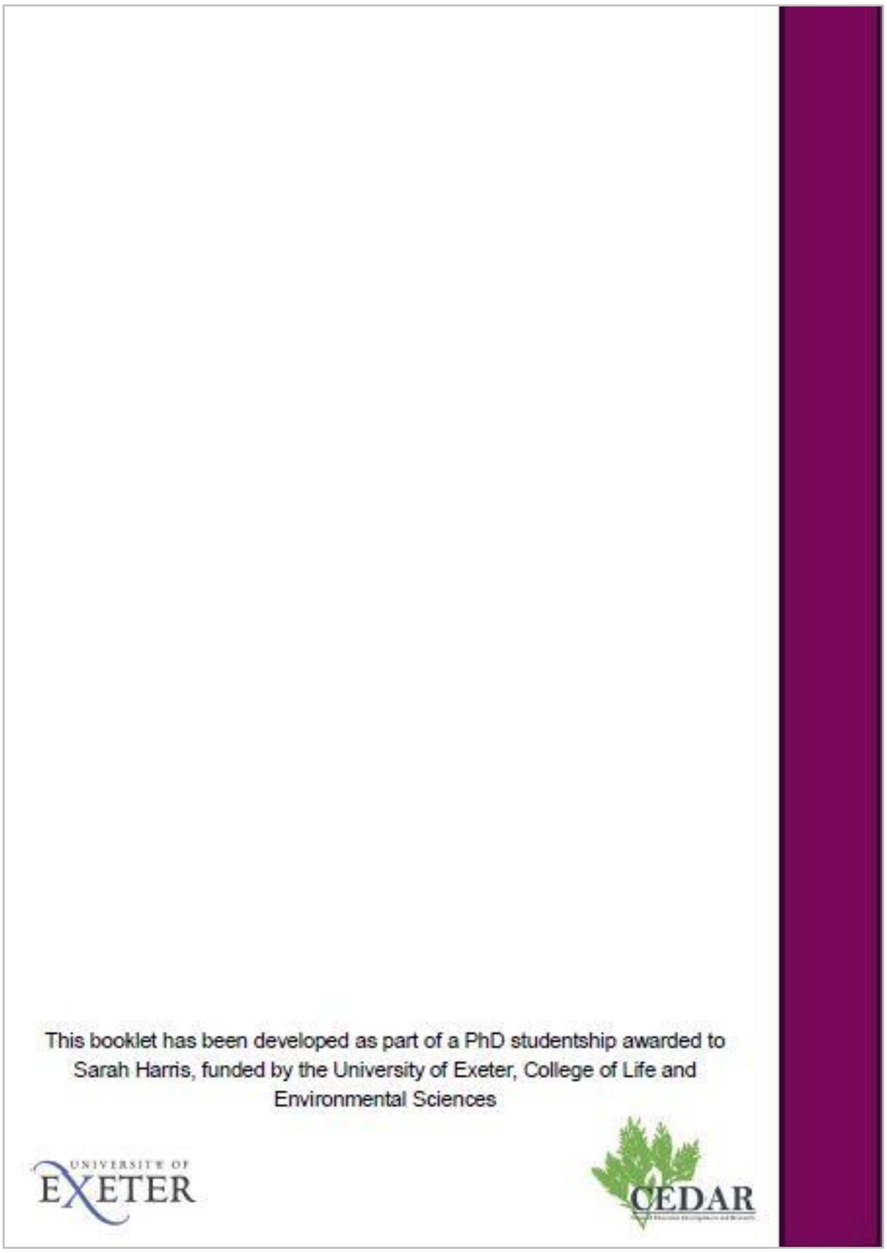
Version 1.1, April 2015



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Appendix 5.1 Interview Guide for Therapist Interviews

