



**The British
Psychological Society**

Promoting excellence in psychology

DEM 05

Ymchwiliad i strategaeth genedlaethol ddrafft
Llywodraeth Cymru ar ddementia

Inquiry into the Welsh Government's draft
national dementia strategy

Ymateb gan: Cymdeithas Seicolegol Prydain

Response from: The British Psychological Society

Psychological dimensions of dementia: Putting the person at the centre of care



British Psychological Society Dementia Advisory Group

Contents

Executive summary	1
Recommendations	2
Introduction	3
Dementia in the UK: Facts and figures	4
Prevention	5
Assessment	6
Planning care	8
Families and carers	16
Training and research	17
Expanded recommendations	18
About the authors	21
References	22

© The British Psychological Society 2016

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Telephone 0116 254 9568 Facsimile 0116 247 0787

E-mail mail@bps.org.uk Website www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.

Executive summary

The term ‘dementia’ describes a group of conditions which lead to progressive changes in the structure and function of the brain. These changes in turn alter how people think and behave and their ability to manage everyday life. Dementia therefore has a profound psychological impact on the people who experience it and on their families. As every individual is different, the impact is different for each person.

Psychological research has made, and will continue to make, a significant contribution to our understanding, diagnosis and treatment of dementia. In addition, it can contribute to the development of programmes aimed at reducing the risk of developing dementia. Psychologists are instrumental in the developing focus on asserting and upholding the human rights of people with dementia and ensuring their active and meaningful involvement in decisions about their own lives and in planning and evaluating the services they receive. Focusing on the person rather than the disease leads to an emphasis on what helps people to live well with dementia.

This report presents a psychological perspective on the nature and experience of dementia and outlines the extensive contribution that psychologists make in this field. It highlights a number of areas where action is needed to improve understanding and care, and makes recommendations for commissioning services. The document reflects universally applicable principles of good psychological practice, while recognising that there are differences between the four UK nations in policy and strategy emphasis, and in service delivery.

The best way to diagnose, treat and support people with dementia is through multi-disciplinary teams that include psychological support alongside doctors, nurses and therapists. In many places services do not meet this standard. There is an urgent need to address the gap in provision, and make sure people with dementia and carers receive appropriate psychological support alongside other treatment. Psychologists also contribute to the training of health and social care staff who support people living with dementia and their family carers.

Access to psychological understanding and expertise is essential for those living with dementia and for their families and carers at every stage, from diagnosis to end of life care. Psychologists are well-placed to ensure an emphasis on an individual, person-centred approach in each case as well as being uniquely qualified to carry out specialist assessments and interventions. Psychological interventions play a key role in improving the wellbeing of people with dementia and their family and carers. Improving people’s experience of dementia means improving the support they get to process how they feel, and how they understand and think about the condition, their future and their relationships. Maintaining a sense of control, identity and connection is a key focus as dementia progresses. Without it, there is a risk that the person will experience a sense of isolation and dislocation at a time when the resources to protect against this threat are lacking.

Enhancing the contribution of psychological expertise and skills could have wide reaching benefits, including fewer people with dementia, more timely diagnoses, reduction in the need for medication, reduction in psychological distress and behavioural difficulties, reduction or delay in admissions to residential care, increased staff knowledge and expertise, increased carer wellbeing and improvement in quality of life for people living with dementia.

Recommendations

Prevention/risk reduction

- As lifestyle factors contribute significantly to the risk of developing dementia a psychological approach is needed to enable people to make sustainable changes in behaviour and adopt healthier lifestyles.

Assessment

- As part of the diagnostic process, access to timely and prompt psychological assessment, including specialist neuropsychological assessment, is essential.

Planning care

- Improving people's experience of dementia means ensuring that their care and treatment is individually tailored to their needs throughout the dementia journey.
- People with dementia should be supported in making their own decisions as far as possible. When this is not possible, their wishes, feelings, values and beliefs should be taken into account, in consultation with carers, to the greatest extent possible in making decisions in their best interests.

