

# Behavioural activation self-help to improve depression in people living with dementia: The PROMOTE treatment protocol

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There is an increasing number of people living with dementia and depression, with support for people to live well with dementia becoming a global healthcare priority and seminal to the New Zealand Framework for Dementia Care (Ministry of Health, 2013). This paper overviews the clinical protocol for the PROMOTE self-help programme to inform the delivery of a written low intensity intervention based on behavioural activation for the treatment of depression and low mood in people with dementia. The primary aim of the programme is to decrease symptoms of depression and improve quality of life in people living with dementia. Support to the person living with dementia in the use of the PROMOTE programme is provided by an informal caregiver, who themselves receive guidance over the telephone by an appropriately trained mental health professional. This model of support and guidance represents a novel feature of the intervention, and one that potentially helps to increase access within the community.

**Keywords:** Clinical protocol, depression, dementia, behavioural activation, low intensity CBT

## Background

By the year 2026, New Zealand is set to experience an 18% increase in the number of people living with dementia to over 78,000 (Alzheimer's New Zealand, 2012). This contributes to in excess of 35 million people with dementia on a worldwide scale, with this figure set to triple by 2050 (Prince et al., 2013). Given such increases in prevalence, supporting people to live well with dementia has been identified as a global healthcare priority (World Health Organisation; WHO, 2012) and seminal to the New Zealand Framework for Dementia Care (Ministry of Health, 2013). Given the current absence of a cure for dementia (Winblad et al., 2016), the provision of appropriate physical and emotional support is essential (Samsi & Manthorpe, 2014)

Estimates concerning the number of people with dementia experiencing depression vary between 30% (Enache, Winbald, & Aarsland, 2011; Castilla-Puentes & Habeych, 2010) to 50% (Modrego, 2010). These estimates, alongside anticipated increases

in dementia prevalence, highlight a significant need to focus on improving the long-term quality of life and wellbeing of people living with dementia (Gates, Valenzuela, Sachdev, & Singh, 2014). This is particularly justified given people with comorbid dementia and depression experience poor quality of life (Hoe, Hancock, Livingston, & Orrell, 2006), increased verbal agitation and behavioural symptoms of dementia (Van der Mussele et al., 2013), functional impairment (Thyrian et al., 2016), cognitive decline (Rapp et al., 2011) and increased risk of institutionalisation (Gaugler, Yu, Krichbaum, & Wyman, 2009). However, given the symptom overlap between depression and dementia in memory and concentration difficulties and loss of interest in activities, depressive symptoms are often misdiagnosed as signs of further cognitive decline (Pattanayak & Sagar, 2011).

Furthermore, although evidence based psychological therapies have been identified (Orgeta, Qazi, Spector, & Orrell, 2014), depression in dementia often goes untreated (Curran & Loi,

2012; Thyrian et al., 2016; van der Roest et al., 2009) even when detected. The limited availability of evidence based psychological treatments arising from high economic costs of delivery and shortage of qualified therapists (Kazdin & Blasé, 2011; Lovell, Richards & Bower, 2003) has been cited as contributing to the worldwide treatment gap (Shidhaye, Lund, & Chisholm, 2015). In attempts to overcome the treatment gap, innovative strategies to improve access to evidence based psychological therapies are being adopted worldwide (Rebello, Marques, Gureje, & Pike, 2014). Within the Improving Access to Psychological Therapies (IAPT) programme implemented across England (Clark, 2011), this has resulted in the delivery of psychological therapies within a stepped care model of service delivery (Bower & Gilbody, 2005). The IAPT programme represents a paradigm shift away from the conventional delivery of face-to-face 'high intensity' CBT by experienced and specialist mental health professionals towards the delivery of 'low intensity' CBT (Bennett-Levy, Richards, & Farrand, 2010). Indeed, 'low intensity' CBT is an approach being adopted globally (Gyani, Shafraan, Layard, & Clark, 2013; Pilgram & Carey, 2012; Rebello et al., 2014; Vis et al., 2015), including New Zealand (Merry et al., 2012; Shepherd et al., 2015). Furthermore, similar programmes to IAPT have been adopted in Australia within the NewAccess initiative (Cromarty, Drummond, Francis, Watson, & Battersby, 2016).

With a low intensity approach, CBT techniques are delivered in a self-help format through written material or health technologies such as online programmes or smartphone applications (Donker et al., 2013; Ridgway & Williams, 2011) as opposed to delivery

by a therapist (Farrand & Woodford, 2013). Whilst CBT self-help can be completely self-administered, to improve the effectiveness of low intensity CBT, guidance from a health professional in the use of self-help materials often represents a core characteristic of service delivery (Andersson & Cuijpers, 2009; Gellatly et al., 2007). For example, within the IAPT programme, guidance is provided by a psychological practitioner workforce, termed Psychological Wellbeing Practitioners (PWPs). PWPs are not required to have any core professional mental health/health qualifications or previous training in the delivery of psychological therapy. Instead, this workforce receives graduate or postgraduate level training focused on the competencies required to support low intensity CBT (Roth & Pilling, 2007) and briefer than that received by high intensity CBT therapists (DOH, 2015; UCL, 2015). Increasing evidence also indicates that with similar training, support can be provided by non-professionals within community settings (McClay et al., 2015). Whilst support and guidance in the use of CBT self-help interventions results in improved effectiveness when compared to self-administered CBT self-help (Gellatly et al., 2007), uncertainty remains regarding the intensity of support and guidance required, for example guided versus minimal contact (Farrand & Woodford, 2013; Glasgow & Rosen, 1978). To maximise access and overcome barriers to face-to-face therapy, such as rurality (Vallury, Jones, & Oosterbroek, 2015), lack of financial resources (Parikh et al., 2014) and physical health problems (Matcham et al., 2014) support can be provided over the telephone, email or face-to-face (Bennett-Levy, et al., 2010).