Aim	Topic	Questions	Prompts
First session:	First session – acceptability and understanding	How long was the session? What was the client's GDS-15 score?	
	Delivery.	How did the dementia client appear at the beginning of the first assessment session?	Comfortable? Remember why they were there? Did you remind them why they were there? Were there any issues getting there?
		How did they respond to you and your introduction as a therapist?	
		Was the dementia client able to create a problem statement?	Was the dementia client able to summarise their problem? Did the caregiver help? Did the dementia client feel they have a problem with low mood/depression?
		Was the rationale understood?	Did the dementia client appear engaged? Did the carer become involved?
		How did the dementia client respond to the workbook?	Understand what they need to do? Any initial issues with the format?
		How did the dementia client/carer respond to the carers support role?	Was the carer support role understood?
		How/what are the arrangements for the other support sessions.	All face-to-face? Arranged over the telephone? Arranged with the dementia participant or with carer or both?
		Were there any differences in how you conducted this initial session to how you would conduct it with individuals without cognitive impairment?	Length? Speed? Repetition? Any specific dementia-related difficulties arise? Memory, communication etc.
***Last Session*:** **Delivery**	Support Sessions	What format did you deliver support to the participant?	Face to face? Telephone?
		Tell me about any difficulties you found with	Did AccEPT Clinic administrator arrange them? Could it be

		arranging support sessions.	supported over the phone? Was it difficult to get clients into the Clinic? Any problems getting two individuals (dementia client and carer) in?
		Roughly how long were your support sessions? How many support sessions were there?	Was 40mins max. too short? Do you feel more sessions are needed?
		How long was the last support session?	
		What was the GDS-15 score in the last session?	
		Did you feel you were able to cover everything you needed to in the support sessions?	How far through the workbook did the client get during each session?
		Was there any particular part of the programme which needed more support?	
		Do you think there were any difficulties relating to cognitive decline present in dementia that raised issues with the programme?	Client had difficulty remembering rationale/activities etc? Difficulties with organisation and planning? Any communication issues? Faulty reasoning? Inappropriate behaviour?
		Was the family member involved in the support sessions?	If yes – how? Used to remind client of activities? Tell you how far through the workbook? Etc.
		What were the main problems/barriers you encounter in the support sessions?	What needed problem solving? How did you problem solve these problems?
		Where there any problems encounter that were dementia-specific?	Were you able to deal with the dementia-specific problems/barriers? How did you deal with them? Is there anything that

		In what ways, if any, did your delivery style change from when you deliver support to someone without cognitive impairment? How did the client respond to the workbook? What changes would you make, if any, to the workbook? Is there any other support you feel you need to help you support the programme?	would have help with these? Slower pace? Gave longer time for them to respond to questions? Dealt with different problems – i.e. different reasons for not completing activities. i.e. Further training; more specific dementia training; more guidance on where to signpost for help etc.
***Last session*: Implementation**	Materials	Do you feel the programme was successfully received by the client? What, if any, other resources did you feel you needed to help implement the programme? What, if any, factors affected the ease of implementing the programme?	If yes – why? Why not? i.e. written materials: separate materials? Different written materials? Other resources: i.e. whiteboards, devices to help with memory?
	Summary	*Summarise the main points made by the Therapist*. Does this sound right? Is there anything important that I have missed? Is there anything you would like to add?	

Appendix 5.2 Interview Guide for Dementia Participant Acceptability Interview

Aim	Topic	Questions	Prompts
	Withdrawal from the programme: <u>only for those who withdrew from the programme</u>	*Why did you withdraw from the programme?*	*Time/length?* *The programme itself?* *Attending support sessions?*
Acceptability and feasibility of research materials, methods and procedures	Acceptability of information sheets	What were your first thoughts about the study when you received the information sheets? What did you think of the information sheet? (presentation / layout etc.)	Was the information about the study clear? Did you need further verbal information / clarification about the study? Were there any problems with the information sheet?
	Acceptability of consent forms	What did you think of the consent forms?	Were there any problems with the consent forms?
	Acceptability of data collection appointments	How were the screening questions? How did you find the completion of the questionnaires/ interviews before and after the programme?	Did you find that the length of the data collection appointments were too long? Did you need help with completing any of the questionnaires? Is there anything you would have liked to have changed about the questioning?
Acceptability of the programme	BEAMD materials	What did you think of the workbook? How did you find completing the work book?	e.g. size and length; layout; font; description of BA; provision of list of activities; sections to complete – have copy of workbook to hand. Go through the sections. Did you have much help from your family

