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## PROFESSIONAL DOCTORATES

**A feasibility study to explore the potential benefit of a cognitive therapy treatment approach for depression with individuals fulfilling ICD-10 criteria for dementia : a case study approach.**

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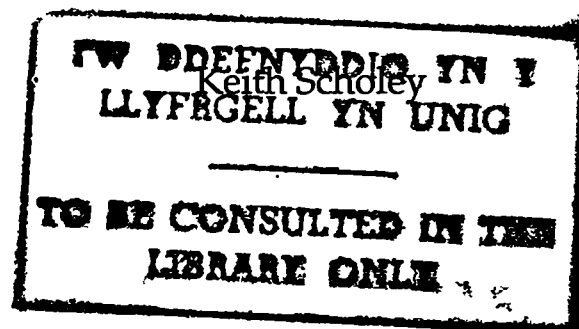
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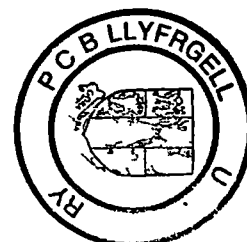
A Feasibility Study to Explore the Potential Benefit of  
a Cognitive Therapy Treatment Approach for  
Depression with Individuals Fulfilling ICD-10  
Criteria for Dementia:  
A Case Study Approach



Thesis submitted for the degree of Doctorate of Clinical Psychology

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## SUMMARY OF THESIS

The following study represents a review of the literature regarding the dual diagnosis of dementia and depression and a description of an attempt to apply cognitive therapy techniques with eight participants (age range: 57 - 83), all of whom had received a diagnosis of dementia and depression. The results appeared to indicate that cognitive therapy for depression, with people experiencing dementia, may be a feasible proposition. Common themes arising in therapy are discussed.

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"Ignorance is not bliss and neither is knowledge"

(Sinason, 1992, p. 87)

## Introduction

"The paucity of research evidence that so far exists means that it is hard to make a case for prioritizing formal psychotherapeutic work with people with dementia on the basis of outcome studies alone. However the arguments that propel clinicians towards this work, whether this is with individuals or with groups, and on a formal basis or an informal basis go far beyond the search for evidence-based interventions. These arguments are essentially moral - that dementia must be understood as a personal tragedy, and that it is unacceptable that its most immediate victims should so often have to struggle unheard and unheeded against personal disintegration and social isolation."

(Cheston, 1998, p. 221)

Cheston (1998) has recently argued that psychotherapy must be available for people with dementia on moral as much as empirical grounds. Whilst it is accepted that the moral arguments are indeed compelling, the objective of this study was to access the possibility that an individual therapist could implement a cognitive therapy intervention, within the normal clinical practice of a consecutive series of referrals of individuals with dementia and depression, and could independently begin to evaluate the progress of these interventions. This was based upon the assumption that effective clinical practice requires the best available evaluation, but that those most likely to practice cognitive therapy with people with dementia will be doing so outside the supportive system of a large scale clinical trial. Given the scale of this study and the current state of knowledge in this area the following could not be considered as a substitute for a clinical effectiveness trial, but as a feasibility study to explore the potential benefit of a cognitive therapy approach for individuals with co-occurring dementia and depression.

The following report will therefore include a literature review describing:

- the incidence of concurrent depression and dementia along with a discussion of factors complicating either single or dual diagnosis.

- the relationship between depression and dementia. It will be argued that the typical age of individuals with dementia is far from the sole influence in this relationship and that a number of other factors including: coping with terminal illness, experience of cognitive decline and social changes have a significant role in the development of depression.
- psychotherapeutic work with older adults and positive approaches to life with dementia, along with the relatively minimal literature on psychotherapy with people with both dementia and depression.

The methodological approach of this study will be detailed case description in accordance with the view, described by Cheston (1998) that this approach is most appropriate so early in the development of such a clinical approach.

The outcome of the therapy sessions will then be discussed along with an attempt to describe the common themes arising in therapy.

## **Incidence and Diagnosis**

### *Incidence of Concurrent Depression and Dementia*

Dementia and depression are two of the most commonly occurring psychiatric disorders amongst older adults. Concurrent depression and dementia should therefore, not be unusual. Studies measuring incidence of this dual diagnosis have shown considerable variation (Table 1.): 25% of geriatric outpatients had both cognitive impairment and depression (Reifler, Larson & Hanley, 1982), 17% of patients meeting criteria for Alzheimer's disease were diagnosed as having major depression (Rovner, Broadhead, Spencer, Carson & Folstein, 1989), 25% to 40% of patients with primary organic dementia will be affected by clinically significant depression at some time during their course (Lezak, 1995). Some of the variation in these samples can be attributed to differences in definition of both dementia and depression. After reviewing the literature, Ballard, Bannister and Oyebode (1996) suggested that approximately 20% of people with dementia had concurrent depression in clinical samples, with lower rates in the community.



Table 1.

Study	% Dual Diagnosis	Dementia Group	Depression Criteria
Reifler, Larson & Hanley (1982)	25%	Alzheimer's Disease	DSM-III Major Depressive Disorder
Rovner, Broadhead, Spencer, et al. (1989)	17%	Alzheimer's Disease	DSM-III Major Depressive Disorder
Greenwald, et al. (1989)	11%	DSM-III Criteria for Dementia	DSM-III Major Depressive Episode
Fisher, Simanyi & Danielczyk (1990)	80%	Alzheimer's Disease	Hamilton Depression Scale Score > 9
Fisher, Simanyi & Danielczyk (1990)	70%	Multi-Infarct Dementia	Hamilton Depression Scale Score > 9
Teri & Gallagher-Thompson (1991)	30%	Alzheimer's Disease	DSM - III Major Depressive Disorder
Forstl, Burns, Luthert, Cairns, et al. (1992)	27%	Alzheimer's Disease	DSM - III Major Depressive Disorder
Forsell, Jorm, Fratiglioni, Grut & Winblad (1993)	11%	DSM-III-R Criteria for Dementia	DSM-III-R Major Depressive Episode
Forsell, Jorm & Winblad (1994)	8.4%	DSM-III-R Criteria for Dementia	DSM-III-R Major Depressive Disorder
Starkstein, Chemerinski, Sabe et al. (1997)	19% (+ 34% with dysthymia)	DSM-III-R Criteria for Alzheimer's Disease	DSM-III-R Major Depressive Disorder

Considerable variation can also be accounted for in terms of the sampling technique used by the study. Population studies show much lower rates of dual diagnosis than studies of referrals to psychiatric or medical services. In general it would appear that depression is found more often amongst people with dementia than in non-dementing populations, although a comparison figure for a non-dementing age matched sample is almost as difficult to obtain. Such measures tend to suffer from the same sampling biases as those previously described. As an estimate a figure for major depressive episode for non-dementing, non-medically ill older adult group would be around 10% (Roberts, Kaplan, Shema & Strawbridge, 1997). The higher rate found in individuals with dementia raises the suggestion that two disorders might be related but as Alexopoulos (1991) points out depression is also common amongst medical patients, suggesting that medicalisation may be involved in the development of depression in dementia. However, as this study will describe, the relationship between depression and dementia shows great complexity.

### *Diagnostic Issues*

Despite being a common reason for referral to psychology services (O'Carroll, Curran, Murray et al., 1994) differentiation of depression from dementia can be a complex process. Depressed patients often appear to experience some degree of cognitive impairment (Beck, 1976; Kapur, 1994; Lezak, 1995).

Psychometric assessment is a regularly used method of attempting to distinguish between depression and dementia (Lezak, 1995). The methods of psychometric assessment vary widely. Neuropsychological discrepancy analysis is one potential method of distinguishing dementia and depression. This entails the comparison of a stable, dementia resistant measure and a dementia sensitive measure. Dementia resistant measures include the vocabulary subtest of the WAIS-R, the NART-R and the attention/concentration item of the WMS-R. Dementia sensitive measures appear to include the block design and digit symbol items of the WAIS-R, the verbal, visual and delayed recall memory components of the WMS-R and the FAS controlled oral word association test (Almkvist & Bäckman, 1993; Lezak, 1995; Miller & Morris, 1993; O'Carroll et al., 1994). Discrepancy analysis is reliable in differentiating groups of patients with dementia, patients meeting criteria for major depression and 'normal' healthy volunteers. However, when applied to individuals there is a high degree of overlap between patients with dementia and patients with depression (O'Carroll et al. 1994).

Magnetic resonance imaging (MRI) of the temporal lobe has been demonstrated to be useful in differentiating depression from dementia of Alzheimer type (O'Brien, Desmond, Ames et al., 1994). O'Brien et al. (1994) used neurologists ratings of hippocampal atrophy to distinguish between the groups, claiming a high degree of accuracy. Computed tomography (CT) atrophy measurement techniques have, as yet, proved to be less sensitive (Ames, Dolan & Mann, 1990).

Cognitive and neurological tests are only part of a full psychological evaluation. Woods and Britton (1985) stressed the importance of assessment of 'real-life' behaviours such as coping strategies, morale and ability to learn and adapt in new situations. This is especially true if the condition proves to be treatable, when differential diagnosis becomes secondary to therapeutic change. Although, where treatment is specific to a particular condition, treatment and diagnosis can become symbiotic.

A differential diagnosis is, of course, only improperly made in cases where dementia and depression co-exist. The accuracy of dual diagnosis is made complicated by the possibility of cognitive impairments in depression.

## *Cognitive Impairment in Depression*

Once I had a mind. Ah, fool  
not to understand how precious  
was that shining tool  
of understanding - with some application -  
anything I wished, that came to hand.  
...  
Tasks now beyond me; more to follow;  
slowly to slip away, defeated,  
into depths  
I can no longer trawl.  
The memory  
slips gears and falters at the name of things,  
stutters around the properties and may  
come up with synonym, or something like,

(Extract of a poem written by a depressed client describing several cognitive impairments, with no identifiable neurological signs. Permission granted, 1996)

It has been suggested that depressed patients experiencing impairment of cognition tend to be more aware of the nature of the impairment than patients with dementia and can frequently report when and where the impairment first occurred, in contrast to people with dementia who tend to be less keenly aware of their cognitive deficits (Lezak, 1995).

"The therapist should assure the patient that problems in concentrating and remembering are symptoms of depression. These are problems that the depressed patient is 'supposed to have' and are not signs the patient is losing his mind."

(Beck et al., 1979, p. 196)

Mild cognitive performance deficits have been demonstrated in depressed older adults (Beats, Sahakian & Levy, 1996). These deficits were particularly apparent on tests sensitive to frontal lobe dysfunction and appeared to improve on recovery from depression.

The term 'pseudodementia' has been used to describe disorders in which depressive disorder mimics the symptoms of dementia (Kiloh, 1961; McAllister & Price, 1982; Wells, 1979). In studies of diagnosis of dementia a significant proportion (8% - 15%) of those initially diagnosed as dementing were later diagnosed as having a depressive disorder (McAllister & Price, 1982). Lishman (1987) describes several forms of pseudodementia: Ganser syndrome (characterised by the phenomena of 'approximate answering'), hysterical pseudodementia, simulated dementia and depressive pseudodementia; considering depressive pseudodementia as the most difficult to distinguish from a biological dementia.

"In depressive illness several situations may lead to a spurious impression of organic cognitive impairment. The affective disorder may activate hysterical mechanisms in the predisposed patient."

(Lishman, 1987, p. 410)

The treatment recommended by Lishman for this condition is antidepressant therapy or ECT, improvement following these treatments confirming the diagnosis. Improvement following ECT treatment was similarly used to confirm the diagnosis in McAllister and Price's (1992) study. A difficulty with basing diagnosis on successful treatment is that no treatment for depression is effective in all cases. Further the use of the term 'pseudodementia' is to imply that the person is falsely or spuriously exhibiting dementia symptoms. The term 'pseudodementia' has now fallen out of use and is not included as a diagnosis in DSM-IV (American Psychiatric Association, 1994) or ICD-10 (World Health Organization, 1992). Studies of 'reversible dementia' in older age groups have also demonstrated that such patients have a much higher chance (4.7 times) of developing a true dementia than do patients with depression alone (Alexopoulos, Meyers, Young, Mattis & Kakuma, 1993). Reding, Haycox and Blass (1985) reported that 57% of their patient group presenting with symptoms of depression went on to develop dementia. In a long-term follow-up study Kral and Emery (1989) described even higher rates (89%). These observations are extremely important when considering the possibility of a link between dementia and depression.

Carpenter, Strauss and Kennedy (1995) found that a sample of patients with major depression and no dementia were approximately three times more likely to have had a past history of depressive episodes than their sample of

people with Alzheimer's disease and major depression. Most of the depressed Alzheimer's disease patients were experiencing their first episode of depression. This again suggests a link between dementia and depression.

## **The Relationship between Depression and Dementia**

### *Depression and Older Adults*

Whilst not exclusively an illness of older adults, the majority of people with dementia are within this age group. It is therefore important to consider the issues relating to older age and depression. Some perceptions of depression in older age groups appear to be that they: are more likely to be depressed than younger age groups, are more hypochondriacal/somatizing, have a chronic problem and have a more 'endogenous' depression. These views may not be completely accurate.

It is difficult to gauge whether non-dementing older adults living in the community are more likely to be depressed than younger people given the methodological difficulties of defining depression and changing cohort and environmental effects (Blazer, 1989). However, in a review of psychiatric epidemiology studies between 1950 and 1989 Feinson (1989) found that:

"none of the impairment categories of the preponderance of studies document more disorders among older than younger adults. In contrast, studies indicate more disorders reported by younger than older adults for depressive symptoms, major depression (clinical), and clinical affective disorders."

(Feinson, 1989, p. 1175)

It has however been suggested that in the future the rate of mental health problems shown by older adults may increase as the 'baby boom' cohort, with its higher rates of emotional disorder, ages (Koenig, George & Schneider, 1994).

Despite being no more common in older adults than in younger age groups, depression is the most frequently observed psychiatric disorder observed in the older adult age group (Muller-Spahn & Hock, 1994; Woods & Britton, 1985). Psychopathological investigations of a group of 'primary major depressives' failed to confirm the common clinical stereotypes which ascribe greater somatisation, hypochondriasis and chronicity to old age (Musetti, Perugi, Soriani et al., 1989). Musetti et al. (1989) found a relatively uniform

picture in older and younger people with depression. They did note that depression in older adults is often precipitated rather than being part of a recurrent disorder. Precipitating factors may be social and physical problems (Muller-Spahn & Hock, 1994). Higher rates of depression have been found among older adults living in residential and nursing homes (Ames, 1991; Cohen, 1990). Depression appears to have a generally negative effect on the older person's close social relationships (Murphy, 1985); the egocentric preoccupation and lack of confidence being detrimental to intimate relationships. This may additionally have an influence on the mental health state of the person's family members and carers (Hinrichsen & Zweig, 1994). A positive finding was that capacity for forming new social relationships appears to increase once the depression has lifted (Murphy, 1985).

Completed suicide rates are disproportionately high in the older adult age group (Cohen, 1990). This is particularly true of white male populations (Pritchard, 1992) which have shown an increase between 1974 and 1987 in the USA and in several European countries. Since suicide appears to be strongly related to mental health problems (Williams, 1997) this would argue for a higher rate of such problems in the older adult age group. Pritchard (1992) concluded that this is not the case and argued that the higher suicide rate in older adults is the result of other interactive environmental factors such as physical illness, psychosocial support, bereavement and socio-economic change.

The relationship between disability and depression has been shown to be a reciprocal one in which the causal pathways go in either direction (Gurland, Wilder & Berkman, 1988) suggesting that an effective treatment may make a difference to the outcome of depression associated with disability and disability associated with depression.

It has been considered that 'endogenous' depression might be higher in the older adult population (Zimmerman, Coryell, Pfohl & Stangl, 1986). Attempts to examine the extent of such 'endogenous' depression have found difficulties.

"The lack of high agreement among most classification systems argues that confusion about the meaning of the term 'endogenous' may be as common in the geriatric population as it is at any other age."

(Gallagher-Thompson, Futterman, Hanley-Peterson et al., 1992, p. 302)

The confusion may in part be related to the observation that older adults are less likely to acknowledge the dysphoric or anhedonic aspects of depression, but more likely to endorse sleep disturbance and thoughts of death, when compared to younger adults at the same level of depression (Gallo, Anthony & Muthen, 1994).

#### *Dementia, Terminal Illness and Coping*

Despite recent indications that drug treatments may be improving in their efficacy, dementia is as yet a terminal condition (Bryson & Benfield, 1997; Lishman, 1987; McGuffey, 1997). To receive a diagnosis of a dementing condition may provide an unwelcome reminder of one's own mortality. The diagnosed person may additionally have many misconceptions as to the dementing process.

Few studies have examined the subjective experiences of individuals with dementia. In a descriptive account of the coping methods of people with Alzheimer's disease Bahro et al., (1995) found that a number of methods were used, including:

1. *Denial* - either complete or partial. Avoidance of naming the illness or seeking information about it.
2. *Dissociation* - Exhibition of dissociation of affect, vagueness and circumstantiality in discussing the condition.
3. *Minimisation* - Minimisation of the severity of the symptoms.
4. *Somatisation* - Somatic symptoms and displacing feelings.

In only one of their seven cases did they find what they interpreted as 'appropriate mourning' for the losses incurred by the illness (Bahro, Silber & Sunderland, 1995). When denial is found in a therapy situation, it must be approached with caution as evidence of the potential functionality of denial was provided by the observation that denial of cognitive impairment correlates negatively with severity of depression scores (Sevush & Leve, 1993).

In a qualitative study of the early experience of Alzheimer's disease Keady and Gilliard (1997) found several issues that were of great importance for the individual but were rarely mentioned in the clinical literature. They highlighted the existence of a 'preclinical phase' which may last for several years before diagnosis. During this period the individual may develop several strategies to mask their developing symptoms which may lead to considerable

stress and anxiety. Early preclinical experiences noticed by individual's with Alzheimer's disease may include:

1. Problem-solving difficulties.
2. Being unable to concentrate for prolonged periods.
3. Thought block.
4. Inability to quickly recall names.
5. Losing track of conversations.
6. Feeling dissociated from reality.
7. Becoming sad and depressed.
8. Feeling unduly angry.
9. Tearfulness.
10. Feeling and becoming lost in familiar surroundings.
11. Not being able to fully co-ordinate and control speech and actions.
12. Writing block.
13. Heightened sense of taste and smell.

(Keady & Gilliard, 1997, p. 53)

In order to cope with these experiences and in attempting to maintain an appearance of normality the individual has often been forced to develop a number of strategies, the maintenance of which can become increasingly difficult with the progression of cognitive decline. Keady and Gilliard (1997) also describe the personal, secretive nature of the process of coping with onset and transition into Alzheimer's disease. The life experiences of people with dementia can be extremely frustrating.

