Services for younger people with dementia and the role of Clinical Psychology
Page 2  Section 1. Aims

Page 2  Section 2. Introduction
2.1  Lack of specialist services
2.2  A psychological framework for service development and delivery

Page 5  Section 3. Needs
3.1  The needs of younger people with dementia
3.2  The needs of families of younger people with dementia
3.3  The needs of professional carers of younger people with dementia

Page 7  Section 4. Service provision for younger people with dementia: Components of a good service
4.1  Staffing levels
4.2  Diagnosis and assessment
   4.2.1  Consent issues
   4.2.2  Diagnostic needs
   4.2.3  Needs assessment
   4.2.4  Assessment of carers
4.3  Support and psychosocial interventions
   4.3.1  Information and psycho-education
   4.3.2  Children
   4.3.3  Support groups
4.4  Clinical examples of psychological interventions for people with dementia
   4.4.1  Early stage interventions
   4.4.2  Early /middle interventions
   4.4.3  Late stage intervention
4.5  Liaison with statutory services
4.6  Liaison with voluntary and non-statutory Agencies

Page 17  Section 5. Further roles of clinical psychology in services for younger people with dementia
5.1  Teaching and training
5.2  Research and service evaluation
5.3  Advocacy and service user involvement

Page 18  6. References
1. Aims of Paper

(i) Address the gap in the present literature on the role of clinical psychology in health and social care provision for younger people* with dementia.

(ii) Promote a psychological framework for service development and provision for younger people with dementia.

(iii) Outline the role of clinical psychology across the components of a comprehensive service for younger people with dementia illustrated by examples of good practice.**

2. Introduction

Dementia is generally characterised by the development of deficits in multiple domains of cognition, including memory, language, comprehension and orientation. It is often associated with changes in social behaviour, which can precede cognitive impairment in some cases. Dementia has a number of causes including specific degenerative conditions such as Alzheimer’s disease or vascular dementia, infections, metabolic disorders, or persistent exposure to toxic substances. The course of dementia is extremely variable according to the different type and the individual affected. Progression from mild impairment to severe impairment and death, can take anything from months to many years.

Although dementia is usually associated with older people, it is estimated that there are approximately 18,500 people with a dementia under the age of 65 in the UK (Harvey, Skelton-Robinson et al., 2004). Epidemiological work during the 1990s (Newens, Forster et al., 1993; Woodburn, 1999) found varying prevalence rates depending on samples and inclusion criteria. Most widely quoted is a prevalence of 67.2 cases per 100,000 population between the ages of 30 and 64 (Harvey 1998). In the light of experiences of recently developed services this is now seen as a conservative estimate.

Despite the increasing recognition of the occurrence of this condition in people under the age of 65, specialist services have been slow to develop. The Alzheimer’s Society first drew attention to the needs of this group in their Declaration of rights of young people with dementia (Alzheimer’s Disease Society, 1996).

The Health Advisory Service’s 1997 review (Williams, Barret & Muth, 1997) made extensive recommendations on the commissioning and provision of mental health services for people with Huntingdon’s disease, brain injury and young onset dementia. However, a survey by Barber (1997) found only 12 Trusts in England with specialist services.

In 2000 the Royal College of Psychiatrists published their Council report outlining the role of psychiatrists in developing and providing services to younger people with dementia. They recommended that the responsibility for the provision of mental health services for younger people with dementia should be located in old age psychiatry services with two sessions of input from a named consultant old age psychiatrist per ‘old-style health district’ (250,000 people).

* The terms ‘younger’ and ‘younger people’ are used throughout to refer to men and women aged under 65 years
** Examples of good practice are disguised case studies known to the authors. Anonymity has been preserved and where appropriate consent has been granted.
The National Service Framework (NSF) for Older People (Department of Health, 2001) specifically advocated the development of specialist services for younger people with dementia.

The Alzheimer’s Society, building on their previous work, produced a Guide to Service Development and Provision (Alzheimer’s Society, 2001), which was revised in 2005 (Alzheimer’s Society, 2005a). A further Alzheimer’s Society document was published in 2005 (Alzheimer’s Society, 2005b). Whilst this strategy paper highlights the need for more multi-disciplinary and inter-agency working, there is a general lack of awareness of the psychological perspective and the role of Clinical Psychology within the existing literature.

In 2005 the Faculty of Old Age Psychiatry, Royal College of Psychiatrists and the Alzheimer’s Society published a review of their policy paper of 2000 (Royal College of Psychiatrists, 2006). This paper highlights several issues:

- A positive start has been made in implementing the recommendation that a consultant in old age psychiatry should act as a focus for referrals. Also, that following this appointment, the rudiments of a local service will evolve on the basis of existing services and facilities.
- A crucial factor in the co-ordination of the care and management of younger people with dementia is collaboration with other specialties, particularly neurology.
- Improved co-ordination between existing services has the potential to significantly improve the management of younger people with dementia.
- There should be an incremental development in specialist services. For a population of 500,000 or more the creation of a specialist multi-disciplinary team is justified. In smaller populations it is recommended that, according to local variations in need, provision and manpower, a dedicated service may commence with a specialist community post from either social work or nursing.