		What could be improved about the workbook if anything?	member/friend to complete the workbook?
	Increasing activities	Did you add more activities into your schedule? If yes, what helped you increase your activities?	What activities? How? Why? Why not? Information in workbook i.e. rationale? Therapist? Carer support? Using the workbook – filling in schedule/diary? Anything else?
	Involvement of the family member/friend	What did your family member/friend help you with in the programme? Is there anything else you think a family member/friend could help support in the programme?	Completing workbook? Reminding you about rationale? Identifying activities? Scheduling activities? Reminding you about activities? Completing activities with you? Reminding you about support sessions?
	Mood	Have you noticed any changes in your mood? Was this an improvement in your mood?	If YES – what particular activity helped your mood? What about that activity helped?
Delivery and implementation of the programme	Support sessions	What did you think of the support sessions with the Therapist?	Where they face-to-face? Over the phone? Were they too short/too long? Did you discuss in them what you needed to/expected to?
	Therapist delivery	What did you like about the way the therapist went through the programme with you? What did you not like or what was not useful?	Listening; empathy; explanations; pace; collaboration in goal setting; referring to workbook.
	Implementation	Are there any other materials/devices/objects that you would have	i.e. whiteboards, more detailed case studies, different

		found useful to help you through the programme?	written materials etc.
	Summary	*Summarise the main points made by the participant*. Does this sound right? Is there anything important that I have missed? Is there anything you would like to add?	

Appendix 5.3 Interview Guide for Carer Acceptability Interview

Aim	Topic	Questions	Prompts
	Withdrawal from the programme: <u>only for those who withdrew from the programme</u>	*Why did you or your family member/friend withdraw from the programme?*	*Time/length?* *The programme itself?* *Attending support sessions?*
Acceptability and feasibility of research materials, methods and procedures	Acceptability of information sheets	What were your first thoughts about the study when you received the information sheet from your family member/friend? What did you think of the information sheet? (presentation / layout etc.)	Was the information about the study clear? Did you need further verbal information / clarification about the study? Were there any problems with the information sheet?
	Acceptability of consent forms	What did you think of the consent forms?	Were there any problems with the consent forms?
	Acceptability of data collection appointments	How did you find the completion of the questions about your family member/friend with Sarah before and after the programme?	Is there anything you would have liked to have changed about the data collection appointments?
Acceptability of the programme	BEAMD materials	What did you think of the workbook? What did you think of the guidance provided on how to support your family member/friend through the programme? What could be improved about the workbook if anything?	e.g. size and length; layout; font; description of BA; provision of list of activities; sections to complete – have copy of workbook there. Go through the sections. Did you need more information on how to support the intervention? If so, what?
	Increasing activities	Did your family member/friend add more activities into their schedule? If yes, in your opinion, what helped them increase their activities?	What activities? How? Why? Why not? Information in workbook i.e. rationale? Therapist? Your support? Using the

			workbook – filling in schedule/diary? Anything else?
	Involvement of the family member/friend	In what ways did you help support the programme? What, if any, difficulties did you encounter when supporting the programme? Is there anything else you think a family member/friend could do to help support the programme?	Completing workbook? Reminding them about rationale? Identifying activities? Scheduling activities? Reminding about activities? Completing activities with your family member/friend? Reminding them about support sessions?
	Mood	Have you noticed any change in your family member's/friend's mood? Have you noticed a change in your own mood?	If YES – what particular activity helped with their mood? What about that activity helped? What do you think has changed your mood?
Delivery and implementation of the programme	Support sessions	What did you think of the support sessions with the Therapist? What involvement did you have in the support sessions?	Where they face-to-face? Over the phone? Were they too short/too long? Did you discuss in them what you needed to/expected to?
	Therapist delivery	What did you like about the way the therapist went through the programme with you? What did you not like or what was not useful?	Listening; empathy; explanations; pace; collaboration in goal setting; referring to workbook.
	Implementation	Are there any other materials/devices/objects that you would have found useful to help your family member/friend through the programme? Is there anything else that would have helped you to support them through the programme?	i.e. whiteboards, more detailed case studies, different written materials etc.
	Summary	*Summarise the main points made by the participant*.	