Given the contribution of low-intensity CBT to improve access, alongside an emerging evidence base for the treatment of depression and anxiety (Coull & Morris, 2011; Cuijpers, Donker, van Straten, Li & Andersson, 2010; Farrand & Woodford, 2013) the approach presents a potential solution to improve access to currently underserved patient groups. Development of a low-intensity CBT approach for the treatment of depression in people with dementia is currently being piloted within the PROMOTE study, a one-arm feasibility

trial (Farrand et al., 2016). The clinical protocol for the PROMOTE self-help programme is presented in this paper and may hopefully serve to stimulate further research within a New Zealand context.

### Introduction

The PROMOTE self-help programme, named '*Getting More Out of Every Day with Memory Difficulties: A Guide for People Living with Memory Difficulties*' (Farrand, Woodford, Anderson, & Lovis, 2015), is designed for the treatment of at least mild depression in community dwelling adults aged 18 and over experiencing any type of dementia of mild-to-moderate severity (e.g. score between 12-24 on the mini-mental state examination; Folstein, Folstein, & McHugh, 1975). Patients may, or may not, have the capacity to consent for treatment. An assessment of capacity to consent should be conducted with all people with dementia, whilst providing support to maximise their ability to provide consent (Warner, McCarney, Griffin, Hill, & Fisher, 2008). If the person with dementia does not have capacity to consent, consultee consent can be obtained from an informal caregiver (Hope, Slowther, & Eccles, 2009). Exact procedures for determining consent may differ between healthcare services and countries, and as such local policy concerning consent should be adhered to. The PROMOTE self-help programme is not suitable for people with dementia who have a diagnosis of a severe and enduring mental health difficulty (for example, psychosis), activity suicidal, have a history of persistent self-harm or currently misusing alcohol, prescription drugs or other substances to an extent that use severely interferes with everyday activity.

The programme is based on a simple model (Ekers et al., 2014) of behavioural activation (BA; Richards, 2010), a psychological approach targeting behavioural avoidance, common in depression, by increasing engagement in activity (Farrand et al., 2014). Further, the programme is designed to be supported by an informal caregiver of the person with dementia to enable them to utilise the programme within their own home. To help provide support, the informal caregiver is supplied with their own workbook ('*Getting More Out*

*of Every Day with Memory Difficulties: A Guide for Family and Friends*'), Farrand, Woodford, & Anderson, 2015). In addition, the informal caregiver receives training in the use of the programme, alongside weekly telephone guidance provided by a psychological practitioner or other trained mental health professional.

Several features of a simple BA protocol suggest it may have potential utility for people with dementia and their caregivers (Farrand et al., 2016). For example, the BA protocol adopted represents a simple model (Ekers et al., 2014) making it easier for people with dementia and caregivers to understand. This contrasts to the BA model commonly employed in high intensity CBT (Dimidjian, Barrera, Martell, Muñoz, & Lewinsohn, 2006) that often also includes cognitive components, potentially making it more difficult for people with cognitive impairment to understand. Further, as a simple psychological treatment, a recent definitive RCT has demonstrated psychological practitioners can be trained to deliver BA thereby making the approach both a clinically and cost-effective solution (Richards et al., 2016). In addition, participation in meaningful activity is essential to maintain wellbeing in people with dementia (Rolland & Chappell, 2015). However, decreased activity is common in dementia, impacting negatively on social inclusion, relationships, psychological wellbeing and results in an increased reliance on informal caregivers (Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008). As such, research has suggested the importance of developing interventions that support engagement in meaningful activity, including supporting caregivers to enable the person with dementia to continue participation in meaningful activities (Roland & Chappell, 2015). A simple BA approach may therefore represent a solution. Indeed, initial evidence has demonstrated enlisting informal caregivers to support BA may be an acceptable and effective approach, reducing symptoms of depression in both people with dementia and informal caregivers themselves (Teri, 1994). The PROMOTE self-help intervention may therefore have the potential to improve

depression and quality of life in people with dementia, the primary intervention target, as well as reduce depression and burden in informal caregivers.

### **Treatment setting**

People with dementia and informal caregivers experience a number of barriers to accessing face-to-face support, such as transportation difficulties, lack of time or living in a rural setting (Tremont et al., 2015). Furthermore, people with dementia often experience uncertainty in unfamiliar environments causing anxiety and agitation (Kings Fund, 2013). Therefore, as far as possible and when requested, face-to-face sessions are delivered within the home of the person with dementia or a familiar community setting. To overcome access difficulties, telephone delivery may be considered. However, the person with dementia and informal caregiver will need a speaker phone to allow for each person in attendance to participate.

### **The low intensity CBT programme: PROMOTE**

The programme consists of two separate workbooks (available on request from the authors). One workbook (Farrand et al., 2015a) is specifically designed for the person with dementia to work through the simple BA model (Ekers et al., 2014; Richards, 2010), providing information on the steps of BA and supplementary worksheets to aid completion of the steps within the home. The second workbook (Farrand et al., 2015b) is provided to the informal caregiver to facilitate supporting the person with dementia work through the BA approach within their own home. The workbook for informal caregivers provides information regarding depression and dementia and supports the caregiver through the steps of the simple BA approach and relapse prevention. Further, advice concerning the management of common setbacks when using BA is provided, alongside tips for the caregiver themselves to manage their own difficulties and access sources of support within the community.