Whilst there has been considerable progress over the past five years in moving towards realising specialist services for younger people with dementia, little has been mentioned about how clinical psychology could contribute to this endeavour. Indeed, the latest Royal College document cited above, whilst acknowledging the diagnostic difficulties with this group and the high level of functional and behavioural problems (Ferran, Wilson et al., 1996), pays little attention to the potential contribution of psychology. The Royal College of Psychiatry advocate an old age psychiatry lead for services for younger people with dementia, but do not view this as essential. Certainly, services exist currently where this is not the case and where clinical psychology plays a lead role. For example:

- The Teeswide young onset dementia team in Teesside is led by a clinical neuropsychologist.
- The Leeds service for younger people with dementia includes a joint diagnosis and assessment clinic with clinical psychology and old age psychiatry.
- The Cambridge fronto-temporal dementia clinic was created by a behavioural neurologist and a clinical psychologist.

In 2001, at the national conference of the British Psychological Society’s faculty of psychology specialists working with older people (PSIGE), a section was dedicated to the presentation of pioneering work by clinical psychologists such as those above. This generated much interest and led to the proposal of a national network of Clinical Psychologists working with younger people with dementia.
A task group, supported by the PSIGE national committee, was formed to survey the network membership and to publish further guidance for Clinical Psychologists developing and delivering services to younger people with dementia, their families and carers.

Fifty-four psychologists responded to the survey and of those only 20 per cent were working in a dedicated service for younger people with dementia. Sixty per cent of the psychologists surveyed were working with younger people in services designated to older people, but 40 per cent were involved in planning or development of specialist services.

2.1 Lack of specialist services

The Royal College of Psychiatry and the Alzheimer’s Society have highlighted that people who develop dementia before they are 65 have traditionally occupied a precarious position with regard to receipt of services. This is largely due to the fact that they are a group of younger people who experience an illness typically associated with old age. Within current mental health services, there is a lack of coherent and consistent service provision that combines expertise in dementia care with skills in individual and systemic work with adults of working age.

Younger people with dementia have often been left in limbo between adult mental health services and older adult mental health systems, leading to lack of consistent service input and exclusion from health care. People frequently experience difficulties in obtaining diagnosis and access to appropriate treatment and support. These are often provided via complex and ill-defined pathways of care. For example, Williams et al. (1999) identified 38 different routes that younger people with dementia in Leeds had taken in order to gain access to full ranges of services. Four main referral pathways were identified and most people had been referred to at least two consultants. A small number of people in the study had seen five consultants prior to diagnosis.

2.2 Psychological framework for service development and delivery

Since Tom Kitwood’s work on new approaches in dementia care (Kitwood, 1997) the biopsychosocial model of understanding dementia has provided an alternative to the more traditional biomedical model, which had dominated dementia work until the early 1990s. Kitwood’s approach advocates a multifactorial view of the causes of deterioration and disability in dementia, particularly emphasising the role of social psychology, physical environment, quality of relationships and personal history as well as biological factors.

Kitwood’s model has emerged as the accepted blueprint of psychological practice in this field and also underpins the recommendations of this document. It emphasises the personhood of the individual with dementia, highlighting the centrality of self-concept, identity and emotional experience. The interplay between biological and psychosocial factors is necessarily mediated through individual psychology, in terms of the way in which the individual adapts to, and copes with, the onset and progression of dementia (Clare, 2002).
3. Needs

3.1 The needs of younger people with dementia

The Alzheimer’s Society (2001) suggest that many of the needs of younger people with dementia are the same as those of older people with dementia:

- Early diagnosis, clear pathways to diagnosis.
- Better communication, co-ordination and monitoring by services.
- Emotional support (especially pre- and post-diagnosis, and while awaiting diagnosis).
- Better information (e.g. on the condition, on the process of assessment).
- More creative and flexible service.
- Advice and support for family carers.

However, more recent literature has emphasised the particular subjective experience of younger people with dementia and their age-specific need for emotional support and psychological intervention (Ivey, 2002; Whiting, 2002; Hawkins, 2004). Issues highlighted by these recent studies include:

- being ‘out of sync’ or ‘off–time’ (Hendry & Kloep, 2002) with social expectation of developmental life stages;
- premature retirement with implications for financial situation and self esteem;
- impact on family role and responsibilities (e.g. dependent children or caring for ageing relatives);
- a greater sense of social isolation;
- being less psychologically prepared to adapt to implications of diagnosis; and
- impact on self-identity.

3.2 The needs of families of younger people with dementia

Clearly the issues faced by younger people with dementia also impact on their families. However, families too have their own specific needs and experience a greater burden of care than those caring for an older person with dementia (Luscombe et al., 1998; Freyne et al., 1999). These are:

- longer periods of uncertainty over diagnosis;
- loss of employment and income due to caring;
- dealing with feelings of frustration and grief;
- lack of peer support; and
- responsibility for families and children.