		Does this sound right? Is there anything important that I have missed? Is there anything you would like to add?	

Appendix 5.4 Summary of the Acceptability of Research Materials, Methods and Measures

	Positive Comments	Difficulties and concerns	Changes
Eric		○ Could not understand the questions half the time and had difficulty answering them. The questions did not seem to be direct. Could not understand the question about mood.	
Pam (Carer)	○ The information sheet is easy to read and understand as it has short paragraphs. ○ The consent form is easy to understand and quite straightforward. ○ Baseline data collection was easy to understand. Eric understood it and was agreeable. ○ Enjoyed the researcher’s company.	○ Was not quite sure what BEAMD was going to involve. It was hard to understand what it was all about at the beginning but it becomes clearer when working through the intervention. ○ Baseline data collection took longer than expected. ○ Did not necessarily understand why the questions were being asked at baseline, but understood more post-intervention.	
Betty	○ Even though her eyesight is very poor she could read the information sheet quite well.	○ Was initially worried that it would be too complicated that she would not benefit from it. ○ Had no idea how to answer the baseline questions.	
Brian (Carer)	○ The ‘purpose of the study’ on the information sheet was fine. ○ The consent form is fairly straightforward.	○ Did not understand the meaning of the title, 'behavioural activation for mood in people with memory difficulties', on the information sheet. ○ The questions are too specific to establish a state of mind, the answers are black and white. Yes or no answers do not work. It is not establishing the participant's thoughts but looking for a specific answer. It was a 'tick box operation'.	○ Simplify the title for lay people. 'To increase wellbeing' would be easier to understand. Simplify 'you have been identified' to 'you have been chosen'.

Note: BEAMD = Behavioural Activation for Mood in Dementia

Appendix 5.5 Summary of the Feasibility of Delivering BEAMD and Suggested Changes

Aspect of BEAMD	Difficulties delivering BEAMD	Positives	Ideas for future delivery of BEAMD
BA Model	*Rationale* ○ Difficulties for PwD to remember rationale and understand the link between behaviour and mood faces. ○ Never remembered what BA was. *Problem statement* ○ Difficulties creating a problem statement for multiple participants. Not held on to and the statement changed later on. *Goals/activities* ○ Setting of goals was confusing and difficult without therapist support. ○ Step 2 (identify, organise and plan activities) was quite confusing and all sections were too complex. ○ When focussing on 'things I often do' there was no link with things they had stopped doing. ○ Identifying activities is more difficult than usual as it involves processing whether the activity is possible, overcoming barriers, more problem solving and then realising the activity is not possible. ○ Problem solving was needed to identify and simplify activities.	*Rationale* ○ Carer had a grasp on the rationale (but not necessarily the types of activities). ○ 'Low mood and fewer activities cycle' diagram (p.11) worked well, maybe more so for the carers.	*Goals/activities* ○ Might not be about understanding routine, necessary and pleasurable activities (routine activities did not seem to be a problem as carers involved with routines) more about purposeful activities. Working around problems, goals and activities is simpler. ○ Step 2 needs to be linked better to the planned activity diary. ○ Use understandable, interesting repetitive phrases, such as 'little and often'. ○ A checklist of pleasurable activities would save time thinking of activities. ○ Concentrate on pleasurable activities and social connection. ○ Could potentially use cards with pleasurable activities on and sort them. ○ Do not identify memory dependent tasks. ○ Get PwD and carer to negotiate and 'buy in' on activities. ○ Obtain a greater understanding of what the PwD can and cannot do, maybe using a checklist, in an 'orientation assessment'. Need to understand