"Rarely have people with dementia been seen as partners in the process of their dementia with viable support available for the empowerment of their own decision-making."

(Keady & Gilliard, 1997, p. 4)

### *Insight*

Beck et al. (1979) stressed the primacy of cognitive factors in depression. Beck described the depressed persons pattern of regarding himself, his future and his experiences (the 'cognitive triad') in an idiosyncratic, negative manner. An important feature of this model is the concept of depressive 'schema', which



determine how an individual will interpret and structure different experiences. Beck further stressed the importance of faulty information processing, such as arbitrary inference, selective abstraction and over-generalisation, as often leading to a pattern of systematic logical errors. Even with such a brief description of Beck's model of depression it can be seen that some relatively sophisticated thought is necessary to maintain depression. If this model is to be accepted then it might be suggested that there will come a point in a dementing illness where depression is no longer possible because the necessary schema cannot be sustained; giving rise to the suggestion that depression will resolve in dementia as the individual loses insight into his own condition and situation.

It might be unfortunate that there is little clinical evidence to support this resolution of depression during the process of dementia (Ott & Fogel, 1992; Verhey, Rozendaal, Ponds & Jolles, 1993). Verhey et al. (1993) found a highly significant correlation between their measures of severity of dementia and awareness of dementia ratings. They did not observe a significant relationship between either severity of dementia and severity of depression ratings or awareness of dementia and severity of depression ratings.

#### *Autobiographical Memory*

The observation that depressed individuals find it more difficult to recall specific personal memories than non-depressed controls is well established (Kuyken & Dalgleish, 1995; Williams, 1996; Williams & Scott, 1988; Williams, Watts, MacLeod & Mathews, 1997). Individuals with depression have a tendency to produce overgeneral memories. In the follow up of a group of participants, meeting DSM-III-R criteria for major depressive disorder, failure to recover from depression was predicted by the extent of overgeneral memory recall at initial assessment (Brittlebank, Scott, Williams & Ferrier, 1993). Phillips and Williams (1997) found that specificity of autobiographical memory decreased with increasing levels of cognitive impairment in a group of elderly participants. This effect remained when the effects of depression were partialled out.

Any causal relationship between depression and overgenerality of autobiographical memory remains unclear. However it would appear reasonable to suggest that the decline in memory functioning observed in dementia, particularly specific personal memories, may have an influence on the development of depression. This influence may take several forms: a

vulnerability to depression, a causal influence on the development of depression, or a reduced ability to recover from depressive states.

### *Chronic Pain*

The relationship between dementia and pain is poorly understood (Farrell, Katz & Helme, 1996; Porter, Malhotra, Wolf et al., 1996). Chronic pain has been associated with psychiatric difficulties in non-dementing adults (Pearce & Mays, 1994; Salkovskis, 1989). It remains open to suggestion that in some individuals with dementia perception of pain experiences may be complicated by cognitive and neurological degeneration. The finding that 64% of carers describe concern over the pain experienced by the individuals with dementia they cared for (McCarthy, Addington-Hall & Altmann, 1997) makes this an issue for further study and one that professionals involved with people with dementia should be aware of.

### **Psychotherapy with People Experiencing Depression and Dementia**

Until recently there was widespread nihilism in the clinical approach to the demented patient (Miller, 1997). The effects of dementia on cognitive functioning are important if psychotherapy is to be used with people with dementing conditions.

"Cognitive techniques are most appropriate for people who have the capacity for introspection and for reflecting on their own thoughts and fantasies."

(Beck, 1976, p. 216)

The ability of a person with dementia to introspect and reflect may be impaired with cognitive decline and therapy made progressively more difficult. The point at which cognitive therapeutic interventions become ineffective with this cognitive decline is unknown. Thompson, Wagner, Zeiss and Gallagher (1989) suggest that cognitive behaviour therapy is most likely to benefit patients with early dementia, where more insight and cognitive capabilities remain. Of the available psychotherapeutic interventions that can be made cognitive therapy may be one of the therapies of choice because of its short term nature and proven effectiveness. There are not as yet any published

controlled studies assessing the effectiveness of cognitive interventions in the treatment of depression in dementia, although Teri and Gallagher-Thompson (1991) described such programs as under evaluation. Similarly there have been few case studies published in this area (Cheston, 1998).

The view taken within this study was that successful therapy with people with this dual diagnosis would require the integration of psychotherapy approaches with older adults with a positive approach to life with dementia.

### *Psychotherapy with Older Adults*

"The age of patients has this much importance in determining their fitness for psychoanalytic treatment, that, on the one hand, near or above the age of fifty the elasticity of the mental processes, on which the treatment depends, is as a rule lacking - old people are no longer educable - and, on the other hand, the mass of material to be dealt with would prolong the duration of the treatment indefinitely."

Freud (1905/1953, p. 264)

Freud however, was well aware that the concepts of psycho-analysis were in an early stage of development and that at least one older adult was capable of new models of thought.

"As you know, we have never prided ourselves on the completeness and finality of our knowledge and capacity. We are just as ready now as we were earlier to admit the imperfections of our understanding, to learn new things and to alter our methods in any way that can improve them."

Freud, aged 63 (1919/1953, p. 159)

Not all of Freud's contemporaries or followers were quite so open to developments in psychological therapies and until relatively recently older adults have not been seen as ideal candidates for psychological therapies. In the last two decades there has however been a rise in interest in psychological therapies with older adults. Reviews of this literature have argued that psychodynamic therapy (Knight, 1996; Newton, Brauer, Gutmann & Grunes, 1986) and cognitive behaviour therapy (Dick, Gallagher-Thompson &

Thompson, 1996; Koder, Brodaty & Anstey, 1996; Woods, 1994) are suitable for older adults and there are now treatment trials demonstrating significant improvements in individuals receiving psychotherapy compared to control conditions (Koder, Brodaty & Anstey, 1996; Thompson, Gallagher & Breckenridge, 1987).

With some adaptation, the outcome of older adults in cognitive therapy for depression appears to be of comparable efficacy to that of younger adults (Koder et al., 1996). Koder et al. (1996) describe nine techniques useful for the adaptation of cognitive therapy for older adults.

1. *Therapy induction* - Emphasising the rationale for treatment and challenging negative concepts such as 'I'm too old to change'.
2. *Selection of realistic, concrete goals* - a greater emphasis on activities, behaviours and early achievement of success and less on cognitive restructuring.
3. *Additional reinforcement* - provision of printed handouts, slower pace and a greater reworking of issues.
4. *Group work* - attempting to lessen the isolation and encourage openness.
5. *Attention to common themes of ageing* - such as low self-esteem and anxiety about the future.
6. *Life review and reminiscence* - allowing the incorporation of previous coping strategies and placing current issues in perspective.
7. *Involvement of significant others* - including relatives and close others in the latter stages of therapy to enhance maintenance and generalisation.
8. *Gradual termination of therapy* - including a gradual deceleration of frequency of sessions and the offer of additional review.
9. *Follow-up sessions* - appear to be particularly important.

Other factors might be added to this list, including: an awareness of real social, economic and physical limitations, a more flexible approach to session timing, a more active role from the therapist and consideration of ageism in therapy (Woods, 1994). Dick et al. (1996) also stress the importance of summarising in working with older adults.

The general approach to cognitive therapy with older adults appears to be more eclectic allowing for cautious integration of dynamic issues. However, such modifications have yet to receive detailed empirical analysis.

### *Positive Approaches to Life with Dementia*

It is not difficult to find references describing in detail the unpleasant aspects of the process of dementia, particularly with regard to the later stages (for example: Lishman, 1987; McKeith, Perry, Fairburn, Jabeen & Perry, 1992). On reading this literature it becomes easier to consider the disease, rather than the person experiencing the disease. If we are to work successfully as clinicians with people with dementia it may be useful to consider a more positive approach to life with dementia.

Attitudes toward the older age groups in modern Western societies have often in the past been discriminating, rejecting and negative (Holden & Woods, 1995). Where positive qualities are identified they are often relating to a sense of cumulative experience, wisdom and a sense of perspective. Unfortunately for the person with dementia the loss of cognitive skills can lead to a devaluation of their views and opinions amongst those around them, in turn leading to a perceived loss of the few positive aspects of older age that are recognised by their friends, relatives and carers.

An important step in a positive approach to dementia is the separation of the primary and secondary effects of dementia. Sinason (1992) has particularly stressed the importance of understanding the development of secondary handicap. Secondary handicap arises as an interaction of the individual's disability and environmental perception of the disability.

"Here, individuals compliantly exacerbate their original handicap to keep the outer world happy with them. For instance, some handicapped people behave like smiling pets for fear of those they are dependent on."

(Sinason, 1992, p.21)

In describing this development of secondary handicap Sinason uses the term "stupidity". This 'stupidity' can be exhibited by either or both the individual with dementia and their carers.

"To be stupid is to be numbed with grief and those who bear the burden of mental handicap carry an enormous amount of grief."  
(Sinason, 1992, p.31)

Sinason's views on the development of secondary psychopathology are more frequently associated with a learning disability context, although her views on this issue can easily be applied to a dementia model. Indeed Sinason's first case example in her book is of a man with a dementing condition.

People with dementia often live in an environment of reduced sensory stimulation and have a low level of physical activity (Holden & Woods, 1995). Their environment may not have been designed with an older person in mind, let alone an older person with a cognitive impairment. Occasionally relatively straight-forward modifications may lead to immediate quality of life improvements.

Holden and Woods (1995) concluded that many problems can be better managed with a structured program, responsive to the individuals behaviour patterns. In describing their positive approach to dementia care, they make efforts to point out that a realistic appraisal of goals and achievements must be taken.

"Despite the promising research findings, indicating the responsiveness of people with dementia to the environment in which they live, and the expectation that answers may soon be found to some of the disease processes, progressive deterioration remains so often the norm in dementia care. In this context, goals must reflect the knowledge that a relatively small improvement may be a major achievement."  
(Holden & Woods, 1995, p. 193)

### *Psychotherapy with people experiencing both dementia and depression*

"Clearly, cognitive and behavioural therapies are inappropriate with patients who have memory impairments or extensive delusional systems."  
(Miller & Morris, 1991, p. 412)

This view now seems limited, particularly as there are no studies demonstrating these assumptions, and in the case of delusional systems quite

incorrect (Drury, Birchwood, Cochrane & Macmillan, 1996; Tarrier, Beckett, Harwood et al., 1993). It has also been demonstrated that cognitive impairment does not provide an insurmountable barrier to cognitive-behaviour therapy with people with learning disabilities (Kroese, Dagnan & Loumidis, 1997).

Despite having cognitive impairments it seems that many people with dementia can still learn, particularly in terms of implicit memory (Eslinger & Damasio, 1986; Nebes, Brady & Huff, 1989) and where events arouse high levels of emotion (Ikeda, Mori, Hirono, et al., 1998; Williams & Garner, 1998). They would appear to be able to learn new skills if a learning program is appropriately structured, but may not be able to recall explicitly what they have learned. Studies have also demonstrated that behaviour modification procedures can be effective with people with dementia (Johsephson, Backman, Borell et al., 1993).

Assessment forms the cornerstone of any psychological intervention. In work with older adults the sheer mass of life history, that so intimidated Freud (1905/1953), means that both the therapist and the participant will be forced to make judgements regarding what is relevant to the current problem (Knight, 1992). With the older adult who has dementia assessment is further complicated by memory loss. The study of this memory loss is not, as yet, sufficiently advanced to state whether information relating to an individual's psychopathology will be better or less well preserved. The therapist of the dementing participant will therefore have to keep an open mind.

"Many people take a bad situation and make it even worse by exaggerating the impact of the problem and by overgeneralizing its effects. For the chronically ill/disabled older person, reality is bad enough. Active cognitive work to keep the individual dealing with the reality can help to reduce the 'excess depression.'"

(Knight, 1996, p. 138)

Reality may be bad enough for the individual with both dementia and depression but it is important that the therapist does not reinforce the "inevitable misery" of the client's situation. In applying cognitive-behavioural psychotherapy to chronically ill older adults Rybarczyk (1992) identified five treatment issues.

1. Resolving practical barriers to participation in therapy.
2. Accepting depression as a separate and reversible problem.
3. Limiting excess disability.
4. Counteracting the loss of important social roles and autonomy.
5. Challenging the perception of being a "burden".

Home visits may be the standard for the depressed and dementing client group and any prospective therapist needs to become comfortable with this manner of working. Utilisation of psychiatric services by depressed older adults is particularly low when compared to younger adults (Cuijpers, 1998). It is therefore important to make services easily available, particularly for older people with dementia. This involves providing home visits and spending more time explaining services available and describing how psychological assistance may be useful.

Accepting that depression is a separate and reversible problem is clearly an issue that must be addressed early in therapy. The view that their compromised health status is the only thing upon which happiness can be based is a view that may be unwittingly reinforced by family and carers agreeing that the individual has "every reason" to be depressed (Rybarczyk, Gallagher-Thompson, Rodman et al., 1992)

"In counteracting global attributions, it is important to help the client focus on the exact nature of the disability rather than to see him- or herself as completely disabled. This process consists of the candid recognition of abilities that are lost combined with the encouragement to recall the abilities that remain."

(Knight, 1996, p. 138)

Whilst the theoretical conceptualisation of the problems and therapeutic techniques involved in work with people with both dementia and depression may become more engaging than might first have been imagined, it is most important to remain focused on the individual and to be sensitive to their physical and emotional state.



## **Summary**

In summary many factors can be identified that relate to the development of depression in a person with dementia. These include:

1. The psychological consequences of terminal illness.
2. The experience and awareness of cognitive decline.
3. Devaluation of social role.
4. Reduced range of abilities.
5. Reduced independence.
6. Experience of personality and behaviour change.
7. Relationship difficulties.
8. Chronic pain.
9. Changes in memory functioning.

Amongst people with dementia, depression provides an additional burden, both for themselves and for their carers (Rosenvinge, Jones, Judge & Martin, 1998) that may prove to be treatable.

### **Aims of the Study**

The theoretical assumption of this study is that the extent to which cognitive therapy is useful for people with a dual diagnosis of dementia and depression is unknown and should not be assumed whilst such a gap in the understanding of the relationship between dementia and depression exists. It is argued that as better understanding of this relationship develops then the boundary point at which cognitive psychotherapy can be applied will be pushed forward.

Explicitly the aims of this study are to

- 1 To provide the first consecutive case series study of cognitive therapy for depression with individuals with a diagnosis of dementia
- 2 Examine issues emerging from cognitive psychotherapy for depression with individuals with a diagnosis of dementia
- 3 Provide support for a controlled effectiveness trial of cognitive therapy for depression with individuals with a diagnosis of dementia

## Method

### *Participants*

Eight participants agreed to take part in the study. All participants were initially referred to psychology services by a consultant psychiatrist. The consultant psychiatrist had been made aware that a cognitive therapy intervention was available for individuals with both dementia and depression. To qualify for inclusion in the study all participants had to fulfil the following criteria (see appendix for ethical approval and consent forms).

1. A diagnosis of dementia (F00), following ICD-10 criteria (World Health Organisation, 1992) (Appendix 2). This diagnosis was made by a team decision including a consultant psychiatrist, a principal clinical psychologist, an occupational therapist, social workers and psychiatric nurses. In addition to the diagnosis the participant had to demonstrate clinically significant cognitive deficits on standardised psychometric tests.
2. A diagnosis of depressive episode or recurrent depressive disorder (F32 or F33), following ICD-10 criteria (World Health Organisation, 1992) (Appendix 3). This diagnosis was again based upon a team decision and supported by a score on the Geriatric Depression Scale of 11 or above.
3. The participant had to be willing to take part in the study. The participants were given a week in which to consider whether they wished to take part following a meeting explaining the nature of the study.

All participants with a dual diagnosis of dementia and depression referred during the study period were consulted on whether they would wish to take part in the study. Two individuals approached declined to take part in the study, both of whom gave the opinion that they did not feel depressed as their primary reason for not taking part. A summary description of the participants can be found in Table 2. All participants had received a Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) from the referring psychiatrist. The MMSE is fundamentally a screening instrument and can be heavily influenced by a number of factors including educational level. However, the range of scores in the study could be taken as indicating that the participants were experiencing mild to moderate levels of cognitive impairment.

Table 2.

Case	Participant	Age	Sex	Marital Status	MMSE
1	John	83	Male	Widowed	20
2	Eric	69	Male	Married	25
3	June	79	Female	Widowed	26
4	Dafydd	79	Male	Married	21
5	Dilys	64	Female	Widowed	21
6	Ifor	72	Male	Married	21
7	Norma	72	Female	Married	23
8	Martha	57	Female	Married	30

### *Psychiatric Medication*

An obvious confounding factor in any psychotherapy intervention is concurrent prescription of psychiatric medication. Four of the participants (Participants: 2, 3, 7 & 8) received no psychiatric medication during the study. Participant 1 had a long standing prescription for fluoxetine to which he was non-compliant. Participants 5 and 6 had long standing (> 4 months) prescriptions (nefazadone & paroxetine respectively) to which they had been compliant. In both cases little apparent effect had been noted by their psychiatrist. In one case, however, prescription may have been a confounding factor, as due to an error in communication participant 4 was started on citalopram, during the study.

### *Measurements*

Many of the clients referred to the study had already been given a psychometric assessment. Where there was a clear consensus of opinion that the client was experiencing a dementing condition, which had been confirmed by a recent psychometric evaluation, it was felt inappropriate to ask the participants to take part in extensive additional tests. However the tests included in these initial psychometric assessments varied dependent on the clinical discretion of the assessing psychologist. Where these were insufficient to support a diagnosis of dementia they were supplemented by additional tests including components of the Weschler Adult Intelligence Scale - Revised (WAIS-R), the Weschler Memory Scale - Revised (WMS-R) and the controlled oral word association (FAS) test. The primary psychometric evaluation of the level of depression was the Geriatric Depression Scale (Yesavage, Brink, Rose et al., 1983).

### *Diagnosis*

It is currently difficult to provide a specific diagnosis of a person's dementia without extensive investigation including volumetric NMRI, CAT and SPECT scans, brain biopsy and a comprehensive neuropsychological investigation. For this reason the ICD-10 diagnosis of dementia was used. Here dementia is defined as a:

"syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement."

(World Health Organisation, 1992, p. 312)

As previously noted this was based upon a team diagnosis. The neuropsychological support for which is summarised in Table 3.

Table 3.