Younger people with dementia are more likely to be a parent to dependent children, and consequently the whole family is affected. Children of all ages require support to understand the illness, how it affects their parent, and what changes to expect as the illness progresses.
3.3 The needs of professional carers of younger people with dementia

For those used to caring for older people with dementia working with this younger age group brings its own challenges:

- younger people with dementia are less affected by physical health problems and consequently more active and mobile (Sampson et al., 2004);
- higher rates of psychiatric morbidity (Gregory & Lough, 2001);
- greater difficulty in dissuading people with dementia from driving;
- greater incidence of challenging behaviours (Lough & Hodges, 2002);
- more complex financial and benefit issues; and
- greater emotional impact on professionals (Kitwood, 1997).
4 Service provision for younger people with dementia – components of a good service

In the following section we will draw together material from the existing literature, recent conferences and workshops to reflect current psychological thinking on best practice in the development of services for younger people with dementia. We consider the psychologist’s role: in aiding diagnosis through neuropsychological assessment, in providing psychological assessments of people with dementia and their families, in providing psychological support and intervention, in evaluation and research, and in training and support for others working with this client group.

4.1 Staffing levels

Staffing levels of 0.5 wte per 250,000 population have been recommended in the revised edition of Briefing Paper 5 (Boddington, 2005) on psychological services for older people and people with dementia. This is seen as adequate for a basic, but not comprehensive, service provision and does not take into account a specialist service for younger people with dementia. The Faculty of Old Age Psychiatry, Royal College of Psychiatrists and the Alzheimer’s Society (2005) recommendation for a specialist provision of one multidisciplinary team for a population of over 500,000 and the need for dedicated specialist time in smaller populations needs to be taken into account in the overall planning of clinical psychology services.

4.2 Diagnosis and assessment

The crucial starting point for specialist services working with younger people with dementia and their families is the provision of timely and comprehensive diagnostic and needs assessment procedures. Neuropsychology has a crucial part to play at this point.

4.2.1 Consent issues

It is essential that neuropsychological services pay due consideration to the development of procedures for obtaining informed consent from their service users at every stage of service provision. Following the person-centred approach (Kitwood, 1997) the process of obtaining consent should begin at the very start of the person’s contact with dementia services, prior to any diagnostic assessment. The purpose of pre-diagnostic counselling is to provide time and space (and information where appropriate) in order for the person to be able to make an informed decision about whether they want to proceed with the diagnostic procedure, whether they want to know what the assessments reveal, and if so, how they want to be told the results.

Whilst the importance of maximising the client’s sense of control over their health care is increasingly being stressed, very little has actually been written about how pre-diagnostic counselling for people suspected of having dementia is done in practice. Williams (2002) provides a useful description of pre-diagnostic counselling procedures for people referred to an older people’s service for neuropsychological assessment as part of their diagnostic assessment for dementia. The author suggests that informed consent for assessment concentrates on the following areas:

- obtaining informed consent to begin the process of assessment; and
- finding out how the person wishes to be told the outcome of their assessment (if at all), in order to maximise the person’s comfort and sense of control over this difficult process.
Williams (2002) suggests that the psychologist considers the following areas when preparing the person to give informed consent for the assessment:

- knowledge and understanding of the reason for referral;
- knowledge of the process of neuropsychological assessment;
- knowledge and understanding of the possible outcomes of neuropsychological assessment which may include a diagnosis or diagnostic uncertainty; and
- the implication of receiving a diagnosis of dementia as a possible outcome of neuropsychological assessment.

### 4.2.2 Diagnostic needs

Diagnosis of dementing conditions in younger people is often difficult. Ferran et al. (1996) reported that a specific diagnosis could not be given in nearly one third of people following an initial comprehensive assessment. There are a wide variety of diagnostic possibilities, some of which are rare (Harvey, 1998). It is estimated that approximately 11 per cent of dementia is partly or fully reversible (Clarfield, 1998) and it is not uncommon for depressed younger adults to present with cognitive impairment that is often overlooked (Ferran et al., 1996). It is, therefore, critical that younger people with dementia are referred to specialist staff with expertise in the accurate diagnosis of dementia in younger adults. Uncommon diagnoses are particularly prevalent in people under the age of 50. It is now emerging that a large proportion of cases of young onset dementia are due to fronto-temporal dementia (Ratnavalli et al., 2002). These people often present to services with behavioural/psychiatric disturbances rather than cognitive decline (Gregory & Hodges, 1996). As a group they therefore present with particular diagnostic difficulties and often go under-diagnosed (Lough & Hodges, 2002). Despite the difficulties of establishing a diagnosis, and the debate within the literature about whether people with dementia should be given a diagnosis (Bamford et al., 2004), we would support the importance of diagnostic disclosure.

Ideally a core team should be established to meet the diagnostic needs of younger people with suspected dementia. Multi-professional input from psychiatry, neurology and neuropsychology is essential for initial assessment in order to facilitate accurate diagnosis. The team should ideally operate out of a central point.

There is some evidence to support a view that if these services are provided by a memory clinic, this may result in improved psychosocial health related quality of life for carers (Logiudice et al., 1999). The ideal therefore is a memory clinic integrated within a specialist service for younger people with dementia to ensure service continuity through the illness process (Moniz-Cook et al., 1998)

Core members of the specialist team, with longer-term support beyond initial diagnosis would include a nurse, psychologist, neurologist, psychiatrist, occupational therapist, and social worker. Initial diagnosis based on clinical opinion, neuropsychological testing and neuroimaging could then be built upon. Every member of the core team would carry out their appropriate assessment including, where possible, home assessment. Assessments should include a focus on areas of strength and retained ability with a view to building on these to maximise well-being.