Treatment and support

- People with dementia should have the opportunity to participate in meaningful activities, and be part of a local community that is dementia-friendly and fully supportive.
- Dementia care plans must cover all the person's needs, including equal access to the right healthcare for other mental or physical health needs.
- To ensure the best possible outcomes for people with dementia, multi-agency multi-disciplinary teams in health and social care should include psychologists, and those receiving care in hospitals and care homes should have access to multi-disciplinary teams which include psychologists.
- Psychologists should be involved in training and supporting a workforce able to deliver excellence in dementia care.

Families and carers

- Families and carers play an important role in improving people's experience of dementia. They should be included in care planning and should have access to psychological support.

Training and research

- Inspiring the change needed to deliver excellence in dementia care means investing in psychological research to improve practice.

Introduction

Dementia is an umbrella term that encompasses a group of conditions that progressively reduce the brain's ability to function. Although dementia results from physical changes in the brain, the effects of dementia are primarily psychological in nature, as they involve progressive changes in mental (or 'cognitive') functions such as memory, language, attention, concentration, visual perception, planning and problem-solving. Sometimes these changes are also associated with movement-related difficulties, such as trouble with reaching, walking or swallowing. The result of these changes is to reduce the person's practical ability to manage everyday activities. This often occurs at a time in life when people are also experiencing other changes in health, lifestyle and social engagement.

Dementia has a profound psychological impact, affecting people's sense of identity, how they behave, their mood, and their overall wellbeing, as well as all aspects of their relationships with others and their ability to manage everyday activities. The impact of dementia is not confined to people who directly experience the condition. It also has a major effect on their families and friends, and ultimately dementia touches everyone in society. As awareness and understanding of the personal and social impact of dementia has increased, there has been a growing interest in the role that psychologists can play in its prevention, treatment and management, and in supporting people to live well with dementia.

One major contribution that psychologists have made is to support the move from a narrow focus on disease to thinking about dementia in terms of disability. In this way, psychologists have helped to highlight the importance of focusing on the person rather than the disease, leading to an emphasis on what helps people to live well with dementia. Providing good psychological care is a key element in supporting people with dementia and carers and enabling them to live well with dementia.

This report outlines the role and contribution of psychologists in these areas and presents recommendations for ensuring good psychological understanding and care. Throughout this document, as well as showing recommendations for psychological care, boxes are used to highlight the manner in which good psychological care can lead to optimal outcomes, based on a set of 'I Statements' developed by people with dementia and carers¹ that reflect universally-relevant aspects of the experience of living with dementia.

Dementia in the UK: Facts and figures

There are many conditions associated with dementia, but 89 per cent of these fall into three main categories: Alzheimer's disease (62 per cent), vascular dementia (17 per cent), and mixed Alzheimer's and vascular dementia (10 per cent)². Rarer types of dementia include Lewy body dementia (4 per cent), fronto-temporal dementia (2 per cent) and Parkinson's dementia (2 per cent), with over 100 other diagnoses accounting for the remaining 3 per cent of cases. It is estimated that there were 773,502 people aged over 65 with dementia in the UK in 2014, representing 7.1 per cent of the 65+ population. This is thought to include about 15,000 people from black or minority ethnic groups. While dementia primarily occurs in people aged over 65, and prevalence increases with age, dementia can also affect people of working age. There were thought to be 42,325 people with young-onset dementia (starting under the age of 65 years) in the UK in 2013². People with learning disabilities may experience dementia at a relatively young age; for people with Down's syndrome, where there is a genetic link to Alzheimer's disease, the average age of onset is 55 years. There is currently no medical treatment that can tackle the cause of the cognitive decline, and no cure for any form of dementia. The main pharmacological treatments currently available for symptoms of dementia have limited benefits and are suitable for only a proportion of those diagnosed¹³.