Case	Participant	Neuropsychology Findings
1	John	RBMT < 10th percentile. WMS-R Logical Memory 1 & 2 < 7th percentile. WMS-R Vis. Reproduction 1 & 2 < 5th percentile.
2	Eric	WAIS-R - Arith., Obj. Ass. & Digit Sym. items all < 25 th percentile (Pred: > 50th). WMS-R Logical Memory 1 & 2 < 15th percentile. WMS-R Vis. Reproduction 1 & 2 < 25th percentile.
3	June	WAIS-R - Info., Pic. Comp., Pic. Arr., Block Des. & Digit Sym. items all < 16th percentile (Pred: > 50th). WMS-R Logical Memory 1 & 2 < 5th percentile. WMS-R Vis. Reproduction 1 & 2 < 5th percentile.
4	Dafydd	DRS: mild to moderate memory probs. WMS-R Logical Memory 1 & 2 < 24th percentile. WMS-R Vis. Reproduction 1 & 2 < 15th percentile.
5	Dilys	MEAMS: 9 out of 12 items. WMS-R Logical Memory 1 & 2 < 15th percentile. WMS-R Vis. Reproduction 1 & 2 < 10th percentile.

6	Ifor	MEAMS: 8 out of 12 items. WMS-R Logical Memory 1 & 2 < 13th percentile. WMS-R Vis. Reproduction 1 & 2 < 15th percentile. (Delayed Scores both < 5th percentile)
7	Norma	MEAMS: 10 out of 12 items. RBMT < 15th percentile.
8	Martha	RBMT < 25th percentile. WAIS-R & GNT at expected level.

Abbreviations: RBMT- Rivermead Behaviour Memory Test; WMS-R - Wechsler Memory Scale-Revised, Vis. Reproduction - Visual Reproduction; WAIS-R - Wechsler Adult Intelligence Scale-Revised, Info - Information, Arith - Arithmetic, Pic. Comp - Picture Completion, Pic. Arr - Picture Arrangement, Block Des - Block Design, Obj. Ass - Object Assembly & Digit Sym - Digit Symbol; DRS - Dementia Rating Scale; MEAMS - Middlesex Elderly Assessment Scale.

### *Geriatric Depression Scale*

The Geriatric Depression Scale (GDS) has been shown to have high reliability and validity (Spren & Strauss, 1998) in the assessment of depression in older adults in a wide range of settings (Burke, Rangwani, Roccaforte et al., 1997; Yesavage et al., 1983). However, the validity of the use of the GDS as a screening tool with people with dementia has been questioned (Burke, Houston, Boust & Roccaforte, 1991; Folstein, 1991). Burke et al. (1991) examined the ability of the GDS to distinguish between depressed and non-depressed people with Alzheimer type dementia. They concluded that, though the GDS was a valid screening test for depression in cognitively intact geriatric populations, it did not maintain its validity in populations that contain large numbers of patients with dementia of Alzheimer type (Burke et al., 1991). Their findings were questioned by Christensen and Dysken (1990) who noted the small size of the depressed sample and their general lack of diagnostic information.

Other studies have described how mild to moderate dementia (MMSE > 16) alone does not appear to significantly affect the accuracy of the GDS as a screening tool (O'Riordan, Hayes, O'Neill, Shelley, Walsh & Coakley, 1990; Ryan, Blackburn, Lawley, Ellis & Musil, 1995; Sheikh & Yesavage, 1986).

"The GDS is a brief and useful screening tool for depressive illness in hospitalised subjects even in the presence of moderate dementia."

(O'Riordan et al., 1990, p. 60)

The GDS has also been shown to be more sensitive than the Hamilton Rating Scale in the detection of depression when compared to psychiatric diagnosis in a group of individuals with a wide range of dementia severity (Mean MMSE = 17.4, Range 3 to 29) (Lichtenberg, Marcopulos, Steiner & Tabscott, 1992). In attempting to explain the discrepancy between their findings and those of Burke et al. (1991) they pointed out that the group of patients included in the Burke et al. (1991) sample had all recently entered institutions potentially exacerbating their confusion through drastic environmental change (Lichtenberg et al., 1992).

Lichtenberg et al. (1992) suggested a cut off score of 10 on the GDS. This cut off level was supported, in a more recent study, when compared to psychiatric diagnosis (Ryan, Blackburn, Lawley, Ellis & Musil, 1995).

Following this brief review of the literature the GDS was chosen for the following reasons.

1. Although a potentially flawed screening instrument where a clinical diagnosis had been made the GDS does appear to be a relatively good indicator of the level of depression experienced by an individual with dementia.

2. It is a quickly completed self-rating scale, with less potential for clinician bias. This was considered particularly important in this study where the assessments were made by the individual performing the psychotherapy.

3. Although caregivers have been seen to be reliable in providing estimates of the level of depression experienced by a person with dementia (Logsdon & Teri, 1995), several of the participants in this study had no clearly identifiable primary caregiver.

The complete GDS was administered at the beginning of the initial assessment and again following eight psychotherapy sessions.

### *Structure of the Psychotherapy Sessions*

Once consent had been given to take part in the study the neuropsychological assessment the participant had received was reviewed. In some cases this was supplemented by additional testing to validate the diagnosis of concurrent depression and dementia.

Following these prerequisites therapy sessions began. The aim of this study was to provide eight sessions of cognitive therapy for each participant. However, several participants continued to receive therapy, at their request, following completion of the study.

The structure of the therapy sessions was largely based upon the Beck (1979) model with the following relatively minor modifications.

As with a 'normal' cognitive therapy approach an agenda was established for each session. This was jointly developed with the participant although a slightly more active role was taken by the therapist when memory constraints appeared to be limiting the participant's ability to recall important issues.

Therapist summarising and attempts to elicit participant summaries were used regularly. Discussion of tangential and peripheral topics occurred relatively frequently and some attempts were made to curtail these when they became extreme. On several occasions the relevance of these discussions emerged later in therapy, they additionally appeared to assist in establishing rapport, particularly important in this type of work as none of the participants were self-referrals for a psychotherapeutic intervention. Despite this diversification attempts were made to address at least one central issue per session.

A significant part of therapy with all of the participants was discussion of their diagnosis and the significance of this in terms of the cognitive changes they were currently experiencing and were likely to experience in the future. All of the participants were made aware of their diagnosis as best as it was known. Where requested they were provided with additional information on dementia and their future. In general it was not necessary to describe details of end-state dementia.

In an attempt to maintain adherence to a cognitive therapy approach the Competency Checklist for Cognitive Therapists (Young, El Shammaa & Beck, In: Beck et al., 1979; Appendix 1) was completed after the second therapy session with each participant. Where discrepancies were found in the approach attempts were made to address these issues in later therapy. Weekly supervision sessions were also undertaken by the therapist to examine matters arising in therapy.

## Results

The initial and outcome GDS scores are shown in Table 4. The mean initial GDS score was 21.17 (s.d. = 5.49). The mean outcome GDS score was 15.43 (s.d. = 4.65). Neither the initial or outcome GDS scores differed significantly from a predicted normal distribution on a Kolmogorov-Smirnov One-Sample Test (Initial  $D=0.142$ ,  $p>0.2$  and Outcome  $D=0.094$ ,  $p>0.2$ ). The variance of the two measures was roughly homogenous (Initial Score Variance = 25.9,



Outcome Score Variance = 21.62 for the seven paired scores). Given these two observations and the robust nature of the *t*-test (Clark-Carter, 1997a; Howell, 1997) it was considered that the GDS measures would approximate sufficiently to an interval scale to allow the application of a *t*-test. The difference between these measures was statistically significant on a matched-sample *t* test ( $t = 3.508$ ,  $df = 4$ ,  $p = .0247$ ).

Table 4.

Case	Initial Geriatric Depression Score	Outcome Geriatric Depression Score (8 Sessions)
1	23	15
2	12	8
3	(20)	14
4	20	17
5	27	23
6	26	-
7	(14)	13
8	19	18

Figures in brackets indicate estimated scores.

Two participants declined to complete the GDS initially, apparently finding it too intrusive given the brief period in which they had known the therapist. Both were able to later complete GDS short-forms in therapy and a full-scale GDS on completion of therapy<sup>∞</sup>. When estimated scores were calculated the difference between initial and outcome measures remained statistically significant ( $t = 4.01$ ,  $df = 6$ ,  $p = .007$ ).

Unfortunately diagnostic complications involved with client 6 made it difficult to complete eight psychotherapy sessions during the time-period of this study. His results were still included in the study for completeness and to illustrate the diversity of this type of work.

Several authors have suggested techniques for measuring the clinical significance of therapeutic change (Christensen & Mendoza, 1986; Hageman & Arrindell, 1993; Jacobsen, Follette & Revenstorf, 1984; Jacobson & Truax, 1991). The Reliable Change Index (RCI) (Jacobsen et al., 1984) was designed to determine whether an individuals observed change was greater than the change which would be expected on the basis of the error in the measure. The original RCI has received several developments largely in an attempt to

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<sup>∞</sup> Various methods were considered to estimate an initial full scale GDS score. The simplest of which was to double the first GDS short-form score they were able to complete.

account for a general regression to the mean (Hageman & Arrindell, 1993). Sufficiently specific reliability measures have not, as yet, been published for the GDS to apply Hageman and Arrindell's (1993) formula. The formula provided by Christensen & Mendoza (1986) is reasonably conservative and has been described as methodologically more sound than the original RCI measure (Hageman & Arrindell, 1993). RCI values for each of the participants are shown in Table 5.

From Table 5. it can be seen that the GDS scores of two of the eight participants appeared to indicate clinically reliable change. Some caution must be applied to these results as the scores were calculated with a test-retest reliability score of .85 (Koenig, Meador, Cohen & Blazer, 1988) derived from an elderly medically ill patient sample, since test-retest reliability scores do not appear to have been published for groups of people with dementia. Although a reliable change in only two out of eight participants represents a modest degree of success, studies of psychotherapy for unipolar depression with non-dementing participants generally show 'moderate' levels of clinical significance (Nietzel, Russell, Hemmings & Gretter, 1987).

Table 5.

Initial GDS Score	Change in GDS score (after 8 sessions)	RCI
23	8	2.66*
12	4	1.33
(20)	(6)	1.99*
20	3	0.99
27	4	1.33
26	-	-
(14)	(1)	0.33
19	1	0.33

Estimated scores shown in brackets. RCI values of greater than 1.96 indicate a reliable change with the level of significance set at 5%. Reliability of the GDS = .85 (Koenig et al., 1988).

## Individual Case Descriptions

### Participant 1.

John\*, the first participant was an 83 year-old man. He was Welsh / English bilingual. He did not express any difficulty in conversing in English. John lived alone, his wife having died some years previously.

#### *Initial Assessments*

He was initially assessed by a consultant psychiatrist, four months before our first meeting. John had been referred to the psychiatrist following complaints of loss of short term memory. He scored 20 out of 30 on the mini mental state examination (Folstein et al., 1975). It was also noted that: "this man has become totally obsessed with his problems relating to his cataract surgery" although the client's mood state was not commented upon. He had however been prescribed an SSRI antidepressant.

The letter from John's GP accompanying the referral letter described how: "much of this gentleman's problems occurred in an incident when he had his cataract operation done... he was extremely concerned as he claimed that he had been assaulted on the operating table... it transpired that an incident had happened on the operating table but he had become totally obsessed with the whole situation... while he was having his cataract operation done he fell asleep. He woke during the operation and unfortunately had to be restrained for a short while for his own safety."

On referral to psychology services for formal neuropsychological assessment the Rivermead Behavioural Memory Test was administered and it emerged that his overall memory performance was "in the lowest 10% for his age group and intellectual level". The short-form of the Geriatric Depression Scale (Sheik & Yeasavage, 1986) was completed giving a score of 11 out of 15 "suggesting quite a moderate level of depression". This assessment had taken place two months previous to the first session of this intervention.

On completing the Geriatric Depression scale a score of 23 out of 30 was given (scoring 12 out of 15 on the short-form).

John had left school early, following the death of his father, when he was fourteen. He had then worked on a farm until the war when he had joined the RAF working in the maintenance of aeroplane bodies. Over this period he had been "blow-up" on two occasions, both causing some mild head injury. Following the war he had worked as a bus inspector, until his retirement.

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\* All participants names have been changed to maintain anonymity.

### *Therapy Sessions*

Several issues were raised in therapy that appeared to have a relationship to John's level of depression.

John had lived alone for about fifteen to twenty years (a precise date was difficult to establish given John's memory difficulties). His wife had experienced a severe stroke and had been taken into a nursing home. John felt that as the person he knew she had died at this point, although she had lived for several more years in the nursing home. Over this time John had visited her regularly. He now felt that he had become used to living alone.

John's frustration over the treatment he had received during and following his eye operation was considerable: "I cannot understand how this operation was still carried on under the circumstances and I will NOT REST until I'm SATISFIED" (from John's written account of his experiences). He felt that he had woken up during the operation as a result of the mishandling of his anaesthetics, at which point he thought he had been "throttled" into unconsciousness. John had also experienced a "terrific bang" to his head which he considered worse than the experiences of being "blown-up" during the war. Additionally as far as John was able to tell the operation had not improved the vision in his eye.

The onset of his dementia was unclear, but he clearly attributed his cognitive impairments to the operation. The progress of his cognitive decline was a issue that concerned John. He had fears that he might be taken from his home against his wishes at any time.

### *Process Issues*

There were several tasks that were identified for therapy:

1. To develop a collaborative trusting therapy relationship.
2. To present an understandable model of dementia and it's possible progress.
3. To provide an opportunity to discuss his feelings for his wife's illness and the later stages of their relationship.
4. To collaboratively examine the evidence supporting his perceived experiences during his cataract operation and consider alternative interpretations of his experiences.
5. To provide reassurance that he would not be taken from his home, supported by the facilitation of additional home support demonstrating health service commitment to community care.

Therapy with John was quite repetitive in that these issues would be raised once or twice during each session. This was viewed in positive fashion in that it allowed repeated opportunities to discuss issues important to John at a rate that he determined.

### *Outcome*

John appeared to become less fixed on the experiences of his operation, an improvement was noted after he was able to give a written account of his experiences which was sent to his consultant psychiatrist. He was able to discuss the feelings of loss he had experienced from the events leading to his wife's death.

His completion of the Geriatric Depression Scale gave a score of 15 out of 30, a reduction of 8 points from his initial assessment.

### *Follow-up*

On follow-up John suggested that he might have experienced a stroke during the operation, this appeared to allow the resolution of his desire to find someone to blame for his experience of cognitive loss.

Two months after the completion of therapy John's GDS short-form score was 8 compared to a score of 12 initially.

Some four months after therapy John was admitted into a residential home and shortly after into an acute ward of his local hospital where he died.

## **Participant 2.**

"In the winter there is too much darkness. In the summer everything is beautiful. I wish it could be that way all the time."

(Eric)

Eric, the second participant, was a 69 year-old man. He was a monolingual English speaker. He lived with his wife. They had two grown-up daughters. Eric had worked in printing and print management for the majority of his working career.

### *Initial Assessments*

Eric had been referred to psychology services by a psychiatrist for neuropsychological assessment, this assessment took place approximately one month from the start of this intervention. The presenting problems were memory and word finding difficulties which were now straining his marital and social life. He had received a comprehensive assessment at this time. Eric's 'pre-morbid' intellectual ability was estimated to be at the upper limits of the average range. His scoring on the WAIS-R produced some discrepant results, in particular his scoring on the arithmetic, object assembly and digit symbol items were poor. The results of the WMS-R demonstrated "global memory deterioration". Eric's mood was also assessed, he scored 12 on the Geriatric Depression Scale and 10 on the Beck Anxiety Inventory.

Eric had first noticed his memory getting worse after the second of two heart valve replacement operations which had taken place approximately four years before this intervention.

Eric's CT scan demonstrated "widespread cerebral atrophy with ventricular dilatation".

### *Therapy Sessions*

Eric was very proud of his career as a print manager, during which time he had made several innovative changes to the printing process at the company for whom he worked. He had also been an amateur comedian and performer with a large vocabulary of jokes and humorous material. Now that his memory was in decline both he and his wife appeared to be in a process of mourning its loss and confusion over why it should be happening. They were unable to understand the reason for this memory loss, although they had been told by his heart surgeon, in whom they had placed a great deal of faith, that some mild deterioration would be normal following a second heart valve replacement operation. They both seemed reluctant to consider a progressive degenerative disorder as the reason for Eric's continued decline. She had repeatedly asked him "Why can't you be like you used to be?" and stated "it's like living with a dummy".

It emerged in individual therapy with Eric, that he and his wife had, in the past, discussed the possibility of future invalidity and had both agreed at that time that the best option would be to place the effected partner in a nursing home so that the other might be able to live an unhindered life. Now that a genuine progressive illness seemed to be emerging this conclusion was beginning to weigh more heavily in Eric's mind, particularly as it had been suggested, partly in jest, that he should go to a "home" by his wife and eldest daughter.

Driving was another issue that seemed to be a source of concern. Eric was at this time still driving but had begun to notice a decline in his skills and ability to remember route finding information. Living in a rural area losing the ability to drive was seen as a considerable issue by Eric.

Positive features of Eric's life were identified and included his continued enjoyment of golf and his contribution to the local Rotary club.

### *Process Issues*

The issues that were identified were:

1. To understand and recognise the 'bereavement' type responses of Eric and his wife to his cognitive impairments.
2. To identify the relationship difficulties that were leading to the strained communication between Eric and his wife.
3. To recognise the change in power and dependency roles within the family.

4. To attempt to facilitate better communication between Eric and his wife.
5. To gradually begin to consider the possibility of dementia and to promote a positive attitude should this emerge as the source of Eric's cognitive impairment.
6. To encourage Eric's continued involvement in playing golf and attending his Rotary club.

#### *Outcome*

Eric was able to form a collaborative therapeutic relationship relatively quickly. He was keen to try to improve his memory skills and was able to implement several mnemonic strategies into his daily routine.

A joint session with Eric and his wife rapidly diminished his fears that she would place him in a home if his memory got worse. Now that such an issue was more immediate she strongly felt that she would like Eric to stay at home for as long as possible and whilst not being a natural 'carer' she expressed considerable determination that it would not be beyond her.

#### *Follow-Up*

One month after the completion of therapy Eric remained positive about the changes that had been made by therapy but remained cautious with regard to future developments. His GDS short-form score at this point was 4.

### **Participant 3.**

"It's not that she has lost it, just that she never had it."

(June's Son-in-Law)

June the third participant was a 79 year-old woman living in a retirement flat. Her husband had died 5 years previously. She had three daughters, two of whom lived abroad. The daughter who lived near-by appeared to be very supportive of her mother. Her older brother also lived in the same block of flats and was able to provide assistance with her practical difficulties.