Therefore, in addition to supplying a diagnosis, the person with dementia and family are already being engaged in a long-term process of structured support. Sometimes an accurate diagnosis cannot be given at the first point of contact and may only emerge over repeated assessments that could last for months or years. In this instance the focus for the team will be helping the family to cope with
living with this uncertainty. Often when children are involved heritability of the disease is a primary concern. Access to genetic counselling is therefore an important consideration.

The above account represents an ideal, which services should strive for. More likely, if diagnostic processes are not integrated within a broader specialist team, the assessment/diagnostic team will often need to refer onto appropriate services and will need to liaise closely with relevant community personnel. It is recommended that a community worker from either social work or nursing should be appointed to ensure communication and co-ordination between the diagnostic team and community services (Royal College of Psychiatry, 2005).

A good example of the role of a co-ordinator between hospital based clinics and community services is the Cambridge young onset dementia service. The team should offer regular re-assessment appointments to monitor change and provide advice on evolving care plans tailored to individual need. Those initially presenting with ‘mild cognitive impairment’ should have cognitive functioning and needs closely monitored, particularly in light of the potential benefits of anti-cholinesterase agents.

### 4.2.3 Needs assessment

The impact of dementia on younger people and their families is a process dependent on the complex interplay of neurological, physical, psychological, relational and social factors, and thus no two younger people with dementia have identical needs. Individuals have differing strengths and weaknesses and it is important that these are accurately identified in order to formulate appropriate needs based management and support programmes that are individually tailored and optimise the use of retained skills. Ideally the assessments necessary to guide this process should occur at, or closely following the point of diagnosis.

Family members (including children and spouse) also have differing but complementary needs and it is critical that the assessment takes account of the needs of all these people. As no single discipline can adequately provide for the wide variety of need that will be encountered, needs assessment requires multi-disciplinary input. However, clinical psychology can contribute greatly to this process, providing expertise in neuropsychological understanding, behavioural analysis and intervention, and systemic approaches. From the needs assessment, a clear co-ordinated pathway of care should be developed for each person, as recommended in Standard 7 of the National Service Framework for Older People (2001).

As stated earlier, the allocation of a co-ordinator to oversee service input to meeting the needs of families and act as an ongoing point of reference for the family and involved professionals is crucial in this regard.

The needs of people with dementia and their families will inevitably change over time. There is, therefore, a requirement for ongoing monitoring and planning throughout the course of the person’s illness in order to continue to inform a person-centred care pathway so that services respond flexibly to changing needs. The information gained from regular review is critical to service delivery on an individual basis and also for the strategic planning and development of services over time.

### 4.2.4 Assessment of carers

The combined policy guidance for the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 (DoH, 2005) gives carers a statutory right to an assessment of their own needs, independent of the cared for person. While Councils are encouraged to make use of the Direct Payment Scheme and Carers grants, as well as providing new and innovative services, there is as yet no statutory obligation to provide services for carers’ assessed needs.
However, psychological assessment of carer’s needs has long been good practice (Gilliard, 1992), and levels of stress and psychological morbidity are known to be particularly high amongst carers of people with young onset dementia (Sperlinger & Furst, 1994). Delaney and Rosenvinge suggest carers of younger people with dementia experience a significant level of carer burden (1995). Freyne et al. (1999) compared the level of burden in groups of carers with early and late onset dementia and they found that higher carer burden showed an inverse relationship to the patient’s age. Luscombe et al. (1998) found that the younger the carer, the more psychological and physical effects were experienced. A recent study by Colville (2005) looked at the potential mediating factors of problem solving, optimism and pessimism in carers of younger people with dementia.

Psychology has a key role to play in research and evaluation of people’s needs, but also in assessing need and providing appropriate interventions following diagnosis. Psychological assessment of coping strategies and levels of knowledge and information about the cared for person’s condition can form the basis for psychoeducational approaches as well as therapeutic interventions designed to assist carers (Charlesworth, 2001). Although there is little work specifically on interventions for carers of younger people with dementia there is literature on carers of older people that applies equally to this client group.

4.3 Support and psycho-social interventions

4.3.1 Information and psycho-education

People with dementia and their families frequently report that there is a lack of adequate information provided by services, particularly around the time of diagnosis (Williams et al., 1999; Jones et al., 2005).

There is a requirement to explain how neurological damage can manifest itself, the treatment and support options that are available, and how the changes likely to occur in the future may affect the person with dementia and their family. The experience of dementia and the caring role can place limitations on employment and lead to financial hardship. These difficulties can be compounded by the complex nature of the benefits system and there is a requirement for expert advice in this area.