	○ Confusion around routine, necessary and pleasurable activities. ○ Did not understand the examples of necessary activities in the workbook, other than medication, as not capable of doing some of the others. ○ Examples of activities in the workbook were taken literally rather than as prompts to the category. ○ Some goals/activities were memory dependent, creating strain on the carer. ○ Difficulties with future orientation and planning activities for one PwD. ○ Suggested activities limited by physical health problems. ○ Completing activities was dependent on physical ability on the day. ○ Sometimes could not fit activities with other physical health appointments. ○ Confusion with 'what I need' on the 'planned activities diary'. ○ Anxiety at engaging in activities they may not be able to do. ○ Both participants wanted to do activities all in one go rather than stopping and starting. *<u>Relapse prevention</u>* ○ Difficulties completing the relapse prevention, both PwD and carer had difficulties recalling the purpose and understanding the instructions.	sleeping and functional impairments to plan activities. Could also assess comprehension, recall, ability to physically see, barriers to physically filling in workbook, and whether the carer has the time and ability to provide required support. ○ 'Little and often' concept as participants wanted to complete activities in one. ○ Problem solving needs to be worked through with the therapist. ○ Sell as more of an exercise programme – i.e. exercise this number of tasks.

My Five Areas™ Model	○ Difficult and confusing for multiple participants. Too complex. The main difficulty was with the ‘My situation, relationship or practical problems’ box.		○ Three boxes may have been better than five.
Selection, optimisation and compensation	○ Focussed on driving, for which it was not possible to create a functional equivalent. A lot of time spend moving away from impossible activities. Objections to alternative activities.		
Workbook	○ A lack of engagement with and completion of the workbook between sessions from both participants. ○ Worries and anxiety about writing in the workbook (including handwriting and spelling) and getting it wrong, despite carer support. ○ Information from the workbook could not be recalled. ○ Difficulty remembering the purpose of exercises and that the workbook is a programme. ○ Worksheet boxes were confusing and a lot to go through and keep focussed on over telephone support. Additional diary sheet needed to be sent in the post. ○ Difficulty navigating around the workbook, carer needed to find page numbers. ○ PwD felt things in boxes were particularly important and was stuck on them.	○ The workbook became a good focus in the assessment for one PwD and she understood the concept of homework.	○ Be more explicit about Bernard’s story helping people to understand how the intervention works. ○ If the workbook creates strain then just use one handout at a time. ○ Condensing the workbook a bit may give longer to spend on the ‘orientation assessment’.

	o Uncertainty about the comprehension of the case study. PwD did not understand Bernard’s example worksheets (p. 30).		
Carer involvement	o Carers appeared to think it was the PwD’s programme and did not really want to get involved, for example not writing in their workbook. Their responses indicated that it was their partner’s book and they did not want to get involved. o The intervention was sold as ‘collaborative patient first’ which de-emphasised using the carer to collect data. o One carer found supporting BEAMD hard and stopped doing housework to help with the activities as the demands on her had increased. o One carer was distressed and upset. One session needed to be used to help with carer upset. o When leaving time for the PwD to respond/recall information sometimes the carer would answer rather than the PwD. o Carer reported not remembering what they needed to do between sessions in the workbook. o In the assessment session one carer appeared to have a propensity to want to close her mother down in regards to activities to ensure she does not harm herself and is safe.	o One carer understood her role before reading the workbook tips.	o Complete a functional analysis of carer demands. o Keep the patient as the focus but consider the impact on the carer – this could be discussed between the dyad. o Consider effort and time/impact on both the person with dementia and the carer, maybe a hierarchy of intensity on the carer. o Have a separate briefing with the carer about understanding, comprehension and heightened safety concerns from doing activities. o A separate manual/workbook is needed for the carer about their role. Be explicit in the carer’s workbook how much they may be involved in supporting the programme. It could also include support tips for the carer. o Carer to complete their own observational diary (and to include periods of sleeping). o The carer could rate pleasurable activities for the person with dementia. o Be more explicit about the carer engaging in the homework and doing it alongside the person with dementia.