The development of both workbooks were closely informed by qualitative research with people with dementia and caregivers (Farrand et al., 2016) and written in a manner consistent with

guidance informing the development of dementia friendly material (DEEP, 2013). Vignettes, written in a way to integrate common factors essential to the therapeutic relationship (Cahill et al., 2008) and associated with improved therapy outcome (Wampold, 2015), were also incorporated into the workbooks. For example, vignettes were written to generate a belief in recovery and the helpfulness of the techniques, alongside the provision of guidance, feedback, empathy and warmth (Richardson & Richards, 2006; Richardson, Richards, & Barkham, 2010).

During workbook development, it was identified that the use of standard mental health related terminology was considered unacceptable by both people with dementia and informal caregivers (Farrand et al., 2016). In particular, there was limited acceptability for terms such as 'depression', 'low mood', 'psychological' and 'dementia'. Evidence indicates varied willingness towards adopting diagnostic labels (Clare, Quinn, Jones, & Woods, 2016), potentially being dependent on the awareness and acceptance of a dementia diagnosis being a gradual process (Lishman, Cheston, & Smithson, 2016). 'Memory difficulties' was therefore adopted, however use of the term dementia may be appropriate with patients dependent on stage of diagnosis acceptance. Following guidance concerning improving wellbeing in people with dementia (Department of Health, 2012), workbooks were written adopting positive language with a focus on 'wellbeing' and 'learning to living well with dementia'. Furthermore, informal caregivers rarely identify with the term 'carer' (Cameron, Aggar, Robinson, & Kurrie, 2011), reporting the term negatively impacts upon and threatens the identity of the person they care for (Knowles et al., 2016). As such, 'family member or friends' was adopted as an alternative (Molyneaux, Butchard, Simpson, & Murray, 2011).

### **Supporting and guiding the PROMOTE self-help programme**

As the PROMOTE self-help programme is designed to be supported by the caregiver of the person with dementia within their own home, caregivers themselves also receive guidance in the delivery of the programme from

the psychological practitioner or other mental health professional trained in the competencies required to support CBT self-help (Roth & Pilling, 2008). An informal caregiver (defined as a family member or friend) with at least weekly contact with the person with dementia and willing to support the programme should be identified. Given that relationship difficulties between people with dementia and caregivers are associated with higher levels of carer burden and poorer family functioning (Steadman, Tremont, & Duncan Davis, 2007), it is important to work with the person with dementia and their caregiver to ascertain suitability to provide support.

The role of the caregiver is to attend face-to-face sessions with the person with dementia and support them use the programme within the home. Specific tasks may include supporting the person with dementia to: (a) complete homework worksheets; (b) carry out planned activities; (c) provide prompts and reminders to complete activities and (d) check planned activities have been completed. The level of support provided by the caregiver will depend on the person with dementia's needs and level of cognitive and functional impairment. To help resolve any difficulties or set-backs encountered when using the programme, caregivers also receive weekly telephone guidance from the psychological practitioner or other trained mental health professionals. This weekly telephone guidance can be classified as minimal contact support (Farrand & Woodford, 2013) and follows the 'Plan, Do, Review' model (Williams, 2014).

### **Informing support, guidance and overcoming setbacks**

Due to the symptoms of dementia and associated complications of aging there may be a number of difficulties experienced by people with dementia when working through the PROMOTE self-help programme. These difficulties can be understood by adopting the COM-B behavioural change framework (Michie, van Stralen, & West, 2011), and recognise the difficulties people with dementia may experience arising from an interaction of 'Capability', 'Opportunity' and 'Motivation'. As such, a COM-B analysis may be used to gain

an awareness of difficulties experienced across these areas, helping inform the provision of support and guidance to help overcome difficulties that may be experienced using the programme. Such difficulties can include the following.

### *Behavioural and psychological symptoms of dementia (BPSD).*

At some point during the progression of dementia, 90% of people living with dementia will experience BPSD (Cerejeira, Lagarto, & Mkaetova-Ladinska, 2012). Common symptoms include emotional changes (e.g. anhedonia; depression; anxiety; apathy; hypomania; irritability; aggression); delusions and abnormal thought content, perceptual disturbances or changes to motor function (e.g. motor retardation or motor hyperactivity, agitation, wandering, repetitive behaviours; social inappropriate behaviours), changes to sleep and extreme increases or decreases in eating. Increases in BPSD may indicate progression of dementia severity and inform decisions as to whether the person with dementia needs to be referred on for more appropriate support from dementia specific healthcare services.

### *Difficulty identifying activities*

As people age, functional losses are experienced (Baltes, 1991; Baltes & Carstensen, 1996; Baltes & Smith, 2003) making identification of new, or adaptation of old activities to enable them to be achieved, a common difficulty. The psychological practitioner or other trained mental health professional should use the Selection Optimisation and Compensation (SOC) model (Baltes, 1991; 1997) if difficulties in this regard are experienced. The SOC model provides a theoretical framework informing an approach to working with older adults to help them achieve their goals despite these losses (Baltes, Staudinger, & Lindenberger, 1999). Research indicates some older adults with Alzheimer's Disease successfully utilise SOC adaptation strategies to maintain functioning (Rapp, Krampe, & Baltes, 2006) and the model has been used to develop interventions for people with dementia (Golden & Lawlor, 2006).