The provision of information is a task requiring skill in order to ensure that it is given in an appropriate and sensitive manner. It is not uncommon for younger carers and people with dementia to struggle to accept a diagnosis associated with old age, and denial and resistance can often result. If this happens time should be allowed for adjustment, as any provision of information at these early stages will not be absorbed. Contrary to this the diagnosis can often come as a relief to some carers, particularly when the presentation is inter-personal rather than cognitive as in frontotemporal dementia. In these cases carers are usually extremely eager to receive as much information as possible about their spouse’s condition.

4.3.2 Children

As discussed earlier there may be particular issues for children of all ages whose parents are under the age of 65 and have been given a diagnosis of dementia. Areas of change to consider may include the child-parent relationship (including relationship with the non-affected parent), changes in lifestyle, and the daily structure of family life. Younger children can also find that relationships outside of the home (e.g. with peers at school) may be affected by their parent’s illness.

The Alzheimer’s Society’s advice sheet Explaining to Children (2001) provides useful guidance to parents on how to support their children in understanding what is happening within their family, and emphasises the importance of adapting explanations to meet the developmental needs of the child. The Society
also recommends that specialist counselling is available for children with a parent with dementia. Psychologists within the team are well placed to provide this support, which may also involve liaison with other health professionals with knowledge and expertise in child mental health issues.

The support needs of children with a parent with dementia is a new and emerging clinical field. As such, there is a current dearth of research literature concerning this area. Jones et al. (2005) explored the needs of three carers aged 18–35 whose parents were younger people with dementia. Although these carers were happy with the services provided for their parents they identified a gap in services for themselves which contributed to their feelings of isolation. They stressed the need to be involved in their parent’s care from diagnosis onwards, and requested more information and support. There is a requirement for sustained service-development oriented research in order to understand what children require from specialist services for younger people and their families.

4.3.3 Support groups

Whilst some people may wish to know about what the future may hold as soon as they have been given a diagnosis, this may be overwhelming for others. The manner in which the information is provided is also an important consideration to ensure the most effective means of information transmission during information-giving sessions.

Some carers and persons with dementia may wish for more detail in addition to the information provided. It is therefore an important responsibility of the psychologists and others involved to keep well abreast of the current research literature. With increased public awareness of dementia through the media and the internet there is a role for psychologists and other professionals to assist people in selecting and evaluating the most appropriate material for their needs.

One approach to providing support, education and advice for people with dementia and their families is through group work. Kitwood (1990) emphasises the importance of the social environment in influencing how people cope with dementia and Bender and Cheston (1997) suggest that a safe empathic environment may help people to talk about their feelings and acknowledge their losses. Support groups for people with dementia can provide such an environment (Yale, 1995; Hawkins & Eagger, 1998; Hawkins & Green, 2000; Marshall, Bucks et al., 2005). Usual criteria for inclusion in a group for people with dementia include a diagnosis and a degree of insight (Hawkins & Green, 2000; Cheston, 2005), but also an interest and willingness to talk about their feelings and experiences.

Group work has also been used effectively with caregivers of people with dementia (Brodaty et al., 2003). Much of the evidence base comes from work with carers of older, not younger, people with dementia.

4.4 Clinical examples of psychological interventions for people with dementia

Psychological support and intervention will vary according to the stage of dementia and the circumstances of the person and carer. Information should therefore be tailored to the stage of the dementia and the needs of the person with dementia and family members. For example, provision of information about nursing homes is clearly not appropriate in the early stages when most families wish to maximise the quality of life they have together in the time available. Throughout this process procedures to minimise carer stress are essential. In order to show the role of psychology throughout the progression of dementia, we have provided examples of interventions at different stages of the condition. Progression will vary in individuals and we would advocate a person-centred approach with needs based assessment in all cases; the use of stages or phases is purely for illustration and does not suggest that we support a stage model of dementia.
4.4.1 Neuropsychology

Neuropsychology uses the principles of objective science to examine the effectiveness of the brain’s functioning in a wide range of cognitive abilities.

Neuropsychology is an essential component of the assessment and diagnostic process as it can:

- detect signs of cognitive impairment at a very early stage;
- inform the choice of neuro-imaging;
- assist in differential diagnosis;
- provide a profile of strengths and weaknesses;
- establish a base-line from which to measure future change; and
- guide approaches to communication.

Case Example 1

Mr B, a 54-year-old teacher, had experienced difficulties at work for the past year. His GP prescribed antidepressants and eventually referred him to the general psychiatry service. Mr B and his partner were upset at the suggestion that he was depressed and described symptoms of forgetfulness, which they felt were not just stress related.

Further medical examinations, including CT scans, were all normal. Finally, a neuropsychological assessment showed deficits in verbal short-term memory, reduced processing speed and beginning visual perceptual problems, leading to a diagnosis of Alzheimer’s disease.