#### *Initial Assessments*

June was initially seen by a consultant psychiatrist, he described her as a "sad woman" who "claimed that her life has not been all right since the death of her husband". The referral had been made by June's GP as a result of her daughter's concerns over her memory impairments and difficulties in operating household machinery. At this time, one month before starting

therapy, she scored 26 out of 30 on the mini mental state examination (Folstein, 1975). She was prescribed an SSRI antidepressant and advised to drive only on local, familiar roads.

From the first meeting June's sadness and forgetfulness were immediately apparent. Her scoring on the WAIS-R was considerably below that which would have been expected from estimates of 'pre-morbid' intelligence. This was particularly apparent on the performance scale which was below the tenth percentile for her age group. Her responses to items of the WMS-R were again very impoverished. It was concluded that "her test profile appeared similar to those produced by individuals with the early stages of dementia and most like those of a person with dementia of Alzheimer type". Two notes of caution were made in relation to this conclusion. Firstly her test performance may have been effected by her mood state, although her attitude appeared relatively good and secondly her CT scan was interpreted as showing "normal age related pathology... with chronic infarcts of the fronto-parietal regions".

On completion of the short-form of the Geriatric Depression Scale June gave a score of 10 out of 15.

#### *Therapy Sessions*

It was clear from the first meeting with June that engagement in a therapeutic relationship would be difficult. She found it quite challenging to complete the depression scales that she was given as they were "too personal". June was quite sceptical that psychotherapy might help. However as the assessment process continued a stronger therapy relationship began to develop.

Several issues appeared to relate to June's depression, the most important of which seemed to be her bereavement. It appeared that throughout her life June had been encouraged to be emotionally and physically dependent on her family and husband. Following the death of her husband and her daughters' increasing preoccupation with their own families June had become more lonely and emotionally isolated without the skills she needed to cope with this situation.

June lived in an elegant and expensively furnished retirement flat. The flats appeared to be largely populated by lonely widows but the physical and social arrangements were such that little interaction took place between occupants. The positioning of the flat made the use of a car a practical necessity. This became particularly relevant after the decision, mid-way through therapy, by her psychiatrist that June should be considered medically unfit to drive.

The memory dysfunction that June was experiencing made it difficult for her to understand the process of her dementia. She experienced great frustration that no-one had told her what was wrong with her despite having had the nature of her dementia explained to her on a weekly basis in therapy.



### *Process Issues*

Specific areas of focus for therapy were:

1. To develop the therapy relationship of which she was initially quite sceptical.
2. To allow an opportunity for discussion of feelings and emotions relating the death of June's husband.
3. To present an understandable model of dementia and it's possible progress.
4. To facilitate the longer term retention of this model by the use of client led summarising and the provision of a written account.
5. To facilitate the acceptance of the loss of the opportunity to drive and to assist in the planning of alternative methods of transportation.

Again, therapy with June was quite repetitive in that these issues were frequently revisited.

### *Outcome*

June remained melancholic throughout therapy and pessimistic with regard to the future. Her scoring of the GDS short-form demonstrated a gradual though modest decrease as therapy progressed from an initial score of 10 to a score of 7 in the later stages of this intervention. Her outcome GDS score was 14 after eight sessions.

Given the initial difficulties in June's engagement in therapy, the immediacy of her diagnosis as having dementia and the loss of her ability to drive mid-way through therapy it was decided that therapy should continue on a weekly basis beyond the eight-week trial period.

### *Follow-Up*

Improvements in June's mood did appear to emerge as therapy progressed although she remained vulnerable to rapid fluctuations in mood-state. A further positive outcome was that June was able to begin to tolerate additional assistance from outside her family with home-care and medication. Her family had previously described their concern over how June would cope without this additional help.

## **Participant 4.**

Dafydd, the fourth participant, lived with his wife. He was a baker by trade, beginning his apprenticeship on leaving school, serving as an army baker during the war and running his own bakery until his retirement. He had no children.

### *Initial Assessments*

Dafydd had been referred to psychology services three years prior to this intervention for psychometric assessment following a deterioration in short-term memory, confidence and motivation. A "mild memory deficit" had been demonstrated at this time. He had received a repeat assessment shortly before this assessment which had found that although he was "performing just below the cut off for dementia of Alzheimer type" he still had "a number of preserved abilities".

Dafydd's consultant psychiatrist had found him "a difficult man to assess as he is extremely fearful as to what is happening to him" he had also noted that Dafydd was getting into "frequent arguments" with his wife.

Having lived locally for the majority of his life Dafydd was a popular local figure. He had been the youngest of nine children. Dafydd and his wife had been married for 48 years. His wife was now quite seriously ill with a condition that her GP had apparently described as unlikely to be treatable.

On completing the GDS a score of 20 out of 30 was given.

### *Therapy Sessions*

A number of issues were raised in therapy that appeared to be influencing Dafydd's depression and anxiety levels.

Dafydd had good insight into the decline of his cognitive skills. This in itself appeared to be an influential factor in Dafydd's mood. He was also greatly occupied by concerns that he might be forced to leave his home against his wishes.

Although Dafydd and his wife had never had children themselves their roles as carers had been extremely important to them. They had frequently looked after the children of their brothers and sisters. They had additionally taken on responsibilities caring for many of the older people who had lived in their street. Dafydd appear to be finding the transition from carer to cared-for quite difficult. This transition of roles was complicated by his wife's coping mechanisms for her own illness. It seemed that her self-esteem was strongly related to her ability to care for those around her and provided a means by which she could psychologically combat her illness. For Dafydd this meant a change of role that was too extensive and was leading to frustration and argument.

Having seen the process of dementia in several other people and the disinhibited behaviour that they had shown, Dafydd was particularly concerned that he might become violent. This anxiety was heighten by the increased regularity of disputes between himself and his wife.

### *Process Issues*

Key issues within therapy were:

1. To collaboratively examine the evidence that Dafydd would be forced to leave his home against his will.
2. To understand his fears that he might become violent and to examine evidence as to whether this might occur.
3. To consider how his wife's illness was influencing her behaviour toward him.
4. To examine how he might begin to accept the transition from carer to cared-for appropriately, allowing his many cognitive assets to be valued.
5. To appreciate his quite reasonable sadness of his own declining abilities and the ill health of his wife.

Despite their occasional relationship difficulties he and his wife were quickly able to describe many positive features to their marriage.

A strategy that became important to Dafydd was to try to "take each day as it comes". This appeared to allow Dafydd to concentrate more on the here-and-now rather than thinking of a future alone and dementing following the death of his wife.

### *Outcome*

The outcome of the psychotherapy sessions was complicated by the prescription of an SSRI antidepressant mid-way through therapy.

Dafydd described a modest improvement in his mood over the sessions. This was supported by the gradual decline of his GDS scores over the sessions. It is also interesting to note a modest improvement in Dafydd's reassessment psychometric test scores. Naturally this might have been due to any number of factors such as practice effects or a more relaxed test-taking attitude. However, given that it is extremely unlikely that the therapies received by Dafydd had led to an improvement in the biological process of dementia they could also argue for a positive change in his mood state.

Following the intervention several issues remained. Dafydd's wife remained unwell and their relationship was at times quite strained. The process of his dementia still saddened Dafydd, and anxiety with regard to the future remained. Dafydd appeared to view the therapy positively and requested further follow-up sessions.

### *Follow-up*

In follow-up Dafydd described how the progress made in therapy had been sustained but that this was complicated by his wife's terminal illness. His anxiety with regard to the future had lessened but he remained realistic in that their future contained several 'dark clouds'.

## Participant 5.

Dilys, the fifth participant, had been known to local psychiatry services for several years prior to this intervention. She was 64 years old and had been widowed 7 years previously. Dilys lived alone but was regularly visited by her daughter.

### *Initial Assessment*

Dilys had a two year history of "mood disorder". Her psychiatrist had noted her "nocturnal confusion" and "disorientation". EEG results from this time demonstrated "frequent, single or brief runs of temporal slow waves arise both bilaterally, generalised and independently" with a left sided emphasis at the T4 and T3 electrodes. A CT scan demonstrated "a small area of lacunar infarction in the region of the internal capsule on the left" with no further abnormality. Following her scan she received two independent psychometric assessments, both of which demonstrated considerable impairment. However, both psychologists noted that Dilys' mood state might have influenced her test results.

Dilys had first been a psychiatric inpatient some nine years previously following the collapse of her husband's business and the repossession of their home. Following this she and her husband had moved to the local area. Two years after this move her husband had died. She had experienced several depressive episodes since, occasionally these required inpatient care. However her current depression had been deeper and longer lasting than previous episodes. She was also experiencing feelings of her abdomen "churning all the time" which was causing her some anxiety.

Dilys gave a score of 27 out of 30 on the GDS at initial assessment. She also completed the Health Anxiety Questionnaire (Lucock & Morley, 1996) giving a score of 33 (Hypochondriasis Group Mean = 35.34, SD = 13.36; Control Group Mean = 8.62, SD=7.96).

### *Therapy Sessions*

Therapy with Dilys was characterised by attempts to motivate her to participate in therapy and a struggle to describe any of the cognitive processes involved in her condition.

Characteristic patterns of interaction with Dilys were:

Therapist:	How are you feeling?
Dilys:	Oh, not too good.
Therapist:	Better or worse than yesterday?
Dilys:	About the same.
Therapist:	How about the day before that?

Dilys: Oh, not too good.

Therapist: Are there any things that you think about when you're not feeling too good?

Dilys: No not really.

Therapist: Is there anything that you sometimes worry about?

Dilys: No not really. I haven't got anything to worry about.

Therapist: Are there ever times that you feel just a little bit better?

Dilys: No not really.

Use of diaries revealed little in terms of the cognitive processes that Dilys was experiencing.

Equally characteristic was the exasperation and frustration that Dilys appeared to create in her carers, both professional and non-professional. Due to her medical conditions it was only possible for her psychiatrist to prescribe one anti-depressant which she had been taking, apparently with little effect, for several months.

Dilys was very unhappy about the flat in which she lived and expressed a strong desire to go into a residential home. Despite the misgivings of her keyworker this was arranged.

During therapy self-injurious behaviour occurred on two occasions, once as 'wrist-scratching' and once as a paracetamol overdose. These both occurred immediately prior to her attendance at a psychiatric day centre which she disliked attending.

#### *Process Issues*

The specific tasks identified for therapy were as follows:

1. To identify any factors that influenced Dilys mood state.
2. To facilitate an increase in Dilys motivation to 'activate' herself.
3. Following the parasuicidal episodes it was considered important to attempt to develop Dilys' assertiveness skills, in an attempt to reduce the need to resort to self-injurious behaviours.
4. To present a cognitive-behavioural model of health anxiety symptoms and to make links between this and Dilys' anxiety experiences.

### *Outcome*

After eight sessions Dilys' scores on the GDS remained high, at 23, although lower than her initial score. Her score on the Health Anxiety Questionnaire had also fallen to 25.

Unfortunately Dilys came to regret her decision to move into a residential home, finding the other residents were generally much older, had greater memory complaints and rarely spoke in English.

Given the pervasive and generalised nature of Dilys' problems it would have been easy to speculate a strong 'functional' element in her symptoms. The genuine picture may have been considerably more complex involving a number of interrelated factors including her low self-esteem, poor assertiveness skills, cognitive dysfunction, medical conditions, bereavement and previous life experiences.

### *Follow-up*

Following the eight sessions Dilys remained in once-a-week therapy. There were no repeats of the self-injurious behaviour.

The focus of much later therapy was to assist Dilys in finding the motivation to increase her general level of activity and to socialise outside the residential home.

Dilys' difficulty in producing a verbal account of factors involved in her depression did not appear to have the amnesic quality of many of the other participants. Several views were considered: that it represented a functional, therapy maintaining technique: that it represented a 'therapy-interfering behaviour' (Linehan, 1993); or that it demonstrated the endogenous quality of Dilys' depression. To explore these possibilities Dilys continued in therapy.

## **Participant 6.**

Ifor, participant 6, lived with his wife in a small village. At the time of referral he was 72 years of age. Ifor had left school at 14 to begin work in a local mine, he served in the RAF during the war and worked as a lorry driver until his early retirement at the age of 43. Early retirement had been precipitated as the result of a chronic back problem. Ifor and his wife had five children.

### *Initial Assessment*

Approximately four months prior to the referral to this study Ifor had received a neuropsychological screening from his local clinical psychologist, following episodes of obsessional type behaviour. He had passed only three items on the MEAMS and had been referred on to older adult services with the suggestion that he might have a "multi-infarct type

of dementia". He was also seen by a neurologist who did not feel there was "any-thing organic in this man's case". On CT scan he was found to have slight cerebral atrophy with no other abnormality.

The 'older adult' psychiatrist receiving the referral performed a mini mental state examination which gave a score of 21 out of 30. The psychiatrist felt, however, that this might have been something of a under-estimate of Ifor's ability. He also noted that Ifor appeared somewhat angry, giving short and snappy answers. The conclusion of the psychiatrist was that Ifor had dementia with obsessional symptoms and that the dementia in his opinion might be of fronto-temporal type.

The initial reason for referral had been Ifor's development of a number of unusual habits. He had developed a habit of regularly checking that doors were locked and that the television and freezer were unplugged. This had become irritating for his wife, particularly when it took place during the early hours of the morning. She also described how Ifor could become "cross as hell for no reason".

On completing the Geriatric Depression Scale Ifor gave a score of 26 out of 30 representing a relatively severe level of depression. During the assessment sessions Ifor described experiencing a severe headache. An improvised scale to assess this was constructed during the session (including five point Likert scale responses, covering the range: no pain - so much pain it's unbearable, for the front, sides and back of the head and the neck). Ifor gave a score of 14 on this scale.

### *Therapy Sessions*

Engagement in the therapy process with Ifor proved to be extremely difficult. Ifor was reluctant to be seen at home for therapy sessions. To accommodate this he was seen at the day hospital where he was receiving a wider ranging psychiatric, neuropsychological and occupational therapy assessment. In sessions Ifor appeared easily distractible and extremely preoccupied with his headaches. His memory for recent events was extremely poor and he found it difficult to remember anything from previous sessions.

### *Process Issues*

The primary issue was to engage Ifor in therapy and to present an acceptable model of how psychological factors might be useful in reducing his depression and headaches.

Unfortunately the complexity of Ifor's presentation and his reluctance to be seen at home meant that neuropsychological investigations began to take precedence over therapy presenting an additional burden on the therapeutic relationship.

### *Outcome*

It emerged from Ifor's medical file that he had been experiencing chronic pain for over 45 years. In addition he had been treated by his GP with antidepressants on and off for over thirty years. No cause had been found for his chronic pain. On several occasions in the interim Ifor had refused to consider a psychiatric referral.

For some weeks work with Ifor had a unproductive feeling to it and a sensation that an essential piece of the jigsaw was missing. In case conferences it appeared that this feeling was shared by the rest of the team. This feeling remained until it emerged from a brief note in his medical notes that suggested Ifor had suffered from impotence. This was a problem that Ifor had never mentioned and had never been directly asked in therapy. When the subject was broached it became clear that Ifor had experienced considerable sexual dysfunction for a period of time similar to that of his chronic pain. At this point two therapy options presented themselves: to continue to focus on the 'here-and-now' issues of Ifor's current situation or to take a more developmental view and to attempt to understand the development of Ifor's chronic pain and sexual dysfunction from a psychological perspective. Both possible approaches were curtailed by Ifor's decision to cease attendance at the day hospital and continued reluctance to be seen at home.

### **Participant 7.**

The seventh client Norma lived with her second husband in a particularly rural area. She had three successful children, from her first marriage, who now had families themselves. All her children lived some distance from her home.

Norma had noticed a gradual decline in her memory which had begun to cause her distress. She had given up several of her household chores and was finding social events distressing. In addition she had ischaemic heart disease for which she was receiving treatment.

### *Initial Assessment*

The psychiatrist who saw her initially administered the mini mental state examination and she scored 23 out of 30. On neuropsychological assessment she passed 10 of the 12 items on the MEAMS and scored 10 out of 24 on the Rivermead Behavioural Memory Test. The summary of the psychologist was "[Norma] is suffering from cognitive impairment which particularly affects her memory. As you are aware, [Norma] has a great deal of insight into her memory loss and she is very distressed by it."



Her psychiatrist concluded that her dementia was possibly of a vascular nature rather than of Alzheimer's type. The picture was also complicated by Norma's rather large alcohol intake. She was advised by her psychiatrist that she should cut this down considerably.

Norma had remarried five years previously and it had been noted by several members of staff of her assessment unit that her husband was quite protective. She had found the assessment unit quite distressing in that she had been obliged to dine with individuals with dementia somewhat more severe than her own. Her husband had been angered by this and they had decided not to continue to attend the unit for further assessment.

### *Therapy Sessions*

The first step in therapy was to facilitate some engagement to the therapy process. On the first home visit both she and particularly her husband were ambivalent about her taking up therapy. It was therefore important to rapidly demonstrate the effectiveness of cognitive therapy intervention. Fortunately this proved relatively straight-forward as she had been experiencing considerable anxiety and confusion over her diagnosis and future experiences. When her diagnosis had been explained along with a few self-help skills she described feeling considerably better after the first session and requested that further sessions take place.

Within a few sessions it became clear that her husband's ambivalence may have been due to his own insecurity and anxieties. He found it difficult to leave his wife alone with a therapist for any length of time and would return to the room to "check how things were going on". This checking largely took the form of describing his own problems and feelings of depression, although he was able to muster considerable indignance at the suggestion that he might wish to discuss these matters independently.

### *Process Issues*

Specific issues that were targeted in therapy were:

1. To facilitate a rapid engagement to the therapy process.
2. To clarify anxieties regarding her diagnosis.
3. To demonstrate an ability to understand and empathise with some of her experiences.
4. To identify possible future difficulties and to collaboratively develop coping strategies.
5. To encourage Norma's abstinence from alcohol use.
6. To facilitate communication between Norma and her husband.
7. To additionally assist Norma's husband in dealing with his anger and frustration that so little should be done for his wife.

### *Outcome*

Therapy with Norma progressed relatively smoothly. She described feeling considerably better as she began to understand the nature of her cognitive impairment and how this might have been influenced by her alcohol intake.

Repeat assessment by her psychiatrist described a four point increase in her mini mental state examination score and a positive change in her mood state.

Progress with Norma's husband was less smooth. At the start of sessions he would frequently confront the therapist with statements such as: "She's been a naughty girl", which he would repeat several times without further explanation. He appeared to be finding it extremely difficult to come to terms with his wife's illness and behaviour being beyond his control. This frustration appeared to gradually diminish as information for carers on dementia, both written and verbal, was provided.

### **Participant 8.**

"I took her some flowers two days before she died. She put them in a vase but she didn't put any water in, even when my sister told her. She never loved me, even though I was the one who cared for her every day. The flowers just died."