Specifically, the SOC model provides a framework to assist the person with dementia select new activities of importance and value to them, or

adapt the way in which they work to complete goals, using optimisation and compensation strategies. If an activity had to be given up due to limitations, the caregiver should help the person with dementia identify activities of importance and value to the person with dementia and consider other more achievable activities of similar value. Sometimes an activity may not need to be given up entirely in which cases the person with dementia will alternatively be supported to identify resources they may need to focus on to achieve the activity (optimisation) and consider other ways to achieve it taking into account current limitations (compensation) (Freund & Baltes, 1998).

Finally, if identification of activities remains difficult, the Pleasant Events Schedule for Alzheimer's disease (PES-AD; Teri & Lodgson, 1991) may be used to help inform selection. The PES-AD is a 53 item questionnaire designed to help identify pleasurable activities the person with dementia may be able to engage in. Once activities are identified the psychological practitioner or other trained mental health professional, or informal caregiver, will support the person with dementia plan these into the 'My Next Steps Diary' worksheet included within the programme workbooks.

### *Memory, communication and language difficulties*

Memory (Burns & Iliffe, 2009), communication and language (Young, Lind, & Steenbrugge, 2016) difficulties are common to most dementia types and can threaten the competency (Michie et al., 2011) of the person with dementia to engage with the programme. Therefore, support and guidance provided by the psychological practitioner or other trained mental health professional and caregiver should be delivered in small chunks, as one-step instructions, with increased use of yes/no and choice questions (Eggenberger, Heimerl, & Bennett, 2013), at a slow pace and repeated or rephrased where necessary (Chand & Grossberg, 2013). Finally, people with dementia often find it easier to access older rather than new memories (Sagar, Cogen, Sullivan, Corkin, & Growdon, 1988). It can be helpful therefore to talk about old photographs, listen to music or watch familiar films

to help identify activities when planning to include them within the PROMOTE workbooks. People with dementia and caregivers may already use techniques such as a white board or electronic device to aid memory difficulties. Discussions concerning how to integrate any such techniques when working through the workbooks may therefore be beneficial.

### *Repeating questions*

Repeating questions are common in people with dementia and can be frustrating for family members and friends. Caregivers should remain calm and answer the question as if it were the first time it had been asked or try and answer it in a different way, for example, writing the answer down or use other memory aides or cuing systems (Bourgeois, Bugio, Schulz, Beach, & Palmer, 1997). Sometimes repeating questions may also indicate the person with dementia is trying to communicate something else, therefore the caregiver may need to consider the emotion the person is trying to communicate.

### *Lack of motivation*

Lack of motivation is a common symptom of both dementia and depression (Teng et al., 2008) and can negatively impact on engagement with the programme (Michie et al., 2011). Motivation in the person with dementia may therefore be increased by using the following strategies to enhance engagement: (1) picking times of the day associated with increased energy or motivation; (2) choosing activities of importance and value; (3) providing praise and encouragement to reinforce gains; (4) choosing a quieter place to work through the activities and (5) working on the programme little and often. Several of these are also common strategies adopted within the simple BA model (Richards, 2010) forming the basis of the PROMOTE self-help programme.

### *Relationship difficulties*

Relationship difficulties between caregivers and people with dementia relating to problems with communication or language are common (Savundranayagam, Hummert, & Montgomery, 2005). Specific communication strategies may be helpful in reducing the impact of these (Eggenberger et al., 2013). However, if persistent it may be advisable to

consider involving other family members or friends better suited to support the programme.

**Co/multi-morbid health complications**

People with dementia or their informal caregivers may be experiencing other physical health difficulties that may result in barriers to working through the programme such as lack of energy; physical disabilities; transportation problems; medication regimes and managing multiple healthcare appointments. Any difficulties that may negatively impact on the opportunity (Michie et al., 2011) of the person with dementia or caregiver to engage with the programme should be identified during the assessment. A collaborative decision can then be reached to either utilise problem solving to overcome difficulties to facilitate continued engagement, or consider other types of support that may be more appropriate.

**Treatment Protocol**

**Guidance structure**

An overview of the guidance provided to the caregiver by the psychological practitioner or other trained mental health professional can be seen in Figure 1. A maximum of 12 guidance sessions (including the assessment) over a period of 3 months is provided. Given evidence that frequent sessions are more effective, weekly sessions should be offered (Cuijpers, Huibers, Ebert, Koole, & Andersson, 2013). However, establishing treatment frequency and total number of guidance sessions to provide should be informed by a patient centered discussion with the person with dementia and their caregiver surrounding potential adaptations to the structure of sessions.

**Session one: Assessment**

**Aims**

The psychological practitioner or other trained mental health professional will: (a) gain an understanding of the main difficulties the person with dementia is experiencing with their mood; (b) assess suitability for treatment; and (c) introduce the PROMOTE self-help programme if suitable.