Case Example 2

Mr G had been given a diagnosis of Alzheimer’s disease based on psychiatric opinion and neuro-imaging four years prior to referral to neuropsychology. Over that period of time the nurse monitoring his anti-cholinesterase medication had noted that his Mini-Mental-State Examination (MMSE) Score had remained stable in the mid 20s; however, his wife reported that her husband was becoming increasingly ‘chaotic’ at home and at work. Mr G owned and managed his own business. The business was financially connected to their home and investments. Mrs G was concerned that all their finances were in jeopardy. Mr G had allowed his daughter, who lived some distance away, power of attorney, but not his son or wife. Despite pleas from Mrs G, the daughter was reluctant to invoke this power of attorney and Mr G refused to give up work. This reluctance on both parts was due to doubts regarding the validity of the diagnosis four years on. The referral was made to neuropsychology to try to clarify Mr G’s cognitive ability. Testing indicated minimal deficit in verbal learning but extreme loss of semantic function. The diagnosis was changed to semantic dementia which, when explained, fitted better with all the family’s experience of Mr G’s difficulties. Mr G agreed to have help in winding down his business and his daughter now felt able to invoke the power of attorney.

4.4.2 Early stage interventions

Adaptation and adjustment to the diagnosis is a principal task in this phase. A key task is to maintain quality of life for both carer and person with dementia. At this stage the person is relatively independent and needs practical and emotional support. A comprehensive assessment of the person’s cognitive and interpersonal deficits and strengths should be conducted. A programme designed to maximise abilities and compensate for deficits should then be constructed (Clare et al., 2003). Psychological interventions to alleviate the anxiety, depression and anger often present in the early stages of a dementia should be available (Woods, 1999).
If the person with dementia is still working, and wishes to continue doing so, this should be supported through liaison with employers. If employment has terminated then appropriate, alternative activities will need to be found in order to maintain self-esteem. The emphasis at this stage is on flexible home-based support driven by the individual’s personal choice. The carer and family may require ongoing counselling to adapt to the significance of the diagnosis.

4.4.3 Early/middle stage interventions

Most often people slowly deteriorate and often the psychologist may find his/her role changing.

As dementia progresses there is an increase in cognitive loss and breakdown in social skills. There is an increased need for professional support and supervision for the person with dementia. Carer stress tends to increase and there is a greater need for emotional and instrumental support. Challenging behaviour often escalates during this phase as the person with dementia struggles to communicate. There may also be more marked reduction in executive control. It is during this stage that the team will have to closely liaise with other services such as day care, inpatient assessment and respite care.

Case Example 3

Mr C is a 53-year-old man with a diagnosis of frontotemporal dementia. He had very little insight into his difficulties and it was his wife who first became aware of changes in his personality and social behaviour and persuaded him to consult their GP. He was diagnosed recently by a specialist team for younger people with dementia and is in the relatively early stages of the disease. He worked as head of department in a university and, following an initial period of sick leave whilst reports of his functioning were obtained, he was advised to take early retirement. His main hobbies include rally car driving and shooting. He found it difficult to accept his diagnosis initially and did not feel that it was impacting on his working life.

Mr C had many questions about the cause and symptoms of his dementia and what he could do to get better. Having lost his job, his role and being in conflict with his employers placed Mr C at increased risk of developing depression. Initially Mr C was offered an assessment for individual psychotherapy to address the emotional impact of his diagnosis. A number of options for continued support were discussed with Mr C.

He was assessed by the Occupational Therapist from the specialist team, who considered with Mr C alternative meaningful activities to replace work and his more potentially hazardous social interests. Initial support to carry out these activities was offered by the outreach team. His wife and family were informed about carer support groups.

Case Example 4

Mr P was a 57-year-old retired musician living with his wife when he was referred to psychology. He had a diagnosis of Alzheimer’s disease and had become depressed as his abilities failed. A cognitive behavioural (CBT) approach was adopted with some success until Mr P’s verbal and written communication deteriorated markedly. At this point the psychologist referred Mr P for music therapy as he could still communicate his emotions through this medium. Concurrent with the deterioration in his language there was an increase in behavioural disturbance. The role of the psychologist consequently shifted to supporting Mrs P in behavioural management.
4.4.4 Late stage interventions

Due to a general lack of specialist care homes, young people with dementia are frequently placed in environments where staff find it difficult to meet their needs. Negotiating and supervising additional one-to-one care, staff training and support, ongoing assessment and monitoring are ways of addressing this. Sensory stimulation approaches such as Snoezelen, complementary medicine interventions, such as aromatherapy and massage, and careful person-centred support have been shown to greatly improve clients’ quality of life (Burn et al., 2002). However, Moniz-Cook, Bird et al., (2003) advise that the cause of behavioural and psychological symptoms of dementia needs to be established before utilising these methods.

Case Example 5

Mr T is a 56-year-old who had received a diagnosis of Alzheimer’s disease two years previously. He had been successfully supported at home by his wife until a decline in his memory and thinking rendered him increasingly disorientated. This led to him becoming dependent upon his wife to the extent that he became very upset if she went out of his sight. Mrs T was finding this difficult to cope with and was reaching the end of her tether. A community psychiatric nurse arranged for day care with carefully arranged appropriate activities for Mr T, but when his wife took him along he refused to be parted from her. When someone from the day hospital went to collect Mr T he refused to leave and became quite aggressive. Psychology services became involved and a desensitisation programme was instigated with Mr T to help him become more at ease in the absence of his wife. A psychology assistant visited the home on a regular basis and Mr T got to know her. She started to take him out for short walks and then for longer periods of time involving car journeys. Soon she was able to take him to the day hospital for short periods and engaged in pottery classes with him. Eventually she was able to leave him for longer and longer periods at the day hospital and introduced him to other drivers. This enabled Mrs T to get her much needed respite and she was able to continue caring for her husband at home.