(Martha)

Martha, the eighth participant, was the youngest: aged 57 at the start of therapy. She was the mother of five children and had twenty-one grandchildren. Martha had worked as a care assistant in a learning disability team although she had not worked for over ten years due to ill health. She lived at home with her husband.

### *Initial Assessment*

As her psychiatrist noted Martha had experienced an "unfair share of physical problems". She was an insulin dependent diabetic with problems with vision and hearing, she had angina and arthritis. Her first CVA had been approximately two years before this intervention and since then she had experienced numerous TIAs.

She described having difficulties with her memory and regularly experienced situations in which she did not know why she had arrived at certain places. She was also finding it difficult to maintain a dialogue with shop keepers.

Her psychiatrist completed the mini mental state examination with Martha and she scored 30 out of 30. However on more detailed neuropsychological testing several areas of

cognitive impairment were noted including psychomotor speed, verbal fluency, memory and verbal reasoning.

Her psychiatrist concluded that Martha was experiencing "symptoms suggestive of vascular dementia and it is progressive". When Martha completed the GDS she gave a score of 19 out of 30

Martha described having experienced a difficult childhood with considerable physical and emotional abuse.

### *Therapy Sessions*

As the above quote illustrates the relationship between Martha and her mother appears to have been extremely poor. From Martha's accounts it appears that her mother may have experienced several mental health difficulties including depressive and obsessional-compulsive type symptoms. Prior to Martha's birth her mother had a son. Unfortunately he had died 11 months after birth and her mother had been advised by her doctor to have another child as quickly as she could. When the child, Martha, was born she was a girl and quite different in appearance. Martha's childhood seems to have been extremely strict and punitive. From a relatively early age she spent weekends and holidays in the local "work-house".

Martha also disclosed two experiences of sexual abuse. The first, at the age of eleven, was perpetrated by a local man known to the family and appears to have been with her mother's knowledge and consent. The second, a few years after, was a sexual assault perpetrated by a man still occasionally seen by Martha. That her mother knew of this abuse and yet still denied that it occurred was particularly distressing for Martha, as was the fact that her mother was a generally respected church-going lady.

As a young woman Martha appears to have been particularly vulnerable to bullying and had several unpleasant experiences with her peers.

Despite these experiences Martha appears to have been a good mother herself and was still providing regular support and advice for her children and grandchildren. However, following her first CVA she had begun to lose confidence and had gradually found it more difficult to cope with her traumatic experiences.

### *Process Issues*

Process issues identified were:

1. To allow Martha to control the rate and nature of disclosure of her experiences.
2. To provide a 'safe' therapy relationship for Martha to describe and explore her emotional reactions to traumatic life experiences.
3. To collaboratively examine the positive achievements of her life.
4. To present a cognitive model of her anxiety and depression experiences and to examine the potential for cognitive changes.

5. To describe a model of the influence of her CVA on her cognitive abilities.

#### *Outcome*

Martha was able to disclose the full extent of her physical and sexual abuse for the first time. The true depth and severity of her mother's own psychopathology began to be revealed. Martha's considerable achievement in breaking the 'chain of psychopathology' from one generation to the next became starkly clear as comparisons between her relationship with her mother and those of her children with herself emerged.

Following the presentation of a cognitive anxiety management model she was able to use these skills whilst outside her own home. She additionally described a greater level of assertiveness in a number of settings.

She declined to make a statement to the police about her abuse but was grateful that this had finally been taken seriously after over forty years.

#### *Summary of Specific Cognitive Techniques*

A summary of the specific therapy techniques used with individual participants is described in Table 6.

Table 6.

Case	Participant	Cognitive Therapy Techniques
1	John	Collaborative identification and testing of John's belief that he had received abusive treatment which had resulted in his cognitive impairment. Followed by examination of alternative interpretations of his experiences.
2	Eric	Identification and modification of Eric's negative automatic thoughts relating to his view of cognitive impairment and subsequent relationship developments.
3	June	Collaborative examination of June's catastrophic world view following self-awareness of dementia. Identification and modification of June's arbitrary inferences and overgeneral responses to life with dementia.
4	Dafydd	Collaborative examination of Dafydd's belief system that implied that people with dementia were: a) obliged to enter a nursing home and b) violently behaved. To understand and modify the selective abstractions leading to these views.
5	Dilys	Presentation of a cognitive account of health anxiety symptoms following the apparent failure to identify Dilys' core cognitive schema relating to her health and depression.
6	Ifor	Required additional assessment and therapeutic engagement to proceed with a cognitive therapy approach.

7	Norma	Presentation of a cognitive account of Norma's dementia experience, explanation of her diagnosis and examination of her own belief systems regarding dementia.
8	Martha	Collaborative examination of Martha's life achievements and to contrast these with her long-standing personalised negative automatic thinking.

Most of the techniques described in Table 6 will be recognised as standard to a mainstream cognitive therapy approach. An issue not considered in the majority of cognitive therapy texts is consideration of the rate at which the schema responsible for depressive thinking can be modified in individuals with cognitive impairments. The working assumption of this study was that the rate of schema modification would probably be slower and that such modification might require more effort on the part of the therapist. In an attempt to facilitate this process of schema modification the therapist made efforts to: discuss key issues repeatedly, broaden the context of discussion for the participant and regularly summarise therapy developments.

Several authors have stressed the importance of 'homework' in cognitive therapy (Beck, 1979; Startup & Edmonds, 1994). A notable failure of this study was the development of a means of assisting the completion of homework tasks, given the nature of their memory impairments. With relatively few exceptions therapy did not include anything more than the most straightforward of homework tasks.

## Discussion

Though statistically significant the changes in depression scores at outcome were still relatively modest (approximately equal to one standard deviation of the scores). It is acknowledged that the improvements demonstrated following cognitive therapy may have represented a 'placebo effect', non-specific therapy effects, or simply the normal resolution of depression that would have occurred with or without cognitive therapy. However, the cognitive shifts made by some of the participants and their descriptions and attributions of changes in their lives over the therapy period suggested that cognitive therapy did have some value.

This value was difficult to empirically evaluate. The therapy experience in working with these participants was the feeling that they were slightly better able to accept their situation. They seemed to be less confused and had

better insight into their condition following therapy. But in terms of questions such as "Do you think it is wonderful to be alive now?", "Do you feel pretty worthless the way you are now?" and "Do you think most people are better off than you are?" (items 15, 17 and 23 of the GDS) their responses remained unchanged.

Whilst the improvements in GDS scoring were modest this should also be viewed within the inclusive nature of the study. Several participants had long-standing depressive problems and two had depressive symptoms that had been non-responsive to a number of pharmacotherapy interventions. By the very nature of the study all participants were likely to have been experiencing ongoing cognitive decline at some rate.

One of the marks of civilisation of a society is how it treats its most vulnerable and powerless members (Gandhi, attrib.). People with dementia are without doubt vulnerable and the legal process is such that it engenders their powerlessness by taking away their rights and freedom of choice. This is most often for benign reasons but the fact that the reasons are benign does not make it any less depressing.

#### *Discussing the Diagnosis with the Participant*

In a questionnaire study of the practice of consultants in old age psychiatry Rice and Warner (1994) found that, unlike carers, patients with dementia were rarely told their diagnosis.

"In 1961, 90% of doctors expressed a preference for not telling cancer patients their diagnosis. By 1977 a complete reversal of opinion had occurred, with 97% of doctors favouring disclosure of the diagnosis. The reason for not telling cancer patients their diagnosis in 1961 were similar to those now given for not telling patients with Alzheimer's disease their diagnosis."

(Maguire, Kirby, Coen et al., 1996, p. 530).

Rice and Warner (1994) argued that people with dementia do have a right to know their diagnosis and where doubts over the person's level of understanding exist the exchange of information should be 'patient led' with support provided through the process.

Within this study all of the participants were made aware of their diagnosis where they responded or requested that they would want to know it. Anecdotally it appeared that the genuine prognosis was no more

unpleasant than the experiences that they had imagined they were going to encounter.

### *Common Themes Arising in Therapy*

The following does not represent an empirical or qualitative analysis of the features of depression in people with dementia but simply describes the impressions from working with a group of individuals with those conditions.

1. An individual with dementia may have a fixed conception of the cause of their cognitive impairments. This may be a harmless feature of the persons individual belief system. Occasionally, however, it may be dysfunctional in that it leads the person to feel blame, anger and frustration that proves difficult to resolve. The aim of therapy in this situation is to collaboratively examine this view seeking if possible to find a more functional view. This conception may be a shared view or one which fits most readily into the individual's construct system.
2. A loss of control leading to a state of hopelessness. The views and opinions of a person with dementia are not generally held in high regard. This may be reinforced by the conduct of health professionals which often takes the form of talking and listening to carers before the person themselves. Beyond simply listening and talking to the individual, the therapist can facilitate a clearer statement of the views and wishes of that individual and to assist in communicating these views to both professional and non-professional carers.
3. A feeling of insecurity. The person may be aware of or even hold the belief that the place for a person with dementia is a group home. This can lead to a situation in which the individual struggles to deny their cognitive impairment or conversely gives up and resigns themselves to the inevitable removal to what may essentially be perceived as a prison.
4. Memory for traumatic events may be well preserved whilst the coping strategies can appear to have become dislocated. Several notable authors have written about the concept of 'repression' as a partially functional coping process. Whilst a detailed analysis is not appropriate at this point it would not seem implausible to suggest that the cognitive processes that underlie 'repression' type coping schema are likely to be more cognitively demanding

than the storage of the repressed event; leading to a 'time-bomb' triggered by the process of dementia.

Therapeutically the individual may benefit from the opportunity to 'reframe' the experiences with the assistance of a skilled therapist. This is most strikingly illustrated by a survivor of childhood sexual abuse. Therapy provides an opportunity to challenge the inappropriate guilt and self-blame that can arise from these experiences.

5. The therapist must be flexible, patient and tolerant. Handouts, diaries and homework tasks may all be forgotten or lost. Interpretations of this type of behaviour must be made cautiously as it is not unusual for a dementing individual to place a precious document in an especially safe location which is rapidly forgotten. Anecdotal accounts of carers finding documents or money in shoes, on top of wardrobes or in more obscure positions are common.

In relation to the previous point the relationships between the participants' cognitions may not be so clear and explicit as is typically presented in models of cognitive therapy. The relationship may gradually become clearer with time and patience.

6. The trigger for depression may be very simple and relate to loss of mobility or daily living skills. Successful liaison with other professionals such as physiotherapists, occupational therapists and social workers may be particularly important.

7. Western culture is becoming increasingly dependent upon the motor-car. The frustration a person can experience following the loss of the ability to drive or even more so the enforced removal of a driving licence is difficult to underestimate. This can be particularly acute when the individual has poor insight into their own driving abilities. Therapeutically it might be beneficial if the person with dementia can be made aware of this possibility as early as possible so that planning and preparations can be made.

8. Many people with dementia find it difficult to maintain a complex medication regimen. With erratic use they may develop nausea or confusional states. Although not specifically an issue for the cognitive therapist they are well placed to identify such difficulties. Where this occurs liaison with nursing and medical staff can bring about a rapid change.



The results of this study appear to indicate that modest improvements in mood are possible for this participant group. It is obviously too early to state whether these improvements are causally related to their participation in a cognitive therapy intervention. However it would appear that further research in this area might well be justified.

### *Critical Evaluation*

The methodology employed raised a number of issues:

1. Reliance upon self-rating scales. The GDS was the primary outcome measure for this study. Although it has received some validation in its use with older adults with dementia it was not designed specifically for this application.

Additionally the implications of the use of self-rating scales with a cognitively impaired individual must be considered. Ideally self-rating should be corroborated by observational and interview based ratings.

2. Therapist administered rating scales. With relatively little exception all rating scales were administered by the therapist. This is of course open to experimenter induced bias either deliberately or unconsciously. The participants may also have felt obliged to demonstrate improvements that had simply not occurred.

3. Small sample size. Although larger than any previously published therapy descriptions of this kind (see Cheston, 1998, for a review) this study had a relatively small sample size.

4. No control group. The study had no control group. The extent to which depression may have resolved without a therapy intervention remains unknown.

5. Insufficient base-line data. The time scale of the study prevented the development of extensive baseline periods for the evaluation of the stability of each participants depressive symptomatology.

6. Insufficient diagnostic information. Accurate diagnosis of dementia is difficult and the classification systems themselves may need considerable review. Standardised neuropsychological and scanning procedures would

however have added considerable information. Post-mortem analysis would again have been of additional academic interest.

7. Insufficient knowledge of test-retest reliability data. Test-retest reliability data have not been published for the GDS with depressed dementing individuals. There is little reason why, given sufficient time, a study should not access test-retest reliability both before and after a therapy intervention. This would allow the application of the more statistically sophisticated Hagman and Arrindell (1993) Reliable Change Index formula.

When combined with the use of an appropriate control group or groups the proportion of participants showing a reliable, clinically significant, change can be calculated.

8. Minimal inclusion criteria. The inclusion criteria for this study were minimal beyond a diagnosis of dementia and depression. More tightly defined studies could reveal important differences in therapy response rates. Such inclusion criteria could include: first onset depression, different levels of cognitive impairment, additional health difficulties, age, rate of dementia progression and possibly dementia type specific studies.

9. Insufficient follow-up data. Again the time constraints of the study prevented collection of extensive follow-up data. It is clearly important to understand the post intervention experiences of therapy participants. Possibly more so with this grouping than others because of the progressive nature of their condition.

All of the above issues are clearly important issues to be addressed. However a similarly important feature of any therapy evaluation is to consider the potential for its day to day application by individual therapists. A crucial feature of cognitive therapy is the evaluation of its effectiveness. Within this study the evaluations were little more than would be normally expected of any therapist. The difficulty in gathering greater information was a feature in these interventions and should ideally be addressed by further research.

#### *Future Research*

It has been argued that a full-scale therapy trial should be evaluated with this participant group. However, it may be premature to attempt such a trial without considerable preparation.

Qualitative evaluation of dementia experience. One of the most useful studies in this series of interventions was considered to be the Keady and Gilliard (1997) investigation of the early experiences of dementia. The personal process of dementia is difficult to fully appreciate. The development of a strong therapy relationship can be assisted by accurate empathy (Beck et al., 1979) which could be greatly facilitated by a better understanding of the subjective and private experiences of individuals with dementia. Qualitative research techniques may be one of the better approaches to developing this understanding.

Establishing valid and reliable measurement techniques As noted above the establishment of valid and reliable instruments for this participant group is as yet at an early stage. Future approaches might include the development of dementia specific depression measures or the validation of existing measures with individuals with dementia.

The practice of establishing the reliability of measurement scales with each group of participants might become common practice. The wide variation in estimates of the rate of comorbid dementia and depression illustrate the diversity of different sample groups which make it unwise to presume the psychometric features of any assessment scale.

Development of a standardised cognitive therapy treatment manual. Therapy adherence is an important issue in the examination of the level of effectiveness of a defined treatment. Assessment techniques of treatment fidelity have been developed (e.g., Startup & Shapiro, 1993) and should be applied in any treatment effectiveness trials. These techniques require the use of either audio or video tape recordings of therapy sessions for later review.

Standardisation of treatment techniques would be assisted by the development of an appropriate treatment manual and regular supervision sessions.

A series of single case design intervention studies. Although these would be of considerable interest for a number of reasons they might be particularly useful in providing an indication of the ideal number of sessions necessary to maximise therapeutic change. It has been demonstrated that there is little empirically measurable benefit from sixteen cognitive therapy sessions as opposed to eight sessions with depressed, non-cognitively impaired adults

(Shapiro, Rees, Barkham et al., 1995). The potential benefits of a greater number of sessions for individuals with dementia remains unknown.

If applied over a longer time period this approach might also be useful in examining relapse rates following therapy. Although relapse rates following cognitive therapy appear to be lower than those observed following pharmacotherapy (Evans, Hollon, DeRubeis et al., 1992; Simons, Murphy, Levine & Wetzel, 1986), rates of relapse have been seen to be higher when relatively high levels of depression exist following a therapy intervention (Simons et al., 1992). Thus the levels of depression observed following these interventions might indicate a high potential for relapse, particularly with the burden of additional cognitive decline and its related sequelae. The evaluation of modes of maintenance therapy might therefore be an additional issue for study.

Development of information packages. There is a considerable literature on dementia. Relatively little of it is aimed at those it most concerns: people with dementia. Accounts of the difficulty of remembering the content of a consultation session where one is told of serious or terminal illness are common. For an individual with dementia this effect may be additionally confounded by cognitive deficits. Where appropriate it may be useful for an individual to have available information relating to their diagnosis of dementia. Such information could be provided by a variety of means including: written, audio or video media.

Development of mnemonic aids and strategies to raise opportunity levels for homework compliance. Mnemonic aids and strategies have been developed for people with memory difficulties this has yet to be integrated into a cognitive therapy package for use with individuals with cognitive impairments.

Cheston (1998), after an extensive review of therapeutic work with people with dementia, concludes that future studies should adopt case study or single-subject design approaches for evaluating new clinical developments in preference to group designs. The emphasis within this study has been a detailed case study approach. However as previously argued, group based designs do have considerable value in examining the effect size and longer term outcome of therapy approaches.

Given the significant findings of this study, with such a small sample size, the numbers needed to demonstrate a significant change from baseline would be relatively small e.g. 20 - 25 participants in the experimental group. This calculation is based upon the assumption of a moderate to large effect size as demonstrated by this study, significance level of 0.05 and a level of power of 0.8. This level of power is often accepted as a reasonable level to aim for to reduce Type II errors (Clark-Carter, 1997a).

It is more difficult to calculate the number of participants needed to ensure a similar level of power for differences between the control and experimental groups (Howell, 1997), particularly as the short-term stability of depression level is unknown in people with dementia. The observed difference between initial and outcome measures in this study was approximately equal to one standard deviation of the samples (initial mean = 19.28 (SD = 5.09), outcome mean = 13.429 (SD = 4.65),  $n = 7$ ). Assuming that half of this difference was due to non-therapy related changes, the difference between a wait-list control and the experimental group would be approximately half a standard deviation. The power of a trial with 20 participants in each group would be around the .32 ( $d = 1.58$ , significance = 0.05). If this were the case the probability of demonstrating a significant difference would be below chance level. To raise the power of the trial to 0.8 the number of participants in each group would need to be raised to around sixty in each group. This would represent a relatively large number of participants, although this estimate is based upon extremely conservative estimations of effect size and a level of power that is rarely observed in psychological studies (Clark-Carter, 1997b).

The consideration of the most appropriate control or control groups is an important issue for a potential therapy trial. Many of the participants were relatively socially isolated; the effect observed in this study may have simply been a reflection of an increase in social contact. To eliminate this effect a therapy trial would have to increase social contact and interaction of the control group by a similar amount as the therapy group. Potential control groups might therefore include: no treatment for depression, treatment as normal, specific antidepressant treatment, increased social contact, alternative psychotherapy approaches or a combination of these.