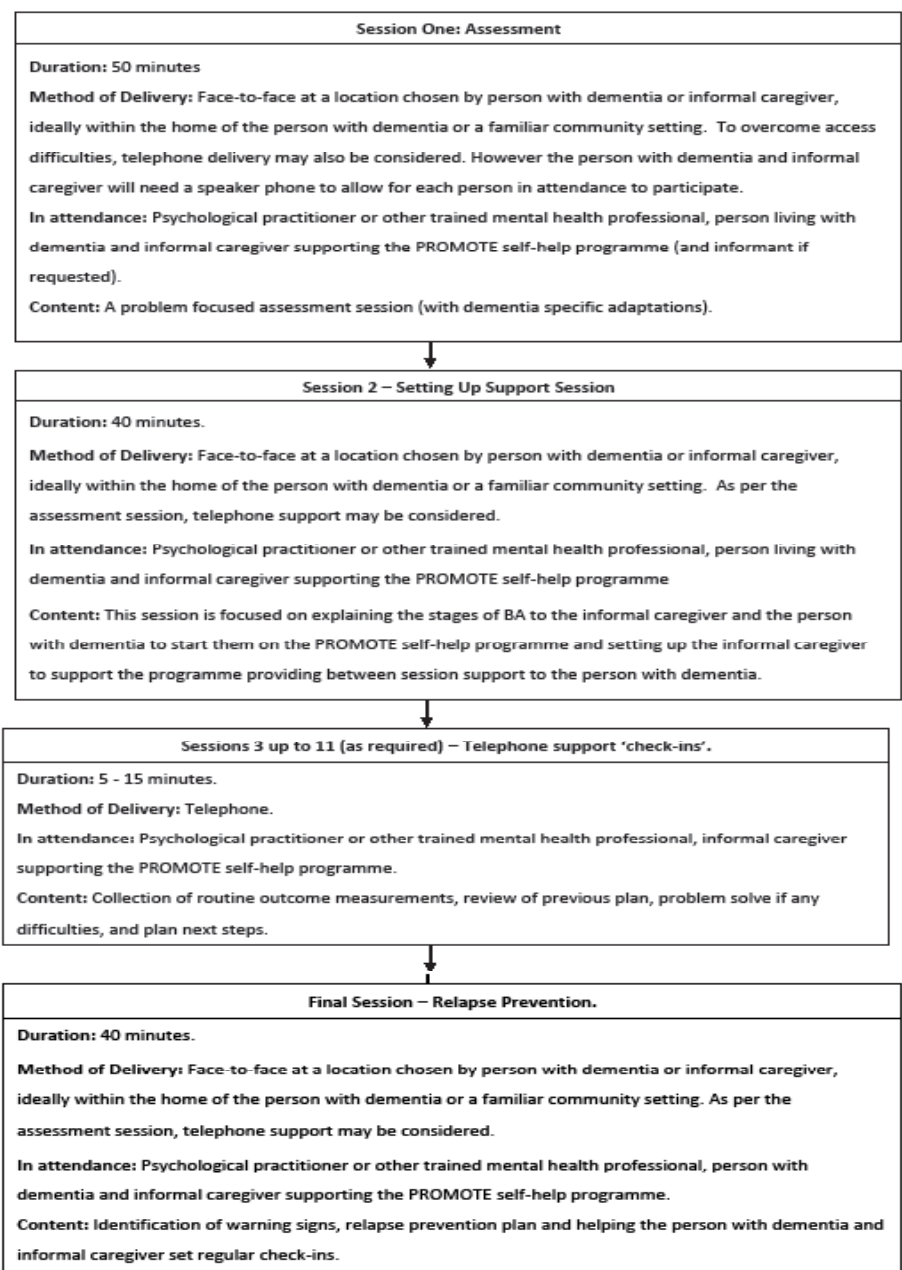
**Introduction**

At the start of the session the psychological practitioner or other trained mental health professional should introduce themselves, their role, state the purpose and duration of the session and check permission with the person experiencing dementia to involve the caregiver as informant and support the programme. It is also important any dementia symptom specific adjustments that may need to be made are also checked. If holding the assessment session within the home or community setting, attention should be given to ensure potential distractions are minimised.

**Five Areas Assessment Model**

Information gathering during the assessment is based on the Five Areas Assessment Model (Figure 2; Williams & Garland, 2002) which is jargon free (Williams, 2001) to maximise acceptability for patients and enhance suitability for use outside of clinical settings (Whitfield & Williams, 2003). Dependent on the person with dementia's need, the techniques described previously to overcome difficulties and setbacks to compensate for memory, communication and language difficulties, may be required alongside increased checking of understanding. However, if required, checking of understanding should be

Figure 1. Overall Structure of the PROMOTE self-help programme



employed with sensitivity and not in a way that appears like a direct test or challenge of knowledge.

The Five Areas Assessment model provides structure to the assessment of current difficulties being experienced (Wright, Williams, & Garland, 2002). Specifically, information should be gathered around: (a) Life situation, relationships and practical problems and difficulties being experienced alongside; (b) Altered thinking; (c) Altered feelings, moods or emotions; (d) Altered physical feelings and symptoms and (e) Altered behaviour. The impact of the difficulties and problems identified within key areas of life (e.g., home management, social and private leisure activities, work/retirement and relationships) should also be explored.

Other information to inform treatment decisions should also be gathered, such as modifying and maintenance factors, medication, drug and alcohol use, current health, social and community support being received, management of the transition to life with dementia/memory difficulties, ability to successfully adapt life goals given diagnosis and previous experiences of treatment for mental health difficulties. Patient centeredness must be maintained throughout the assessment by ensuring the person with dementia is actively involved, with vigilance kept as to any unnecessary situations when the caregiver attempts to answer for the person with dementia. However, at times, the person with dementia may struggle with recall and caregiver involvement may be needed to reduce complexity of the questions or act as informant.