Case Example 6

Mrs M, a 58-year-old legal secretary with a diagnosis of young onset Alzheimer’s disease, was admitted to a care home for people with severe brain injury for periods of respite during two years of rapid deterioration in the community. Due to its younger client group, the care home was more acceptable to Mrs M and her family, the staff’s experience with cognitive impairment assisted in drawing up care plans, and the placement was eventually made permanent. Having lost her verbal abilities and social inhibitions and with increasing perceptual problems, Mrs M began to wander ceaselessly, unable to settle down to eat and suffering increasing numbers of falls and accidents.

A psychologist spent two days ‘wandering alongside’ Mrs M, using a person-centred framework to establish her needs (e.g. exploration of her environment) and remaining abilities (e.g. colour perception). This was used to renegotiate her care plan with additional one-to-one care, assisting with eating while wandering, using brightly coloured objects to engage her during brief periods, guiding her away from potential hazards and ensuring that problems with her interactions with other residents did not escalate. Regular reviews and supervision of one-to-one staff ensure this resource is used to its full potential.
4.5 Liaison with statutory services

Service Boundaries and Inclusion/Exclusion Criteria

Due to the inherent difficulty of firmly locating Young Onset Dementia within the framework of established specialist services in existing health and social care systems, the development of specialist Young Onset Dementia Services needs careful consideration of the inclusion and exclusion criteria at the planning stages. This consideration applies equally when considering dedicated psychology time to the service. As the service becomes operational and more widely known these service boundaries will require repeated review, confirmation or renegotiation in order to maintain its specialist focus, ensure best use of its resources and avoid becoming overloaded with clients whose complex needs challenge other established services.

The following areas should be addressed in early planning stages, for example, by consulting with key staff and negotiation of care pathways and shared care protocols:

When developing services for younger people with dementia consideration needs to be given to whether resources and skill base are sufficient to cater adequately for the needs of the above client groups. In most instances these will be limited. We would suggest that services for younger people with dementia should consider the likely needs of people referred to the service, develop clear inclusion and exclusion criteria and only accept people for whom dementia symptoms are the main focus. From a person-centred point of view continuity of care, including staff and physical settings, becomes more important with the onset of cognitive decline. However, specialist services for dementia also need to determine their role and input with regard to training, consultancy, support and supervision for staff in other services.

Young Onset Dementia Services need to be aware that boundaries and criteria aiming to close gaps in existing service provision have to be applied flexibly. However, early consideration and agreement of guidelines and protocols will protect newly established Young Onset Dementia teams from becoming overburdened.

Case Example 7

Mrs N, a 49-year-old former retail manager, was first diagnosed with Frontal Temporal Dementia and subsequently found also to suffer from Motor Neurone Disease. As she had always mistrusted doctors and refused to attend either her GP or the local hospital, assessments and reviews were arranged at her home, where she lived with her 18-year-old son and his 17-year-old fiancée, who acted as her main carers during a two-year period of rapid deterioration. Her young carers required ongoing psychological assistance to understand Mrs N's deteriorating behaviour, to adjust strategies for changing and increasing caring tasks, for managing community carers attending their home and for coping with their own needs and responses.

Through a local trial of alternative therapies Mrs N had access to aromatherapy massages, described by her carers as ‘the highlight of her week’, lifting her mood and leaving her notably calmer for the rest of the day. The psychologist provided information for the local hospice team and repeated explanations of her condition to assist staff in delivering appropriate care for Mrs N, and support to her young carers. This preparatory work proved invaluable in ensuring medical and nursing input during the terminal stages. Psychological work with the carers continued for some time after Mrs N's death, when her son’s need to understand his experiences during the early stages of his mother’s illness, became more apparent. An understanding of the neuropsychological changes in FTD was vital in helping him come to terms with his experiences of 'odd' behaviour during this time.
Clear service provision boundaries that outline appropriate referrals to the service and fit in with local service provision are important for clarity to stakeholders regarding the core business of the specialist service. Where doubt exists there should be explicit demarcation in terms of responsibility for care provision with the overriding principle that people should have access to services that best meet their needs. For example, if the team does not include a social worker within its core membership it may be more appropriate for a social worker with expertise in younger people with acquired brain injury to become involved rather than one with expertise in old-age psychiatry. Examples of statutory services that require the development of close liaison links include: primary care, neurology, clinical genetics, neuropsychiatry, adult and liaison psychiatry, hospital medicine, alcohol services, services for people with learning disabilities, older adult services, and physical disability.