## Summary

Dementia is not always a benign process in which depressive schema conveniently resolve with cognitive decline. It can be a cruel process in which an individuals coping mechanisms deteriorate long before their self-awareness and memories of traumatic experiences. For some people dementia can be a time of depression. This study has attempted to provide an account of some of the factors involved in the psychological treatment of depression in individuals with dementia. Further research would appear to be justified.

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## Appendix 1.

# Competency Checklist for Cognitive Therapists

Therapist: \_\_\_\_\_

Patient: \_\_\_\_\_

Date of Session: \_\_\_\_\_ Session Number: \_\_\_\_\_

Rater: \_\_\_\_\_

## PART 1. GENERAL INTERVIEW PROCEDURES

### 1. Collaboration and Mutual Understanding

- \_\_\_\_\_ (a). Therapist worked with patient even when using primarily educative role.
- \_\_\_\_\_ (b). Therapist asked for feedback.
- \_\_\_\_\_ (c). Patient gave feedback.
- \_\_\_\_\_ (d). Therapist asked for suggestions and/or offered choices.
- \_\_\_\_\_ (e). Patient offered suggestions and/or made choices.
- \_\_\_\_\_ (f). Therapist responded to patient's feedback and/or suggestions; did not ignore or negate them.
- \_\_\_\_\_ (g). Therapist checked periodically for his understanding of key points made by patient (e.g., gave brief summaries of patient's verbalizations – "What I hear you say is ..." to ascertain whether he is tuned into patient).
- \_\_\_\_\_ (h). Therapist periodically summarized his key points to determine whether patient was tuned into him.

### 2. Established Agenda (not applicable for first session)

- \_\_\_\_\_ (a). Therapist and patient established agenda for session.
- \_\_\_\_\_ (b). Agenda items were specific and problem-oriented, rather than vague or general topic areas.
- \_\_\_\_\_ (c). Priorities for agenda items were established.
- \_\_\_\_\_ (d). Agenda was appropriate for time allotment (neither too ambitious nor too limited).
- \_\_\_\_\_ (e). At some point, patient discussed events during the week since the last session.

### 3. Elicited Reactions to Interview and Therapist

- \_\_\_\_\_ (a). Elicited patient's feelings and reactions to present interview.
- \_\_\_\_\_ (b). Elicited feedback regarding previous interview.

4. Structured Therapy Time Efficiently

- \_\_\_\_\_ (a). Therapist covered most items on agenda and rescheduled unfinished business.
- \_\_\_\_\_ (b). Therapist was flexible enough to include important issues that arose during session but were not on the agenda.
- \_\_\_\_\_ (c). Therapist limited time spent on peripheral or tangential topics.
- \_\_\_\_\_ (d). Therapist limited unproductive discussion on relevant topics.

5. Focused on Appropriate Problem

- \_\_\_\_\_ (a). Therapist identified specific problem(s) to focus on.
- \_\_\_\_\_ (b). Identified problems were central, rather than peripheral, to patient's distress.
- \_\_\_\_\_ (c). Identified problems were appropriate for treatment at this time.
- \_\_\_\_\_ (d). Identified problems were the key ones to focus on; the major problem was not overlooked.
- \_\_\_\_\_ (e). Therapist concentrated on one or two problems instead of skipping around.

6. Questioning

- \_\_\_\_\_ (a). Therapist skilfully blended questions to elicit data regarding symptoms, life situation, current experiences, thoughts, feelings, and past experiences (when applicable).
- \_\_\_\_\_ (b). Used open-ended questions appropriately.
- \_\_\_\_\_ (c). Minimal use of questions requiring yes or no responses.
- \_\_\_\_\_ (d). Avoided rapid-fire questioning.
- \_\_\_\_\_ (e). Interspersed questions with reflective statements, illustrative examples, or capsule summaries.
- \_\_\_\_\_ (f). Used questions to show incongruities or inconsistencies in patient's conclusions without demeaning patient.
- \_\_\_\_\_ (g). Used questions to help patient explore the various facets of a problem.
- \_\_\_\_\_ (h). Used questions to examine patient's arbitrary conclusions or assumptions.
- \_\_\_\_\_ (i). Used questions to elicit alternative ways of solving a problem.
- \_\_\_\_\_ (j). Used questions to consider alternative explanations.
- \_\_\_\_\_ (k). Used questions to predict positive and negative consequences of a proposed action (e.g., doing homework assignments, resigning from a job, or having a personal confrontation).

7. Provided Periodic Summaries during Interview

- \_\_\_\_\_ (a). Therapist periodically recapitulated or reformulated problem being worked on in session.
- \_\_\_\_\_ (b). Therapist explained rationale for specific techniques to be utilized in dealing with problems.
- \_\_\_\_\_ (c). Therapist summarized progress made on identified problems during the session (problem closure).

8. Assigned Homework

- \_\_\_\_\_ (a). Therapist carefully reviewed previous week's homework.
- \_\_\_\_\_ (b). Therapist summarized conclusions derived, or progress made, from previous homework.
- \_\_\_\_\_ (c). Therapist assigned new homework.
- \_\_\_\_\_ (d). Homework assignment was appropriate for identified problems.
- \_\_\_\_\_ (e). Therapist explained rationale for homework assignment.
- \_\_\_\_\_ (f). Homework was specific and details were clearly explained.
- \_\_\_\_\_ (g). Therapist asked patient if he/she anticipated problems in carrying out homework.

## PART 2. SPECIFIC COGNITIVE AND BEHAVIOURAL TECHNIQUES

### 9. Appropriateness and Application of Techniques

- \_\_\_\_\_ (a). Techniques were generally appropriate for identified problems.
- \_\_\_\_\_ (b). Techniques were the most appropriate for identified problems (e.g., preferable techniques were not overlooked).
- \_\_\_\_\_ (c). Therapist executed techniques successfully.

Comments explaining inappropriate or incorrect application of techniques:

### 10. Elicited Automatic Thoughts

- \_\_\_\_\_ (a). Specific automatic thoughts were identified.
- \_\_\_\_\_ (b). Therapist helped patient identify thoughts rather than repeatedly pointing out automatic thoughts to patient in a didactic fashion.
- \_\_\_\_\_ (c). Therapist used appropriate techniques to elicit automatic thoughts (check techniques used):
  - \_\_\_\_\_ Inductive questioning      \_\_\_\_\_ Mood shifts during session
  - \_\_\_\_\_ Imagery      \_\_\_\_\_ Dysfunctional thought record
  - \_\_\_\_\_ Role-playing
- \_\_\_\_\_ (d). Therapist helped patient recognize connection between affect and specific cognitions.

### 11. Tested Automatic Thoughts

- \_\_\_\_\_ (a). Tested or questioned automatic thoughts in systematic manner.
- \_\_\_\_\_ (b). Did not use exhortation or argument to "talk patient out of automatic thoughts."
- \_\_\_\_\_ (c). Helped patient set up specific, testable hypotheses.
- \_\_\_\_\_ (d). Helped patient collect valid evidence systematically concerning hypotheses.
- \_\_\_\_\_ (e). Helped patient evaluate evidence and draw conclusions from evidence.

12. Identified and Tested Underlying Assumptions

- \_\_\_\_\_ (a). Specific underlying ("silent") assumptions were identified.
- \_\_\_\_\_ (b). Therapist helped patient discover relevant assumptions from a joint analysis of automatic thoughts.
- \_\_\_\_\_ (c). Therapist did not rely solely on didactic counterarguments to evaluate assumptions.
- \_\_\_\_\_ (d). Therapist helped patient analyze validity of assumptions (e.g., by inductive questioning or by listing advantages and disadvantages).

13. Other Basic Cognitive and Behavioural Techniques

- \_\_\_\_\_ (a). Techniques used:
  - \_\_\_\_\_ reattribution
  - \_\_\_\_\_ alternative technique
  - \_\_\_\_\_ ascertaining meaning
  - \_\_\_\_\_ cognitive rehearsal
  - \_\_\_\_\_ activity scheduling
  - \_\_\_\_\_ graded task assignments
  - \_\_\_\_\_ role-playing
  - \_\_\_\_\_ diversion procedures
  - \_\_\_\_\_ assertiveness training
  - \_\_\_\_\_ focusing & concentration
  - \_\_\_\_\_ mastery & pleasure rating
- \_\_\_\_\_ (b). Specific instruments, materials and devices:
  - \_\_\_\_\_ Record of dysfunctional thoughts
  - \_\_\_\_\_ Dysfunctional Attitude Scale
  - \_\_\_\_\_ Depression Inventory
  - \_\_\_\_\_ Reading assignment
  - \_\_\_\_\_ Diary
  - \_\_\_\_\_ Videotape of session for patient
  - \_\_\_\_\_ Audiotape of session for patient



### PART 3. PERSONAL AND PROFESSIONAL CHARACTERISTICS

#### 14. Genuineness

- \_\_\_\_\_ (a). Therapist seemed to be saying what he sincerely felt or meant. Seemed honest and "real."
- \_\_\_\_\_ (b). Therapist seemed open rather than defensive.
- \_\_\_\_\_ (c). Therapist did not seem to be holding back impressions or information, or evading patient's questions.
- \_\_\_\_\_ (d). Therapist did not seem patronizing or condescending.
- \_\_\_\_\_ (e). Therapist did not seem to be playing the role of therapist. Did not sound contrived or rehearsed.

#### 15. Warmth

- \_\_\_\_\_ (a). Therapist's tone of voice and non-verbal behaviour conveyed warmth and interest.
- \_\_\_\_\_ (b). The content of what the therapist said communicated concern and caring.
- \_\_\_\_\_ (c). The therapist did not criticize, disapprove, or ridicule the patient's behaviour.
- \_\_\_\_\_ (d). The therapist did not seem cold, distant, or indifferent.
- \_\_\_\_\_ (e). The therapist did not seem effusive, possessive, or overinvolved.
- \_\_\_\_\_ (f). The therapist responded to or displayed humor when appropriate.

#### 16. Accurate Empathy

- \_\_\_\_\_ (a). The therapist accurately summarized what the patient explicitly said.
- \_\_\_\_\_ (b). The therapist accurately summarized the patient's most obvious emotions (e.g., sadness, anger).
- \_\_\_\_\_ (c). The therapist accurately summarized more subtle nuances of feeling or implicit belief.
- \_\_\_\_\_ (d). The therapist communicated through his verbal and non-verbal behaviour that he/she understood the patient's feelings and was responding to them.

#### 17. Professional Manner

- \_\_\_\_\_ (a). Therapist's tone of voice and non-verbal behaviour conveyed confidence.
- \_\_\_\_\_ (b). Therapist made clear statements without frequent hesitations or rephrasings.
- \_\_\_\_\_ (c). Therapist was in control of the session; he/she was able to shift appropriately between listening and leading.
- \_\_\_\_\_ (d). Therapist seemed relaxed and did not seem to be anxious or "trying too hard."

18. Rapport

- \_\_\_\_\_ (a). Patient and therapist seemed comfortable with each other.
- \_\_\_\_\_ (b). Eye contact maintained.
- \_\_\_\_\_ (c). Good affective interaction (e.g., when one smiles, the other smiles).
- \_\_\_\_\_ (d). Flow of verbal interchanges was smooth.
- \_\_\_\_\_ (e). Neither patient nor therapist appeared overly defensive, cautious, or restrained.

Developed by Jeffrey Young, Karen El Shammaa & Aaron T. Beck (1979) In: Beck, Rush, Shaw & Emery. *Cognitive Therapy of Depression*.

## **Appendix 2.**

### **ICD-10 Classification of Dementia**

Dementia (F00-F03) is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

## Appendix 3.

### ICD-10 Classification of Depression

#### **F32 Depressive episode**

In typical mild, moderate, or severe depressive episodes, the patient suffers from lowering of mood, reduction of energy, and decrease in activity. Capacity for enjoyment, interest, and concentration is reduced, and marked tiredness after even minimum effort is common. Sleep is usually disturbed and appetite diminished. Self-esteem and self-confidence are almost always reduced and, even in the mild form, some ideas of guilt or worthlessness are often present. The lowered mood varies little from day to day, is unresponsive to circumstances and may be accompanied by so-called "somatic" symptoms, such as loss of interest and pleasurable feelings, waking in the morning several hours before the usual time, depression worst in the morning, marked psychomotor retardation, agitation, loss of appetite, weight loss, and loss of libido. Depending upon the number and severity of the symptoms, a depressive episode may be specified as mild, moderate or severe.

Includes: single episodes of:

- depressive reaction
- psychogenic depression
- reactive depression

Excludes:     adjustment disorder  
                 recurrent depressive disorder  
                 when associated with conduct disorder

### **F33 Recurrent depressive disorder**

A disorder characterized by repeated episodes of depression as described for depressive episode (F32), without any history of independent episodes or mood elevation and increased energy (mania). There may, however, be brief episodes of mild mood elevation and overactivity (hypomania) immediately after a depressive episode, sometimes precipitated by antidepressant treatment.

Includes: recurrent episodes of:

- depressive reaction
  - psychogenic depression
  - reactive depression
- seasonal depressive disorder

Excludes: recurrent brief depressive episodes

# GDS

Please answer 'yes' or 'no' to each question. Circle the answer that best describes you at the moment.

1. Are you basically satisfied with your life?\_\_\_\_\_Yes / No
2. Have you dropped many of your activities and interests?\_\_\_\_Yes / No
3. Do you feel that your life is empty?\_\_\_\_\_Yes / No
4. Do you often get bored?\_\_\_\_\_Yes / No
5. Are you hopeful about the future?\_\_\_\_\_Yes / No
6. Are you bothered by thoughts that you just cannot get out of your head?\_\_\_\_\_Yes / No
7. Are you in good spirits most of the time?\_\_\_\_\_Yes / No
8. Are you afraid that something bad is going to happen to you?\_\_\_\_\_Yes / No
9. Do you feel happy most of the time?\_\_\_\_\_Yes / No
10. Do you often feel helpless?\_\_\_\_\_Yes / No
11. Do you often get restless and fidgety?\_\_\_\_\_Yes / No
12. Do you prefer to stay at home at night, rather than go out and do new things?\_\_\_\_\_Yes / No
13. Do you frequently worry about your future?\_\_\_\_\_Yes / No
14. Do you feel that you have more problems with memory than most?\_\_\_\_\_Yes / No
15. Do you think it is wonderful to be alive now?\_\_\_\_\_Yes / No
16. Do you often feel downhearted and blue?\_\_\_\_\_Yes / No
17. Do you feel pretty worthless the way you are now?\_\_\_\_\_Yes / No
18. Do you worry a lot about the past?\_\_\_\_\_Yes / No
19. Do you find life exciting?\_\_\_\_\_Yes / No
20. Is it hard for you to get started on new projects?\_\_\_\_\_Yes / No
21. Do you feel full of energy?\_\_\_\_\_Yes / No
22. Do you feel that your situation is hopeless?\_\_\_\_\_Yes / No
23. Do you think most people are better off than you are?\_\_\_\_\_Yes / No
24. Do you frequently get upset over things?\_\_\_\_\_Yes / No
25. Do you frequently feel like crying?\_\_\_\_\_Yes / No
26. Do you have trouble concentrating?\_\_\_\_\_Yes / No
27. Do you enjoy getting up in the morning?\_\_\_\_\_Yes / No
28. Do you prefer to avoid social gatherings?\_\_\_\_\_Yes / No
29. Is it easy for you to make decisions?\_\_\_\_\_Yes / No
30. Is your mind as clear as it used to be?\_\_\_\_\_Yes / No

# GDS - Scoring

Scoring. Depressive answers are shown. Count 1 point for each.

0-10: normal, 11-20: mild depression, >21 moderate to severe depression.

1. Are you basically satisfied with your life?\_\_\_\_\_No
2. Have you dropped many of your activities and interests?\_\_\_\_Yes
3. Do you feel that your life is empty?\_\_\_\_\_Yes
4. Do you often get bored?\_\_\_\_\_Yes
5. Are you hopeful about the future?\_\_\_\_\_No
6. Are you bothered by thoughts that you just cannot get out of your head?\_\_\_\_\_Yes
7. Are you in good spirits most of the time?\_\_\_\_\_No
8. Are you afraid that something bad is going to happen to you?\_\_\_\_\_Yes
9. Do you feel happy most of the time?\_\_\_\_\_No
10. Do you often feel helpless?\_\_\_\_\_Yes
11. Do you often get restless and fidgety?\_\_\_\_\_Yes
12. Do you prefer to stay at home at night, rather than go out and do new things?\_\_\_\_\_Yes
13. Do you frequently worry about your future?\_\_\_\_\_Yes
14. Do you feel that you have more problems with memory than most?\_\_\_\_\_Yes
15. Do you think it is wonderful to be alive now?\_\_\_\_\_No
16. Do you often feel downhearted and blue?\_\_\_\_\_Yes
17. Do you feel pretty worthless the way you are now?\_\_\_\_\_Yes
18. Do you worry a lot about the past?\_\_\_\_\_Yes
19. Do you find life exciting?\_\_\_\_\_No
20. Is it hard for you to get started on new projects?\_\_\_\_\_Yes
21. Do you feel full of energy?\_\_\_\_\_No
22. Do you feel that your situation is hopeless?\_\_\_\_\_Yes
23. Do you think most people are better off than you are?\_\_\_\_\_Yes
24. Do you frequently get upset over things?\_\_\_\_\_Yes
25. Do you frequently feel like crying?\_\_\_\_\_Yes
26. Do you have trouble concentrating?\_\_\_\_\_Yes
27. Do you enjoy getting up in the morning?\_\_\_\_\_No
28. Do you prefer to avoid social gatherings?\_\_\_\_\_Yes
29. Is it easy for you to make decisions?\_\_\_\_\_No
30. Is your mind as clear as it used to be?\_\_\_\_\_No

# GDS

## Short Form

Please answer 'yes' or 'no' to each question. Circle the answer that best describes you at the moment.

1. Are you basically satisfied with your life?\_\_\_\_\_Yes / No
2. Have you dropped many of your activities and interests?\_\_\_\_Yes / No
3. Do you feel that your life is empty?\_\_\_\_\_Yes / No
4. Do you often get bored?\_\_\_\_\_Yes / No
5. Are you in good spirits most of the time?\_\_\_\_\_Yes / No
6. Are you afraid that something bad is going to happen to  
you?\_\_\_\_\_Yes / No
7. Do you feel happy most of the time?\_\_\_\_\_Yes / No
8. Do you often feel helpless?\_\_\_\_\_Yes / No
9. Do you prefer to stay at home at night, rather than go out  
and do new things?\_\_\_\_\_Yes / No
10. Do you feel that you have more problems with memory  
than most?\_\_\_\_\_Yes / No
11. Do you think it is wonderful to be alive now?\_\_\_\_\_Yes / No
12. Do you feel pretty worthless the way you are now?\_\_\_\_\_Yes / No
13. Do you feel full of energy?\_\_\_\_\_Yes / No
14. Do you feel that your situation is hopeless?\_\_\_\_\_Yes / No
15. Do you think most people are better off than you are?\_\_\_\_\_Yes / No



# Acknowledgements

Thank you to all of the participants for taking part in this study during a difficult time of life.