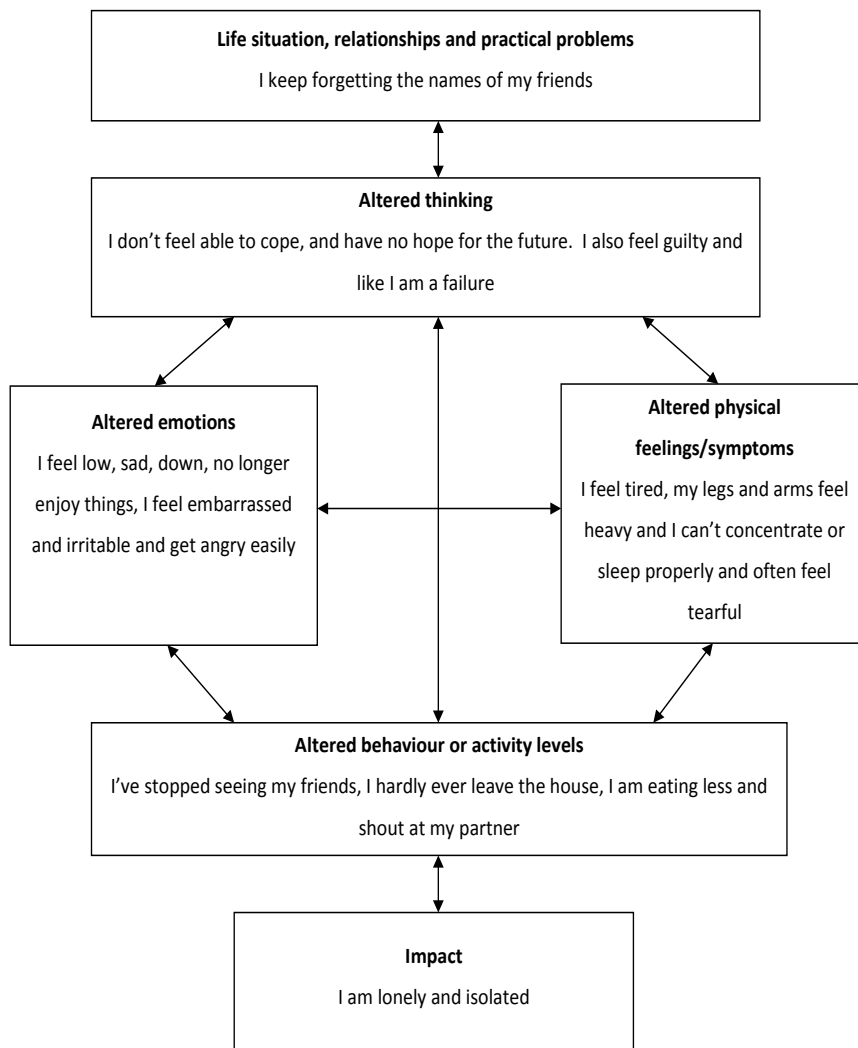
### Outcome Measurements

To allow tracking of patient progress, taking routine outcome measurements of depression and anxiety at each session is advisable. A number of self-report depression and anxiety outcome measurements have been adopted for use with people with dementia such as the Geriatric Depression Scale-15 and 12R (Sheikh & Yesavage, 1986; Sutcliffe et al., 2000), the Anxiety in Cognitive Impairment and Dementia scale (Gerolimatos et al., 2015) and the Geriatric Anxiety Inventory (Pachana et al., 2007). Quality of Life may be measured by using a brief measure such as the EuroQoL-5D-3L (EQ-5D-3L) (Brooks, 1996) which has been validated in a mild-to-moderate dementia population (Hounsome, Orrell, & Edwards, 2011). All outcome measurements suggested have been developed to minimise difficulties with memory and cognition that may be encountered when using commonly adopted outcome measures developed for an adult population (Frank, Lenderking, Howard, & Cantillon, 2011).

### Information giving

At the end of the assessment, information consistent with the ‘probable’ diagnosis reached, should be provided with consideration given to stigma attached to late life depression (Hall & Reynolds-Iii, 2014). If considered suitable for the programme, both the person with dementia and caregiver should also be given the workbooks and introduced to the Five Areas Assessment Model (Williams & Garland, 2002) alongside the ‘My Wellbeing Cycle Worksheet’ within the workbooks. To help personalise the discussion when explaining the CBT rationale, relevant examples identified during assessment should be used to complete the ‘My Wellbeing Cycle Worksheet’. Further, a simple rationale for BA is provided in lay language, explaining the impact of both dementia and depression on withdrawal from meaningful activity and the importance of reengagement with meaningful activity to improve mood. The rationale for BA provided in the workbooks is used to support the explanation for the person with dementia and caregiver.

Figure 2. A Five Areas assessment example, adapted from Williams & Garland (2002)



## Homework

To support psycho-education, ask the person with dementia and caregiver to read the first section of their workbooks explaining depression and the rationale for BA. Additionally, they will work together to set up to four goals for treatment that are: (a) specific, detailed and clear; (b) positive, focusing on striving to achieve something and (c) realistically achievable over the treatment period, using the *'My Goals for the Workbook'* worksheet. Finally, supported by the caregiver, the person with dementia should be tasked to keep a baseline diary of their activities over the following week using *'My Starting Point Diary'* worksheet. As much detail should be noted as possible, including: (a) what the activity is; (b) where the activity took place; (c) who the activity was with and (d) how the activity made the person with dementia feel.

## Session two: Setting up support session

### Aims

The psychological practitioner or other trained mental health professional will: (a) follow-up information gathered in the assessment session; (b) review completion of the *'My Starting Point Diary'* worksheet to identify the type and amount of activity the person with dementia is currently engaged in; (c) explain to the person with dementia and caregiver the three stages of BA and (d) equip the caregiver with a good understanding of the stages of BA to allow ongoing support within the home.