<table>
<thead>
<tr>
<th>Adult Mental Health</th>
<th>Dual diagnosis of increasing cognitive impairment and severe mental illness, e.g. in schizophrenia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disabilities</td>
<td>Dementia in people with learning disabilities, especially Down’s Syndrome.</td>
</tr>
<tr>
<td>Neurological Disabilities</td>
<td>Specialist services may already exist for people with MS, Parkinson’s, Huntingdon’s, stroke, head injury or epilepsy.</td>
</tr>
<tr>
<td>Children &amp; Adolescents</td>
<td>A range of mainly genetic disorders lead to cognitive deterioration in children and adolescents, e.g. Batten’s Disease.</td>
</tr>
<tr>
<td>HIV &amp; AIDS</td>
<td>Specialist resources are available for this client group, however, mainly in larger conurbations.</td>
</tr>
<tr>
<td>Drugs &amp; Alcohol</td>
<td>Chronic alcohol and substance misuse lead to a variety of syndromes affecting cognition, e.g. Korsakoff’s.</td>
</tr>
</tbody>
</table>

**4.6 Liaison with voluntary and non-statutory agencies**

In order to facilitate social inclusion, equitable access and to mobilise additional resources which complement existing support systems, it will be important for specialist staff to develop close links with non-statutory agencies that provide services (e.g. out-reach workers) to people with dementia. The Alzheimer’s Society, together with other voluntary agencies, have an important role in service planning, raising awareness, providing support and non-medical information.

The Citizen’s Advice Bureau is a valuable source of advice on financial and legal issues. If services are provided over a wide geographical area, then maintaining people’s links with their local communities require that liaison links be developed with voluntary agencies in these communities in order for services to be provided close to home, e.g. home sitting services, further education colleges.
5 Further roles of clinical psychology in services for younger people with dementia

5.1 Teaching and training

An important role of the clinical psychologist within a young onset dementia service is to educate others within the service on the role of the psychologist and to disseminate psychological theory and practice. A broader teaching role exists in terms of education of formal and informal carers and the promotion, through education, of this patient group’s existence and needs to general practitioners. A very important role is the education of those working in adult psychiatry as to the varied, and often initially psychiatric, presentation of younger, onset dementia.

5.2 Research and evaluation

Clinical psychology training includes extensive knowledge of and experience with scientific research in a clinical context as well as service evaluation. Young onset dementia and the development of services for this client group are newly emerging fields with a relatively small body of research and literature. Clinical Psychologists are well placed to conduct research and service evaluations as part of their role in services for younger people with dementia, and should in addition supervise and support dissertations and service evaluation projects of clinical psychologists in training.

5.3 Advocacy and service user involvement

Recent policy documents (DoH 2001, NSF for Older People) stress the need for service user involvement at all levels of planning and development of services. Core components of involvement of people with dementia (Dick & Cunningham, 2000) and guidelines for ensuring that involvement is more than passive supply of opinion (Cantley, Woodhouse & Smith, 2005) stress the central importance of psychological and social psychological factors. The combination of neuropsychological understanding of cognitive impairment and person-centred philosophy of care places clinical psychologists in a prime position to advocate effectively for younger people with a dementia on an individual basis, and assist in their meaningful participation in service planning and development.

Model projects of involving younger people with dementia have successfully demonstrated the use of a combination of community psychology, neuropsychological strategies and personal support to assist in the development of client-led day services, young onset dementia groups, and support systems to allow younger people with dementia to speak at conferences, participate in management meetings, staff selection and interviewing procedures (Guss & Cook, 2006). Additional benefits of this approach are observed in younger people with dementia experiencing feelings of usefulness and validation following the loss of their employment role, and a degree of control over issues affecting their lives.


The British Psychological Society was founded in 1901 and incorporated by Royal Charter in 1965. Its principle object is to promote the advancement and diffusion of a knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of Members of the Society by setting up a high standard of professional education and knowledge.

The Society has more than 42,000 members and:
- has branches in England, Northern Ireland, Scotland and Wales;
- accredits nearly 800 undergraduate degrees;
- accredits nearly 150 postgraduate professional training courses;
- confers Fellowships for distinguished achievements;
- confers Chartered Status for professionally qualified psychologists;
- awards grants to support research and scholarship;
- publishes 10 scientific journals and also jointly publishes Evidence Based Mental Health with the British Medical Association and the Royal College of Psychiatrists;
- publishes books in partnership with Blackwells;
- publishes The Psychologist each month;
- supports the recruitment of psychologists through the Appointments Memorandum and www.appmemo.co.uk;
- provides a free ‘Research Digest’ by e-mail;
- publishes newsletters for its constituent groups;
- maintains a website (www.bps.org.uk);
- has international links with psychological societies and associations throughout the world;
- provides a service for the news media and the public;
- has an Ethics Committee and provides service to the Professional Conduct Board;
- maintains a Register of more than 12,000 Chartered Psychologists;
- prepares policy statements and responses to government consultations;
- holds conferences, workshops, continuing professional development and training events;
- recognises distinguished contributions to psychological science and practice through individual awards and honours;
- maintains a Register of Psychologists Specialising in Psychotherapy.

The Society continues to work to enhance:
- recruitment – the target is 50,000 members;
- services – the Society has offices in England, Northern Ireland, Scotland and Wales;
- public understanding of psychology – addressed by regular media activity and outreach events;
- influence on public policy – through the work of its Boards and Parliamentary Officer;
- membership activities – to fully utilise the strengths and diversity of the Society membership.