			○ See the carer separately in each session as they are necessary for understanding what is happening. ○ Therapist needs to help remove barriers to carer and PwD working together. ○ More support for carer mental health.
Support sessions	○ Sessions were longer for several reasons: - Time is needed in the assessment to obtain a full in-depth understanding, explain the intervention and disentangle some relationship dynamics. - A lot to cover with the focus on physical health issue and wanting to familiarise therapist with life changes. - For understanding and comprehension, as intervention was quite complicated. - The need to re-orientate and upskill the PwD in each session (sometimes the carer too). - PwD getting distracted, word finding problems and tangential nature. - Therapist found it harder to cut across/interrupt someone who was struggling to give information. - PwD wanted to spend a lot of time thinking back to things they liked to do, and therapist did not want to rush him. - PwD too anxious to tackle next section - PwD needed to be taken through piece by piece. - Wanting to go back to how they.	○ Support worked well over the telephone after initial minor issues with battery life and understanding of teleconferencing. ○ Not rushing the PwD and giving them space was helpful for rapport.	○ A visual agenda with big letters may be useful. ○ It could possibly be delivered at a quicker speed, however uncertain of the benefit of the length of session, even in longer sessions it reached the same end point of participants not really being able to feedback about the session. ○ May be delivered at a quicker pace for therapists more experienced with people with dementia.

	- Carer helping PwD to understand due to hearing problems. Talking fast made this PwD slightly anxious. ○ Delivering like a formulated manual-driven intervention was not as straight forward as it would be for patients that you can orientate to the intervention. It went off in different directions.		
Assessment of depression	○ Difficulties responding to the GDS-15 for all participants. Wanted to quantify the amount of time or respond ‘sometimes’. ○ PwD uncertain about the meaning of question 15, ‘Do you think that most people are better off than you are?’ ○ Potential problems with the accuracy of self-report on the GDS. One carer disagreed with the responses and would have added another 5 points to the score.		○ Carers could independently rate mood.
Other	*<u>Cognitive abilities</u>* ○ PwD could not always follow the conversation, recall events or recollect agreed points. ○ Could not remember certain parts of the intervention. ○ Poor memory created difficulties for filling out the diary. ○ Confusion about the purpose of BEAMD. In one session PwD felt they were attending for their memory problem. Uncertain if in the memory clinic or what he was doing. Looking for reassurance about dementia diagnosis.	*<u>Cognitive abilities</u>* ○ In some assessment sessions participants did not seem to be struggling with comprehension or recall.	

	Also confusion between BEAMD helping with physical problems versus mood. *<u>Physical health</u>* o Pre-occupation with ill health, physical health concerns or pain for multiple participants. Carer also preoccupied with physical health problems and concerns over mobility issues. o Concerned with sorting out physical health problems rather than mental health. o Problem solving chronic disease management issues was needed. o Tasks have been lost due to ill health. o Physical health problems take up time during the week, for example attending appointments.	

Note: BA = Behavioural Activation; BEAMD = Behavioural Activation for Mood in Dementia; GDS-15 = Geriatric depression scale-15; PwD = Person with dementia