Thanks to Melanie, Llywi and Mo for so much patience.

Huge thanks to Bob for supervising this piece of work and reading drafts and nauseam.

Thanks also to Marilla, Sue, Mel and Thelma for tolerating my interference.

Thanks to Clare, Karen, Jan, Diane, Margaret, Sian, Kay and everyone on the ward and in the day hospital.

Thanks to Deva and Al for an open mind to a different approach.

Thanks to Mary, Narinder, Miki, Paul, Neil, Judy and Ed for supervision in the past.

Thanks also to Sandy, Steve, Steve and Steve.

**NORTH WALES HEALTH AUTHORITY  
RESEARCH ETHICS COMMITTEE (WEST)**

**PWYLLGOR MOESG YMCHWIL (GORLLEWINOL)  
AWDURDOD IECHYD GOGLEDD CYMRU**

**Ffôn/Tel : (01248) 384877 (direct line)**

**Ffacs/Fax : (01248) 370629**

**Room 1/178**

**Ysbyty Gwynedd**

**Bangor**

**Gwynedd LL57 2PW**

**Certificate of Confirmation of Ethics Approval**

**Name of Lead Researcher : Mr K Scholey**

**Date of Ethics Review : 21.8.97**

**Title of Study : Assessment of the effectiveness of cognitive therapy for individuals with depression and dementia.**

**I confirm that all requirements have now been received for the study mentioned above.  
The research therefore has this Committee's full ethics approval.**

**If, during the course of the study, there are protocol changes, serious adverse events, or major subject recruitment problems, you are required to notify the Committee as soon as possible .**

**It is also requested that you provide an annual interim report on the conduct and progress of the study, plus a final report within three months of completion .**

**The Committee wishes you well in your research.**

**Signed : .....** 

**Dr.D.R.Prichard , Chairman .**

**Date : 22.8.97**

**NORTH WALES HEALTH AUTHORITY  
RESEARCH ETHICS COMMITTEE (WEST)**

---

**PWYLLGOR MOESEG YMCHWIL (GORLLEWINOL)  
AWDURDOD IECHYD GOGLEDD CYMRU**

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**Ffôn/Tel : (01248) 384877 (direct line)**

**Ffacs/Fax : (01248) 370629**

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**Room 1/178  
Ysbyty Gwynedd  
Bangor  
Gwynedd LL57 2PW**

6th August 1997

Room 1/178 ext. 4877

Mr Keith A Scholey  
Trainee Clinical Psychologist  
School of Psychology  
University of Wales  
Bangor  
LL57 2DG

Dear Mr Scholey

**Re : Assessment of the effectiveness of cognitive therapy for individuals with depression and dementia.**

Thank you for submitting the above study to the Ethics Committee.

You are invited to attend the next meeting on Thursday, 21st August at 6.40pm in the Committee Room, Ysbyty Gwynedd. Upon entering the main reception at Ysbyty Gwynedd, take the stairway immediately to your left and the Committee Room is through the double doors on your right.

The Committee would be grateful if you could present a brief presentation on your proposal and then answer any questions that may arise. You have been allocated 20 minutes in total for this.

Please could you confirm that will be able to attend.

Many thanks



Miss Liz James  
Clinical Research Officer.

**NORTH WALES HEALTH AUTHORITY  
RESEARCH ETHICS COMMITTEE (WEST)**

---

**PWYLLGOR MOESEG YMCHWIL (GORLLEWINOL)  
AWDURDOD IECHYD GOGLEDD CYMRU**

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**Ffôn/Tel : (01248) 384877 (direct line)**

**Ffacs/Fax : (01248) 370629**

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**Room 1/178  
Ysbyty Gwynedd  
Bangor  
Gwynedd LL57 2PW**

22nd August 1997

scholey/cogok.doc

Mr K Scholey  
Trainee Clinical Psychologist  
School of Psychology  
University of Wales  
Bangor  
LL57 2DG

Dear Mr Scholey

**Re : Assessment of the effectiveness of cognitive therapy for individuals with  
depression and dementia.**

Thank you for attending the recent Ethics Committee meeting to discuss the above.

The Committee is pleased to approve the conduct of this study. Please find an approval  
confirmation certificate enclosed.

Yours sincerely

*Liz James*

Liz James  
Clinical Research Officer.

**FORM B** (Form B Only to be used for Research Projects Using Questionnaires/Interviews Only  
For all other research projects please use Form A)

**RESEARCH ETHICS COMMITTEE (WEST)**  
**APPLICATION FORM FOR ETHICAL APPROVAL**

<b>All questions must be answered Answers should be <u>Typewritten</u></b>	<b>15 Copies of <u>All</u> Documents must be enclosed</b>
--	---

Please retain the order and form of all questions if a word processor is used.  
Copies of Questionnaires/Interview Schedule should be attached.

<b>1 TITLE OF PROJECT</b> Assessment of the effectiveness of Cognitive Therapy for Individuals with Depression and Dementia.
--

<b>2 Name of Researcher(s):</b>	Keith Alan Scholey
<b>Appointment - NHS/University:</b>	Trainee Clinical Psychologist
<b>Address for Correspondence:</b>	Clinical Psychology Psychology Department Bangor University Bangor
<b>Telephone Number:</b>	01248 - 383805

<b>3 OBJECTIVES OF THE STUDY</b>  The objectives of this study are to empirically investigate the effectiveness of a cognitive psychotherapy intervention with people experiencing both depression and dementia
---

ANY QUESTIONS RELATING TO THE CONDUCT OF THE FINDINGS OF THE COMMITTEE  
SHOULD BE ADDRESSED TO THE CHAIRMAN, DR. D.R.PRICHARD, CONSULTANT PHYSICIAN,  
GWYNEDD HOSPITALS NHS TRUST, YSBYTY GWYNEDD, BANGOR LL57 2PW. TEL. 01248  
384341

#### **4 Outline of Study Design**

Following the referral of a person experiencing both depression and dementia there will be:

1. Assessment phase consisting of 4 sessions. During this phase baseline measurements will be taken consisting of - Geriatric Depression Scale, WAIS-R, WMS-R, COWAT, AMT, Articulation Rate and Hamilton Depression Rating Scale measures to be completed with the participant and the Geriatric Depression Scale and Beck Depression Inventory to be completed by the participant's primary carer.
2. Intervention phase consisting of 8 sessions of cognitive-behavioural psychotherapy. During this phase repeat measures will be taken using the Geriatric Depression Scale, Articulation Rate, Digit Span.
3. Outcome phase consisting of 3 sessions. During this phase repeat measurements of the Geriatric Depression Scale, WAIS-R, WMS-R, COWAT, AMT, Articulation Rate and Hamilton Depression Rating Scale measures will be completed with the participant and the Geriatric Depression Scale and Beck Depression Inventory to be again completed by the participant's primary carer.

#### **5 Scientific Background to Study (give a brief account of relevant research in this area with references)**

Please submit a full protocol in addition to the application form.

Cognitive therapy has been demonstrated to be effective in the treatment of depression in individuals without dementia (Beck et al., 1979; Williams, 1984). As yet there have been no published studies demonstrating the effectiveness of such an intervention with individuals with both depression and dementia.

People with dementia appear to have an increased likelihood of experiencing depression (Ballard, Bannister & Oyebode, 1996). The relationship between depression and dementia is not fully understood. Depression in people with dementia does, however, appear to be a treatable condition (Reifler et al, 1989). The most effective treatment is not known.

There have been many recent advances in cognitive and clinical psychology, psychiatry, neurology and neurobiology that have assisted in building an understanding of depression and dementia.

Research into the effectiveness of psychotherapeutic treatments with persons with dementia has not followed the advances made in other patient groups, notably people with learning difficulties (Kroese et al., 1997) and people with psychotic disorders (Fowler et al., 1995). Though these patient groups have many differences to individuals with dementia it is considered that some of the advances in cognitive treatment techniques could be successfully applied to people with both depression and dementia.

## **6 PREVIOUS RESEARCH EXPERIENCE (to include Curriculum Vitae)**

I have previous experience in psychology research in both clinical and non-clinical areas. In addition to previous publications I have recently broadened my experience on the clinical psychology training course. Recent projects have included assessment of the prevalence and causal factors relating to drug induced psychosis, analysis of age related referral patterns to a community mental health team over a ten year period and an assessment of mothers memory for events in their own and their children's lives.

---

## **7. COURSE BEING UNDERTAKEN AND EDUCATIONAL INSTITUTION (if applicable)**

Doctoral Course in Clinical Psychology  
Clinical Psychology Training Course  
Psychology Department  
Bangor University

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## **8 ACADEMIC SUPERVISOR (if relevant)**

Professor Robert T. Woods	Psychology Department Bangor University
---------------------------	--

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## **9 CLINICAL SUPERVISOR (if relevant)**

<u>Name</u>	<u>Contract Address</u>
Professor Robert T. Woods	Psychology Department Bangor University

---

Tel..... 01248 - 383205

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## **10 STEERING/ADVISORY GROUP ARRANGEMENTS**

Supervision of cases will be provided on a weekly basis by Professor Woods.

All Health Authority ward rounds and participant review meetings will be attended and reported to, with regard to referred participants.

---

## 11 SAMPLE

a)

**Please provide a detailed description of the study sample covering selection, number, age, stability viability if appropriate, inclusion and exclusion criteria.**

Participants referred to the clinical supervisor with dual diagnosis of depression and dementia.

It is estimated that 8 - 15 participants will be included in the study.

It is likely that the participants will largely be in the older adults age group.

---

b)

**How are subjects selected?**

Subjects will be selected on the basis:

1. Dual diagnosis of depression and dementia (DSM-IV, 1994).
  2. GP or Consultant Psychiatrist referral of the client for psychotherapeutic treatment of depression.
  3. Participant's willingness to take part in the study.
  4. Participant's carers approval of participation in the study.
  5. Participant's keyworker's approval of participation.
- 

c) **What is the likely harm/benefit for the subjects?**

If the intervention is ineffective the participant may continue to experience depressive symptoms.

The participant will have taken part in several psychometric assessment procedures that might be considered rather uninteresting and perhaps slightly confusing. These, however, will not differ markedly from normal clinical practice.

The client will receive a detailed clinical assessment which may be useful with regard to further treatment.

If the intervention is effective the participant may experience a reduction in depressive symptoms.

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- d) Do you anticipate using patients/clients, students or colleagues as controls? YES/NO  
If YES, please give details.
- 

- e) Please give details of any pilot/exploratory study you intend to conduct:

This piece of work is itself designed as an exploratory study.

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- f) To your knowledge, are the subjects in this study involved in any other research investigation at the present time? If so, please give details.

No.

---

- g) If payments or rewards are to be made to subjects, give amount and details and indicate to which subjects payments apply.

No payments will be made.

---

## 12 DISCLOSURE OF PAYMENT/REWARD TO INVESTIGATORS

- i Is any payment being made, to investigator or department/unit, in respect of this project? YES/NO

If NO.....go to question 13

If YES.....go to question 12.ii

- ii Is the payment?

a) a block grant? YES/NO

b) based on the number of subjects recruited? YES/NO

If there is a block grant is the payment made in order to?

If YES state sum

a) pay a salary (-ies) YES/NO £.....

b) fund equipment YES/NO £.....

c) fund technical/laboratory YES/NO £.....

d) reward time/effort involved YES/NO £.....

e) other reason: (state nature)? YES/NO

..... £.....

If payment is based on number of subjects recruited  
(per capita/payment, state total sum payable for each  
subject completing the study £.....

State number of subjects agreed .....

- iii Are the subjects informed, as part of the consent procedure?

a) the name of the sponsor? YES/NO

b) that the investigator/department will be  
receiving payment YES/NO

- iv Does the investigator(s) have any personal involvement (e.g.  
financial, share-holding etc) in the sponsoring company?

### **13 INFORMED CONSENT**

- a)      How will written consent be obtained?                      Written/Verbal**

**A combined information sheet and consent form is essential and a copy should be attached. (A duplicate copy MUST be available for the subject).**

Participants consent may be either written or verbal. In either case this will be witnessed and supported by the participant's carers, GP, psychiatrist or keyworker.

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- b)      In exceptional circumstances, if verbal consent only is to be obtained, state why.**

If the participant is not able to write verbal consent may be used if considered reliable and supported by participant's carers and GP, psychiatrist or keyworker.

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- c)      How will subjects be invited to participate?**

By GP or psychiatric referral.

---

- d)      When the research has been explained to subjects, how much time will be allowed for them to consider and consult relatives and others before giving consent?**

At least three days will be given.

---

- e)      Is the ability to withdraw at any time without detrimental effect to subsequent treatment and care indicated?**

Withdrawal will not effect subsequent alternative treatment or care.

---

## **14 CONFIDENTIALITY AND ANONYMITY**

### **a) How are confidentiality and anonymity to be ensured?**

All the NHS procedures regarding client confidentiality will be ensured.

---

### **b) Are you aware that you need to comply with the Data Protection Act?**

Yes.

---

### **c) If audio/video taped recordings are made, what is going to happen to them when the research is complete?**

With the participants permission some audio tape recordings of therapy sessions may be made to assist with clinical supervision; they will be erased at the completion of the project.

---

### **d) If relevant, how will consent for access to participants' records be obtained?**

Access as part of clinical service.

---

### **e) How is the research instrument to be administered and by whom?**

Within the guidelines provided for the use of the instruments.

Administration will be performed by Keith Scholey.

---

### **f) How is the research instrument to be collected and by whom?**

Collection of results will be performed by Keith Scholey.

---

**15 ACCESS/CONSENT OF OTHERS CLINICALLY INVOLVED**

- a) Has access been agreed? YES/NO**  
**If YES, where, when and by whom?**

Professor R.T. Woods - Bangor University

Dr Devakumar - Hergest Unit, Ysbyty Gwynedd

- 
- b) Will the consent of clinical colleagues be obtained? YES/NO**  
**If YES, which?**

Professor R.T. Woods - Bangor University

Dr Devakumar - Hergest Unit, Ysbyty Gwynedd

- 
- c) Is observation to be used as a method?**  
**Please describe how?**  
**Has consent been obtained and from whom?**

Not applicable

---

**16 STATISTICAL ADVICE**

**If appropriate, have you had statistical advice in preparing the protocol/questionnaire? If so, from whom?**

Statistical advice will be available from Psychology Department statistics staff.

**17 MULTI-CENTRE STUDIES**

**If this is a multi-centre study, have other Ethics Committees been approached?**

Not applicable.

---

**18 RAISED EXPECTATIONS**

**Have you considered the possibility that you may be raising expectations or focusing attention of fears, worries, sensitive areas, providing new knowledge or be in conflict with other advice?**

**Please describe what steps are being taken to meet any needs that may arise and describe any arrangements for post interview/questionnaire counselling/contact.**

This has been an area considered. The exploratory nature of the study and intervention will be made clear.

The intervention will be intergrated with the participants clinical management.

---

**19 What problems may hinder successful completion of the study?**

The dual symptomatology of dementia and depression places considerable strain and stress on the individual and their carers. The management of these will naturally take priority over the individuals participation in the study.

---

20 Anticipated timing and duration of study ..10 Months.....

21 The information supplied is to the best of my knowledge and belief accurate, I clearly understand my obligations and the rights of the subject, particularly concerning freely-given informed consent.

Date of Submission:

Signature of Research Applicant

.....Keith Sholey.....

.....29/7/97.....

---

22 TO BE COMPLETED BY CONSULTANT IN CHARGE  
OR HEAD OF DEPARTMENT

I hereby endorse this research application with my approval

Signature .....

.....*Shankar Sharma*.....

Name and Appointment .....

.....PROFESSOR/CLINICAL  
PSYCHOLOGIST.....

.....SCHOOL of Psychology.....

.....UNIVERSITY of Wales.....

.....Bangor.....

A REPORT/SUMMARY WILL BE REQUIRED BY THE GWYNEDD  
RESEARCH ETHICS COMMITTEE WITHIN THREE MONTHS OF  
COMPLETION OF THE RESEARCH

**FINALLY**

**Please ensure that you have enclosed (15 copies), if appropriate**

- **questionnaires/interview schedules**
- **letters of explanation**
- **information sheets/consent forms for subjects**
- **Welsh translation where necessary**

**Send to:**

**Miss Liz James  
Secretary to Research Ethics Committee (West)  
Room 1/178 Ysbyty Gwynedd  
BANGOR, Gwynedd, LL57 2PW  
(Telephone No: 01248 384887)**



## References

Ballard, C.G., Bannister, C., Oyebode, F. (1996) Depression in dementia sufferers. *International Journal of Geriatric Psychiatry*, 11, 507-515.

Beck, A.T., Rush, A.J., Shaw, B.F. & Emery, G. (1979) *Cognitive Therapy of Depression*. Guilford Press, New York, USA.

Fowler, D., Garety, P. & Kuipers (1995) *Cognitive Behaviour Therapy for Psychosis, Theory and Practice*. Wiley, Chichester, England.

Kroese, B.S., Dagnan, D. & Loumidis, K. (1997) *Cognitive-Behaviour Therapy for People with Learning Disabilities*, Routledge, London, England.

Reifler, B.V., Teri, L., Raskind, M., Veith, R., Barnes, R., White, E. & McLean, P. (1989) Double-blind trial of imipramine in Alzheimer's disease patients with and without depression. *American Journal of Psychiatry*, 146, 45-49.

Williams, J. M. G. (1992) *The Psychological Treatment of Depression. A Guide to the Theory and Practice of Cognitive Behaviour Therapy*. Second edition. Routledge, England.

## **CONSENT FORM**

### **Assessment of the effectiveness of Cognitive Therapy for Individuals with Depression and Dementia.**

Name of Researcher: Keith Scholey  
Appointment: Trainee Clinical Psychologist  
Address: Clinical Psychology  
43, College Road  
Bangor University  
Bangor  
LL57 2DG  
Supervisor: Professor R.T. Woods

I would like you to take part in a research study to find out if cognitive psychotherapy is useful for people who are feeling depressed or down.

The group of people I am particularly interested in working with are people who may be finding greater difficulty in managing mental tasks than they used to. Such tasks might be remembering to do things, remembering where you are or where you have put things.