### Introduction

The psychological practitioner or other trained mental health professional will reintroduce themselves, their role alongside the purpose and duration of the session. Consistent with the assessment session, consent for caregiver involvement should be re-checked, necessary symptom specific adjustments made and the coexistence of depression and dementia is normalised.

### Information gathering

Routine outcome measurements of depression and anxiety should be taken by the psychological practitioner or other trained mental health professional, with results clearly fed back to the person with

dementia and caregiver, explaining any change in scores from the assessment session. As subsequent outcome measures will be collected by the caregiver, it is important the way in which these will be used in the telephone check-ins is clearly explained and understanding checked. A clear enquiry should be undertaken regarding progress with homework set in the assessment session, alongside a review of the person with dementia and caregiver's understanding of the Five Areas Assessment Model and rationale for BA.

### Information giving

As the caregiver requires at least a basic understanding of the BA steps in order to support the person with dementia work through the programme, information giving should be focused on explaining the three stages of BA.

### A Simple Behavioural Activation Model

The PROMOTE self-help programme is based on a simple (Ekers et al., 2014) BA model (Richards, 2010) commonly delivered within the IAPT programme as a supported self-help intervention (Farrand et al., 2014). BA is informed by behavioural theory and can be used as a stand-alone treatment for depression (Jacobson, Martell, & Dimidjian, 2001; Lejuez, Hopko, LePage, & Hopko, 2001). Although a number of approaches for the delivery of BA exist (see Hopko, Lejuez, Ruggiero, & Eifert, 2003) the underlying aim is to target behavioural avoidance by gradually reintroducing activity thereby improving engagement with positively reinforcing activities whilst overcoming sources of negative reinforcement (Hopko et al., 2003). Within the simple BA model a structured and graded approach is adopted to increase activity to target the behavioural avoidance often accompanying depression (Richards, 2010).

The simple BA model encompasses three main steps:

#### *Step One: Identifying activities*

Activity can be categorised into three main types: (a) routine; (b) pleasurable; and (c) necessary. Routine activities are ones commonly performed many times in a week, providing people's lives with structure, such as cooking, cleaning the

house or doing the food shop. Pleasurable activities can be highly unique to people, but are those providing a sense of enjoyment and commonly include things such as seeing friends, watching a film or engaging in a hobby. Last, necessary activities are those that may have a serious consequence if not done, such as paying a bill, taking medication or going to work. Initially, the completed *'My Starting Point Diary'* worksheet should be reviewed with the person with dementia and caregiver to help categorise the recorded activities into these three types using the *'Identifying Activities'* worksheet in the workbooks. Additionally, the extent to which each type of activity is represented in the baseline diary, alongside a consideration as to how much overall activity has been undertaken, should be considered.

Next, with support from the caregiver, the person with dementia will should use the *'Identifying Activities'* worksheet to initially identify at least one activity in each category they have stopped doing and would like to engage in again. When identifying one of each type of activity, the person with dementia and carer should be encouraged to consider 'valued' activities (Lejuez, Hopko, Aciermo, Daughters, & Pagoto, 2011) related to important areas of life. These may include relationships, health, religious or spiritual life, finances, roles and responsibilities and social and leisure activities. At this stage, unless the caregiver has taken away all responsibility for completing necessary activities from the person with dementia, consideration should be made of any necessary activities the person with dementia may have stopped doing. Where there are consequences if not completed, support should be given to the person with dementia and caregiver to consider ways these activities could be achieved. If the caregiver has removed all responsibility for necessary activities from the person with dementia the possibility that this has been done prematurely, rather than because the person with dementia can no longer manage their completion, should be explored. Once an activity in each category has been identified, the person with dementia and caregiver should be encouraged to continue working on the *'Identifying Activities'* worksheet as

homework.

*Step two: Organising activities*

Next, the 'Organising Activities' worksheet in the PROMOTE self-help programme will be used to support the person with dementia consider the level of difficulty associated with completing each activity: (a) less difficult to do now; (b) difficult to do now; and (c) more difficult to do now. Categorisation of activities into difficulty level is important as BA should support a gradual reintroduction to engagement in activity. Therefore, easier activities to achieve should be planned to begin with, moving to more difficult activities later. Again, this exercise should be continued as a homework task.

*Step three: Planning activities*

The person with dementia and caregiver should be supported to start planning activities to compete using the 'My Next Steps Diary' worksheet in the workbook. Ideally, activities that are easier to achieve, alongside a mix of pleasurable, routine and necessary, will be identified. As per the 'My Starting Point Diary' worksheet, as much information about the planned activities as possible should be recorded. When activities have been planned the psychological practitioner or other trained mental health professional will identify and help problem solve any barriers that may get in the way of their completion.

**Session Ending**

The session should be summarised with understanding regarding homework set checked and the carer directed to useful pages to read in their version of the workbook, such as regarding the steps of BA and overcoming common setbacks. Importantly, caregiver understanding of the steps of BA should be checked as they will be responsible for supporting the person with dementia use the techniques at home. Finally, the first telephone check-in should be scheduled with the caregiver, and paper copies of the routine outcome measurements provided to administer to the person with dementia before subsequent check-ins.

**Homework**

The person with dementia should complete the three steps of the BA protocol as homework. Furthermore,

they will continue to complete the 'My Next Steps Diary' making a note of how each activity made them feel and general comments recorded.