Appendix 5.6 Summary of the Acceptability of BEAMD

	Positive Comments	Negative aspects of BEAMD	Difficulties with BEAMD	Suggested Changes
Eric	o BEAMD gave him something to do. Using his Ipad as one of the activities made him more interested. o Felt like he had learnt a lot from the programme but was not able to express what he had learnt. *Support sessions:* o Telephone support sessions were a good idea as saved travelling to Exeter. o The length of the sessions was 'about right'. The sessions went well. o The case study is a good example.	*Mood:* o Did not think his mood had changed over the intervention.	*Workbook:* o Difficulties remembering the content of the workbook the following day.	*Workbook:* o The lines drawn on the worksheet by Pam were helpful. o Two boxes for each section of the day on the current activities diary are not needed - could be just one box.
Pam (Carer)	o 'Very impressed' with the programme. *Workbook*: o The workbook is easy to read and the information is well organised. o The 'check-in' section was interesting.	*Workbook:* o The part of the rationale that says 'you will not need to think too much or concentrate for a long time' is not accurate as thinking and concentration is necessary for comprehension (unless someone like herself completes it).	o Eric had some difficulties with BEAMD so other people with dementia who are worse may find it difficult. However, the programme is 'quite simple' so unsure how it could be simplified.	*Workbook:* o Adding guidelines to the diaries is a good idea to help with writing. o Additional diary sheets are needed. o The case study would be better all in one place.

	○ The workbook is helpful, especially if you read all of it and not just the worksheets. ○ The case study was interesting. Although not relevant for them, as everyone is different the case study would help some people. ○ The workbook gave Eric an interest, he knew he had to do it, and it made him think. *Support sessions:* ○ The therapist was lovely, very easy to engage with and knew what he was doing. He was good, not tangential and stuck to the programme and hour sessions. ○ Telephone support sessions were brilliant as it saved travelling to Exeter, and the speaker phone worked well (after changing the battery). Grateful for the funded travel. ○ For the face-to-face support sessions it was nice to go out and see the University. ○ Eric enjoyed the support sessions.	○ Reading all the information was a bit beyond Eric as he does not read very much (and never has) and what he does read he does not take in. ○ The case study was not relevant to what Eric and Pam do. *Carer involvement:* ○ Although the programme helped Eric, a lot of the programme fell onto Pam which was a lot of pressure.	*Workbook:* ○ Eric had difficulties understanding some of the workbook and they did not know how to fill it in between them. Pam had some difficulties working out what to put in the diagrams, support from the therapist was needed. Support would definitely be needed for this for people with dementia. ○ Instructions for the worksheets are fine, but it's difficult to know what to put in the diagram. ○ Pam had difficulties knowing what Eric was feeling to fill out in the workbook – what she would write might be different to what he is feeling and Eric is slow at making decisions about what he thinks. ○ It took a long time to fill in the workbook, a whole morning, as Eric writes slowly and practiced everything in another book	*Support sessions:* ○ Need to identify how severe/advanced the person's dementia is. ○ It would be a good idea to have a session focussing on how the carer is feeling and what support they can get and from where.

	Mood: o Feels Eric is definitely better, he had been quite depressed, and his lack of interest was making Pam very depressed. Now Eric is more interested and trying harder to do more and help her out.		before writing in the workbook. o Eric did not understand the faces on the current activities diary. o Eric could not understand the case study, he thought he had to do what Bernard was doing.
Betty	o Did not find anything difficult. If she had, or was worrying about what she was doing, she would have stopped participating. *Workbook:* o The workbook is helpful as what you need to do is all laid out. o Did not find the worksheets difficult. o Statements in the workbook were clear. o The additional printed diaries given by the therapist were good, could be completed at her leisure. *Support Sessions:* o Enjoyed the sessions with the therapist. The therapist was excellent, understanding, a	*Workbook:* o Filling out the workbook was a task, sometimes slightly reluctant, with a 'bit of a sigh' and feeling like she had better fill it out. *Support sessions:* o The support sessions sometimes ended quicker than Betty expected. Would have liked to have gone on further but aware the therapist's time was limited. o Felt the programme went quickly, was surprised it was only 7 weeks instead of 12. o Bernard in the case study was much younger than themselves.	*Workbook:* o Would sometimes find it difficult filling in the diary with respect to thinking back in the evening to what she was like in the morning. o Was not able to complete the diary for the whole day - sometimes sleeping in the afternoon or could not remember what she did days ago.