Cognitive therapy is a possible talking treatment for the feelings of depression and low mood that sometimes accompany these changes. It involves talking about the way we feel and think about things.

The study has three sections:

1. Doing some tests which show if you are having any problems thinking or remembering. It is normal procedure for someone having such problems to do these tests. The tests will take between 3 and 4 hours, but will be broken up into several sessions at convenient times.
2. The therapy sessions - this will involve discussing many of your thoughts and feelings. Sometimes when we feel down it is because of the way we see ourselves and others. Considering other ways of looking at the world may help to improve the way we feel. These sessions will take place once or twice a week for eight weeks.
3. Repeating the tests from the first section following the psychotherapy sessions to see if there have been any changes.

You will not be referred to by name in any file or document in which the project results are described.

If you have any questions about the study or would like to know more before deciding whether or not to take part, please ask me (Keith Scholey).

**Participation in this research is voluntary and you have the right to refuse or withdraw at any time without affecting or jeopardising future medical care.**

**Complaints.**

In the case of any complaints concerning the conduct of research, these should be addressed to:

Professor C.F. Lowe  
Head of School  
School of Psychology  
University of Wales  
Bangor  
Gwynedd  
LL57 2DG.

John Mullen  
Chief Executive  
Gwynedd Community Health Trust  
Ysbyty Bryn - Y - Neuadd  
Llanfairfechan  
Gwynedd

**Consent**

I agree to participate in this study. I have been given this form and had a chance to read it.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of Carer: \_\_\_\_\_

Signature of Investigator: \_\_\_\_\_

## FFURFLEN GANIATÂD

### Asesiad o effeithiolrwydd Therapi Gwybyddol ar gyfer Unigolion yn dioddef oddi wrth Iselder a Gorddrysych

Enw'r Ymchwilydd: Keith Scholey

Swydd: Seicolegydd Clinigol dan Hyfforddiant

Cyfeiriad: Seicoleg Glinigol  
43 Ffordd y Coleg  
Prifysgol Cymru  
Bangor  
LL57 2DG

Goruchwyliwr: Yr Athro R.T. Woods

Byddwn yn hoffi i chwi gymryd rhan mewn astudiaeth ymchwil i weld a ydyw seicotherapi gwybyddol yn ddefnyddiol ar gyfer pobl sy'n teimlo'n isel eu hysbryd.

Y grŵp o bobl y mae gennyf ddiddordeb arbennig mewn gweithio â hwy yw pobl a all fod yn cael mwy o drafferth i reoli tasgau meddyliol nag yr oeddent yn ei chael yn y gorffennol. Gallai tasgau o'r fath gynnwys cofio gwneud pethau, cofio ble rydych chi neu ble rydych chi wedi rhoi gwahanol bethau.

Mae therapi gwybyddol yn driniaeth siarad bosibl ar gyfer y teimladau o iselder ysbryd a hwyliau drwg sydd weithiau'n dod i ganlyn y newidiadau hyn. Mae'n cynnwys siarad am y ffordd yr ydym yn teimlo ac yn meddwl am wahanol bethau.

Mae tair rhan i'r astudiaeth:

1. Gwneud nifer o brofion a fydd yn dangos a oes gennych unrhyw broblemau'n ymwneud â meddwl neu gofio. Mae'n gwbl arferol gofyn i rywun gyda phroblemau o'r fath wneud y profion hyn. Bydd y profion yn cymryd rhwng 3 a 4 awr i'w gwneud, ond byddant wedi'u rhannu'n nifer o sesiynau ar adegau cyfleus.
2. Y sesiynau therapi - bydd hyn yn cynnwys trafod llawer o'ch meddyliau a'ch teimladau. Weithiau rydym yn isel oherwydd y ffordd yr ydym yn ein gweld ein hunain ac eraill. Gall ystyried ffyrdd eraill o edrych ar y byd wella'r ffordd yr ydym yn teimlo. Cynhelir y sesiynau hyn unwaith neu ddwy yr wythnos am wyth wythnos.
3. Ailadrodd y profion o'r rhan gyntaf yn dilyn y sesiynau seicotherapi i weld a fu unrhyw newidiadau.

Ni chyfeirir atoch wrth eich enw mewn unrhyw ffeil neu ddogfen lle disgrifir canlyniadau'r project.

Os oes gennych unrhyw gwestiynau ynglŷn â'r astudiaeth, neu os hoffech wybod mwy cyn penderfynu p'run a hoffech gymryd rhan ai peidio, gofynnwch i mi (Keith Scholey) os gwelwch yn dda.

**Mae cymryd rhan yn yr ymchwil hwn yn gwbl wirfoddol ac mae gennych hawl i wrthod cymryd rhan neu dynnu'n ôl unrhyw bryd heb i hynny effeithio ar ofal meddygol yn y dyfodol neu ei beryglu.**

**Cwynion**

Dylid cyfeirio unrhyw gwynion yn ymwneud â'r modd y cynhelir yr ymchwil at:

Yr Athro C.F. Lowe  
Pennaeth yr Ysgol  
Ysgol Seicoleg  
Prifysgol Cymru  
Bangor  
Gwynedd  
LL57 2DG

John Mullen  
Prif Weithredwr  
Ymddiriedolaeth Iechyd Cymuned Gwynedd  
Ysbyty Bryn y Neuadd  
Llanfairfechan  
Gwynedd

**Caniatâd**

Rwyf yn cytuno i gymryd rhan yn yr astudiaeth hon. Rwyf wedi cael copi o'r ffurflen hon ac wedi cael cyfle i'w darllen.

Llofnod: \_\_\_\_\_

Dyddiad: \_\_\_\_\_

Llofnod Gofalwr: \_\_\_\_\_

Llofnod Ymchwilydd: \_\_\_\_\_

# RESEARCH PROTOCOL

## OUTLINE

1. *Assessment phase* consisting of 4 sessions. During this phase baseline measurements will be taken consisting of - Geriatric Depression Scale, WAIS-R, WMS-R, COWAT, AMT, Articulation Rate and Hamilton Depression Rating Scale measures to be completed with the participant and the Geriatric Depression Scale and Beck Depression Inventory to be completed by the participant's primary carer.
2. *Intervention phase* consisting of 8 sessions of cognitive-behavioural psychotherapy. During this phase repeat measures will be taken using the Geriatric Depression Scale, Articulation Rate, Digit Span.
3. *Outcome phase* consisting of 3 sessions. During this phase repeat measurements of the Geriatric Depression Scale, WAIS-R, WMS-R, COWAT, AMT, Articulation Rate and Hamilton Depression Rating Scale measures will be completed with the participant and the Geriatric Depression Scale and Beck Depression Inventory to be again completed by the participant's primary carer.

## ASSESSMENT PHASE

### *Session One.*

It is considered that the majority of the first session will be taken in an explanation of the nature of the study. The consent form may be difficult for a lay-person to understand particularly a person with dementia. This session will therefore ensure that the participant has fully understood the nature of the study and their decision to consent to participation.

### *Sessions Two - Four.*

A number of psychometric assessments will be completed with the participant. It is estimated that in total this will take around three hours. Given the concentration needed for these tests the length of time taken during these sessions will be tailored to the participants abilities. A number of shorter sessions may be used if the client would prefer.

Geriatric Depression Scale - A 30 item scale consisting of questions relating to the participants mood requiring a yes/no response.

WAIS-R - Wechsler Adult Intelligence Scale -Revised. A standard psychometric assessment scale consisting of 11 subtests relating to information, digit span, vocabulary, arithmetic, comprehension, similarities, picture completion, picture arrangement, block design, object assembly and digit symbol reproduction.

WMS-R - Wechsler Memory Scale. A standard psychometric assessment scale design specifically to assess memory functioning. It is anticipated that a condensed form of this scale will be used, including logical memory, visual reproduction, visual memory span and delayed recall.

COWAT - Controlled Oral Word Association Test. A simple test of verbal productivity. The participant is asked to produce as many words as possible within a one minute period beginning with the letters F, A and S.

AMT - Autobiographical Memory Test. The participant is given ten 'cue' words and asked to describe a memory relating to that word.

Articulation Rate - A test of speed of articulation. The participant is asked to count to ten as rapidly as possible, five times in a row. The time taken is measure with a stop-watch.

Hamilton Depression Scale - The standard psychiatric depression rating scale. This is a rating scale of the participants symptomatology completed by psychiatric staff, observing the participant.

Beck Depression Inventory - The standard psychological depression rating scale. Consisting of 21 items, each of three statements relating to the participants self-perception. Carer ratings on this scale have been demonstrated to have relatively high reliability and validity (Logson & Teri, 1995).

## INTERVENTION PHASE

### *Sessions Five - Twelve.*

Eight sessions of cognitive / cognitive-behavioural therapy structured around the Beck model (1976 & 1979). This model is based upon the concept that cognitive (mental) processes relate and mediate a persons mood state. The process of cognitive therapy is based upon the identification and modification of dysfunctional cognitive processes. Developing alternative cognitive strategies with a depressed person appears to be effective in modifying and raising their mood.

Cognitive and clinical psychology has developed considerably since Beck originally developed his model of therapy. Understanding of cognitive processes, depression, the experiences of older people and dementia have all been advanced considerably since the late seventies. It is considered that the incorporation of this understanding into Beck's tried and tested therapy model may prove effective in reducing depression in client's with dementia.

## OUTCOME PHASE

### *Sessions Thirteen - Fifteen.*

This will consist of repeat measures from the initial assessment phase to provide an empirical evaluation of the effectiveness of the intervention.

Additionally during this phase efforts will be made to ensure appropriate follow-up services are provided for all participants in this study.

## References

Logson, R.G. & Teri, L. (1995) Depression in Alzheimer's Disease Patients: Caregivers as Surrogate Reporters. *Journal of the American Geriatric Society*, 43, 150-155.

Beck, A.T. (1976) *Cognitive Therapy and the Emotional Disorders*, Penguin, Harmondsworth, England.

Beck, A.T., Rush, A.J., Shaw, B.F. & Emery, G. (1979) *Cognitive Therapy of Depression*, Guilford Press, New York, USA.



## PROTOCOL YMCHWIL

### AMLINELLIAD

1. *Cam Asesu* a fydd yn cynnwys 4 sesiwn. Yn ystod y cam hwn nodir mesuriadau llinell isaf (baseline) yn cynnwys: Graddfa Iselder Geriatrig, WAIS-R, WMS-R, COWAT, AMT, Cyfradd Mynegiad a Graddfa Cyfradd Iselder Hamilton - i'w gwneud gyda'r sawl sy'n cymryd rhan - a'r Raddfa Iselder Geriatrig a Rhestr Iselder Beck i'w nodi gan brif ofalwr y sawl sy'n cymryd rhan.
2. *Cam Ymyriad* a fydd yn cynnwys 8 sesiwn o seicotherapi gwybyddol-ymddygiadol. Yn ystod y cam hwn gwneir mesuriadau drachefn gan ddefnyddio'r Gyfradd Iselder Geriatrig, Cyfradd Mynegiad, Rhychwant Digid.
3. *Cam Canlyniad* a fydd yn cynnwys 3 sesiwn. Yn ystod y cam hwn gwneir mesuriadau drachefn gan ddefnyddio'r Gyfradd Iselder Geriatrig, WAIS-R, WMS-R, COWAT, AMT, Cyfradd Mynegiad a Graddfa Cyfradd Iselder Hamilton gyda'r sawl sy'n cymryd rhan, a gofynnir i brif ofalwr y sawl sy'n cymryd rhan nodi'r Raddfa Iselder Geriatrig a Rhestr Iselder Beck unwaith eto.

### CAM ASESU

#### *Sesiwn Un*

Mae'n fwy na thebyg y treulir y rhan fwyaf o'r sesiwn cyntaf yn egluro natur yr astudiaeth. Efallai y bydd yn anodd i leygwr ddeall y ffurflen ganiatâd, yn arbennig unigolyn sy'n dioddef oddi wrth orddryswch. Yn y sesiwn hwn, felly, sicrhair fod y sawl sy'n cymryd rhan wedi deall natur yr astudiaeth yn iawn a'r penderfyniad i gytuno i gymryd rhan.

#### *Sesiwn Dau - Pedwar*

Cwblheir nifer o asesiadau seicometrig gyda'r sawl sy'n cymryd rhan. Amcangyfrifir y byddant yn cymryd tua thair awr i'w gwneud i gyd. O ystyried fod angen canolbwyntio ar gyfer y profion hyn bydd hyd y sesiynau'n cael ei addasu yn ôl gallu'r sawl sy'n cymryd rhan. Gellir cael nifer o seisynau byrrach os byddai'n well gan y client hynny.

Graddfa Iselder Geriatrig - Graddfa 30 eitem yn cynnwys cwestiynau'n ymwneud â hwyliau'r sawl sy'n cymryd rhan. Ymateb ie/nage sydd ei angen i'r cwestiynau hyn.

WAIS-R - Wechsler Adult Intelligence Scale - Revised. Graddfa asesu seicometrig safonol yn cynnwys 11 o is-broffion yn ymwneud â gwybodaeth, rhychwant digid, geirfa, rhifydddeg, dealltwriaeth, cyffelybiaethau, gorffen llun, gosod lluniau mewn trefn, cynllun blociau, rhoi gwrthrych wrth ei gilydd ac atgynhyrchu symbolau digidol.

WMS-R - Wechsler Memory Scale. Graddfa asesu seicometrig safonol a gynlluniwyd yn benodol i asesu'r modd y mae'r cof yn gweithredu. Rhagwelir y defnyddir ffurf gryno o'r raddfa hon, yn cynnwys cof rhesymegol, atgynhyrchiad gweledol, rhychwant cof gweledol ac atgof gohiriedig.

COWAT - Controlled Oral Word Association Test. Prawf syml ar gynhyrchiant geiriol. Gofynnir i'r sawl sy'n cymryd rhan gynhyrchu cymaint o eiriau ag y bo modd yn dechrau â'r llythrennau F, A ac S o fewn cyfnod o funud.

AMT- Autobiographical Memory Test. Rhoddir deg gair awgrymiadol i'r sawl sy'n cymryd rhan a gofynnir iddo/iddi ddisgrifio atgof yn ymwneud â'r gair dan sylw.

Cyfradd Mynegiad - Prawf ar gyflymder mynegiad. Gofynnir i'r sawl sy'n cymryd rhan gyfrif i ddeg cyn gyflymed â phosibl bum gwaith yn olynol. Mesurir yr amser a gymerir gyda stop-wats.

Graddfa Iselder Hamilton - Hon yw'r raddfa safonol ar gyfer mesur iselder seiciatrig. Graddfa gyfradd o symptomatoleg y sawl sy'n cymryd rhan yw hon ac fe'i defnyddir gan y staff seiciatrig a fydd yn cadw golwg ar y sawl sy'n cymryd rhan.

Rhestr Iselder Beck - Dyma'r raddfa safonol ar gyfer mesur iselder seicolegol. Mae'n cynnwys 21 o eitemau, gyda phob un o dri datganiad yn gysylltiedig â hunanganfyddiad y sawl sy'n cymryd rhan. Dangoswyd fod amcangyfrifon gofalmwr ar y raddfa hon wedi bod yn bur ddibynadwy a dilys (Logson & Teri, 1995).

## CAM YMYRIAD

### *Sesiynau Pump - Deuddeg*

Wyth sesiwn o therapi gwybyddol / gwybyddol-ymddygiadol wedi'u llunio o amgylch model Beck (1976 & 1979). Mae'r model hwn wedi'i seilio ar y cysyniad fod prosesau gwybyddol (meddyliol) yn gysylltiedig â chyflwr hwyliau unigolyn ac yn eu hamlygu. Mae proses therapi gwybyddol wedi'i seilio ar adnabod ac addasu prosesau gwybyddol camweithredol. Mae'n ymddangos fod datblygu strategaethau gwybyddol amgen gydag unigolyn sy'n isel ei ysbryd yn effeithiol i addasu a chodi eu hwyliau.

Mae seicoleg wybyddol a chlinigol wedi datblygu'n sylweddol ers i Beck ddatblygu ei fodel therapi gwreiddiol. Mae dealltwriaeth o brosesau gwybyddol, iselder, profiadau pobl hŷn â gorddryswch, i gyd wedi symud ymlaen yn sylweddol ers y saithdegau diweddar. Ystyrir y gall ymgorffori'r ddealltwriaeth hon i fodel therapi profedig Beck fod yn effeithiol i leihau iselder mewn clientiaid sy'n dioddef oddi wrth orddryswch.

## CAM CANLYNIAD

### *Sesiynau Tri-ar-ddeg - Pymtheg*

Bydd hyn yn cynnwys ailadrodd y profion a wnaed yn ystod y cam asesu dechreuol er mwyn cael gwerthusiad empiraidd o effeithiolrwydd yr ymyriad.

Yn ystod y cam hwn hefyd gwneir ymdrechion i sicrhau y darperir gwasanaethau dilynol priodol ar gyfer pawb a gymerodd ran yn yr astudiaeth hon.

## Cyfeiriadau

Logson, R.G. & Teri, L. (1995) Depression in Alzheimer's Disease Patients: Caregivers as Surrogate Reporters. *Journal of the American Geriatric Society*, 43, 150-155.

Beck, A.T. (1976) *Cognitive Therapy and the Emotional Disorders*, Penguin, Harmondsworth, England.

Beck, A.T., Rush, A.J., Shaw, B.F. a Emery, G. (1979) *Cognitive Therapy of Depression*, Guilford Press, New York, USA.

University of Wales, Bangor

School of Psychology

Ethics Committee  
Proposal cover sheet

Chief investigator/Supervisor: PROF R.T. WOODS  
Associate investigator/Student: KEITH SCHOLEY  
Brief project title: COGNITIVE THERAPY FOR INDIVIDUALS  
Date of submission: WITH DEPRESSION AND DEMENTIA  
25/7/97

Form used to prepare submission:

- ☐ School ethics committee outline  
☒ Gwynedd Health Authority  
☐ Other (please give details) \_\_\_\_\_

NB. All relevant paperwork (including consent forms and any translations) must be completed before submission to the School Ethics Committee.

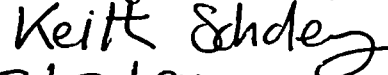
Declaration of ethical compliance

This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research.

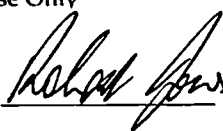
(Chief investigator/supervisor)

Signed:   
Date: 3/7/97

(Associate investigator/student)

Signed:   
Date: 3/7/97

For School Use Only

Reviewer 1  Approved ☒ (Initials) RSPJ (Date) 29.07.97  
Reviewer 2 \_\_\_\_\_ Proposal No. 97/206