**Session 3 up to 11 as required: Telephone guided 'check-ins'**

**Aims**

The psychological practitioner or other trained mental health professional will work with the caregiver supporting the PROMOTE self-help programme to: (a) review routine outcomes measurements taken with the person with dementia; (b) review plans and homework set the previous week; (c) if required, help the caregiver problem solve any difficulties experienced; and (d) set a plan in the use of programme for the following week.

**Introduction**

A standard introduction is given, the psychological practitioner or other trained mental health professional will reintroduce themselves and their role, checking the caregiver's name, describing the agenda and setting a time scale (5-15 minutes).

**Information gathering**

Results of the routine outcome measurements should be gathered over the telephone from the caregiver. An overview of the last week's plan will be conducted, explicitly exploring any difficulties experienced in supporting the programme with any difficulties followed up with a problem focused review.

**Problem Focused Review**

The problem focused review of difficulties experienced in the use of PROMOTE self-help programme has been informed by the Plan, Do, Review Model (Williams, 2014). Specifically, the review should consist of: (a) normalising the problem; (b) providing empathy; (c) directing the caregiver to advice in the workbook to help overcome any difficulties experienced; and (d) encouragement to support continued engagement.

**Session ending**

Understanding and attitude concerning the plan set with the caregiver should be checked and the subsequent telephone check-in arranged.

**Final session: Relapse prevention**

**Aims**

The psychological practitioner or other trained mental health professional will: (a) establish an appropriate ending; (b) guide completion of a 'Staying Well' plan included within the workbook to help the person with dementia and caregiver identify warning signs depression may be returning; and (c) encourage continued engagement with the 'Staying Well' plan following the end of support and stress actions to take if signs are identified.

**Standard session components**

As with other sessions, the psychological practitioner or other trained mental health professional should provide a standard introduction, overview benefits of continued engagement with the 'Staying Well' plan included within the workbook, collect end of treatment outcome measurements and identify any concerns about the end of support.

**Relapse prevention steps.**

The person with dementia should initially be helped by the psychological practitioner or other trained mental health professional to identify their warning signs for depression. Symptoms identified in the Five Areas Assessment (Williams & Garland, 2002) at the beginning of the workbook and recorded using the 'My Warning Signs' worksheet should be used to support this exercise. Activities, skills and techniques learnt during the course of treatment as helpful in reducing depression should then be recorded using the 'Staying Well Toolkit' worksheet. Finally, the person with dementia and caregiver will be encouraged to continue to 'check in' with the 'My Warning Signs' worksheet following the end of the support sessions to consider the person with dementia's level of activity and any symptoms of depression experienced. The person with dementia and their caregiver should be encouraged to use the PROMOTE self-help programme to inform an action plan to re-engage in activities previously found helpful should symptoms of depression return in the future.



### Considering demands placed on the informal caregiver providing support

Whilst the role of the caregiver in the programme is to provide support to the person with dementia, the psychological practitioner or other trained mental health professional should be aware of the impact of supporting the PROMOTE programme on wellbeing of the caregiver. In particular, two main demands may be placed on caregivers providing support.

#### Caregiver burden

Caregiver burden is a common difficulty (Svendsboe et al., 2016) and refers to the emotional difficulties and physical consequences of providing care. Informal caregivers may experience lack of time, poor support, their own physical health difficulties, competing demands and reduced energy. As such, if support for the programme is identified as causing difficulties to the caregiver these difficulties should be explored with help provided to problem solve these. Where appropriate, this should involve a collaborative discussion regarding the appropriateness of the caregiver continuing to support the programme alongside signposting to other sources of available support, for example individual psychological support or community carer support groups.

#### Caregiver anxiety/worry

Understandably caregivers are likely to be protective of the person with dementia. However, at times this can manifest as worry that it may be dangerous for the person with dementia to engage in an activity identified on their 'My Next Steps Diary' or they will be unable to achieve an activity. If anxieties are identified, the psychological practitioner or other trained mental health professional should normalise and reinforce the rationale for BA and emphasise the importance of the person with dementia continuing to work through the programme to increase activity. Depending on the impact of anxiety on the caregiver encouraging them to consider seeking psychological support themselves may be required. However, the psychological practitioner or other trained mental health professional providing guidance should be aware that caregivers experience a number of barriers to seeking support

for themselves including stigma, lack of support services and negative attitudes towards treatment (WHO, 2015).

### Discussion

This clinical protocol describes the PROMOTE CBT self-help programme based on a simple BA model for people living with dementia and depression supported within the home by caregivers who themselves receive guidance by a psychological practitioner or other trained mental health professional. The approach has the potential to be an acceptable and effective treatment to help improve the emotional wellbeing of the increasing population of people living in New Zealand with dementia (Alzheimer's New Zealand, 2012) and meet objectives to improve the wellbeing of people with dementia living in the community (Ministry of Health, 2013). As a guided self-help programme, PROMOTE represents greater flexibility concerning the provision of support and may offer a way of delivering the New Zealand Ministry of Health agenda to provide care closer to home (Ministry of Health, 2014). Currently, a one-armed trial of the intervention is underway (Farrand et al., 2016) examining the feasibility and acceptability of the approach within England. Informed by the MRC Complex Interventions Framework (Craig et al., 2008), if progression criteria are met, research will go on to examine the effectiveness of the intervention in a Phase III definitive randomised controlled trial. Further research could be undertaken to make appropriate adaptations for the New Zealand population, including culturally appropriate adaptations for Māori and other ethnicities (Ministry of Health, 2013).

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