	pleasure to talk to and very knowledgeable in his explanations. o Attending the face-to-face support sessions was no problem as Brian drove, however without this it would have been difficult. o Looked forward to the support sessions. *Carer involvement:* o No problems with having Brian in the support sessions. *Outcome of BEAMD:* o Learnt to be more patient and tolerant, as well as appreciate things she had taken for granted.			
Brian (Carer)	o The programme interested Brian greatly and if it had happened years ago he may have started studying psychology. *Workbook:* o Very good, good layout. o The information in the workbook is good. o Could understand the rationale as it was fairly simple.	o Felt the aim of the programme and questions was as an academic exercise, not to gather information, but to find a phrase, for example ‘low mood’, that could be used. o Dealing with people with dementia is different to people only suffering from low mood, BEAMD is not necessarily ‘geared’ for them.	*Workbook:* o Betty has Macular degeneration, having had treatment for 4.5 years, her sight is poor and she has trouble reading things properly. o Betty had difficulty understanding the Five Areas diagram and other people with dementia, depending on their level of	*Workbook:* o Change the language/tone of the workbook to avoid suggesting the possibility of failure. o Ignore the days in the diary for planning and instead identify activities that the person would like to do at any time during the week to avoid

	○ The support tips are good, for example having a family member help plan activities. *Support sessions:* ○ The support sessions were 'quite adequate' and the right length. ○ The therapist was very good and Betty got on well with him. Both benefited from the therapist's attitude towards Betty and the way he talked about things. ○ The therapist's advice about breaking down goals into smaller steps was a good idea. *Carer involvement:* ○ Brian was happy to support Betty through BEAMD, anything to get Betty out, meeting and talking to people, has to be good. ○ BEAMD gave Brian an insight into ways to help Betty, some that he had not thought of before. It made him think about what he was doing with Betty, which was a good thing.	*Workbook:* ○ Did not like the objective of completing worksheets – if they are not done it creates a feeling of failure. ○ The idea of homework (completing the worksheets or doing activities) was a source of distress/worry if Betty could not complete it. ○ If a person with dementia does not have the comprehension to understand the diagram/worksheet then they will not be able to fill it in. ○ Did not like some of the language used in the workbook as it was establishing the negative aspect, for example highlighting things you have stopped doing - the fact that Betty cannot do it anymore because of physical abilities is a source of distress. Dividing the activities into levels of difficulty also produces negative thoughts. The low warning signs are also worded	confusion, will have difficulty understanding it too. ○ Betty could not completely understand the rationale page. ○ Brian could not understand what the term 'low mood' meant - depression is a better term. ○ Betty was confused having seen the therapist on the Wednesday but the diary in the workbook started on a Monday. ○ Betty allied herself with the case study and compared herself to 'Bernard', implanting problems into her mind. ○ Although the therapist did emphasise the workbook was not homework, once an idea is 'implanted' it is hard for Betty to get rid of.	the feeling of failure or getting in trouble if activities are not done that week. ○ A diary to fill in what was done each day would be better than using the current activities diary worksheet. ○ Do not have homework that is 'construed' as needing to be completed before the next support session. ○ The low mood warning signs should be completed by just the carer - not wanting to get Betty involved and therefore reminding her that low mood may occur again. *Support sessions:* ○ Need to establish what activities are realistic for the person with dementia as you cannot generalise.

	Mood: o Brian felt Betty was better from the programme, even if this was only as a result of the social contact created from the programme, talking to SH, the therapist and the receptionist in the AccEPT Clinic.	for failure rather than being positive. o The case study was not for Betty. Bernard in the case study is more physically capable than Betty. The case study it is about directing him back to activities he had enjoyed, whilst Betty is no longer able to physically do things had she been interested in. *Support sessions:* o There was an insufficient account taken of Betty's physical capabilities, and activities that she could not do anymore were not established. *Mood:* o Brian felt the programme did not achieve the objective of improving Betty's low mood. o Betty would get a bit 'worked up' if she did not complete what was planned.	

Note: BEAMD = Behavioural Activation for Mood in Dementia.

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