Prevention

Most people who are diagnosed with dementia experience symptoms late in life, where the individual risk of developing the condition is related to a complex range of factors including genes, environment and lifestyle. Some rare forms of dementia occur at an earlier age, and these are more strongly genetically-linked.

It has been estimated that up to one-third of cases of Alzheimer's disease are attributable to the effects of potentially-modifiable factors, such as diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking and limited educational opportunity early in life.³ Social initiatives aimed at tackling inequality and deprivation, increasing activity levels, and improving general health and fitness in the population can all potentially reduce the prevalence of dementia.

Reducing the risk of developing dementia, or delaying its onset, is increasingly considered to be an important goal for health policy both in the UK and elsewhere.⁴ Environmental and lifestyle factors may contribute to triggering changes in the brain linked to the development of dementia, with a range of lifestyle and behaviour choices across the lifespan playing a part. Therefore, helping people to make changes in behaviour and lifestyle could reduce their risk of developing the most common types of dementia such as Alzheimer's disease or vascular dementia in later life. Because the brain changes that lead to these forms of dementia can begin many years before symptoms become evident, adopting healthier behaviours earlier in life could help to counteract this process.

Psychologists are well-placed to contribute to the development and implementation of public health initiatives aimed at promoting cognitive health and reducing the risk of dementia. The interventions aimed at prevention of dementia that are most likely to prove effective are those based on psychological theories of motivation and behaviour change. Research has indicated that social engagement, physical and cognitive activity, and a healthy diet are among the key factors that protect against developing dementia.⁵ Alongside medical factors, therefore, it is important at an individual level to target psychosocial and lifestyle factors that may reduce risk.

Prevention

As lifestyle factors contribute significantly to the risk of developing dementia a psychological approach is needed to enable people to make sustainable changes in behaviour and adopt healthier lifestyles.

Assessment

In order to make an accurate diagnosis, offer an appropriate assessment of severity and progression, and provide effective care and support for people with dementia and their carers from pre-diagnosis to end of life care, it is vital to integrate multiple perspectives, including a psychological perspective. A process of individualised assessment leads to an understanding of the complex interplay of factors affecting the extent to which each individual is able to live well with dementia, and guides the provision of person-centred care throughout the dementia journey.

Psychological assessment

Receiving a diagnosis of dementia is a life-changing event. For the person affected by dementia, becoming aware of significant changes in memory or everyday ability creates a psychological dilemma about whether or not to seek help. Making the decision to acknowledge one's difficulties and to seek help can be a frightening experience, exacerbated by the stigma surrounding dementia in the wider community. While opting to carry on as if nothing has changed may enable the person to avoid some of the emotional distress, it can also lead to increased conflict with family members and increased levels of stress. It is vital that health professionals are sensitive to the psychological impact of what people are experiencing, whilst providing an accurate and timely assessment.

Psychologists are key members of multidisciplinary teams engaged in diagnosis of dementia. They are the only professionals qualified to carry out neuropsychological assessment as well as having the necessary skills to undertake the complex therapeutic interventions that may be required following diagnosis. Psychologists also train other professionals in the use of screening tests that can highlight a need for more detailed assessment, and simpler cognitive tests that can help to confirm a diagnosis where difficulties are already more extensive and well-established.

Counselling before a diagnosis is confirmed is an important part of the diagnostic process during which concerns can be discussed and information given. Where a detailed neuropsychological assessment is needed to establish whether the person's difficulties are due to dementia or to a different condition, the individual and family need to understand the nature, purpose and possible outcomes of the assessment if they are to make an informed decision about whether to proceed.

Once informed consent for diagnostic assessment has been obtained, a neuropsychological assessment carried out by a psychologist working as part of a multi-disciplinary team provides essential information that can help to clarify whether dementia is present and, if so, to determine the specific type and severity of dementia. The clinical signs and symptoms of dementia vary in the different sub-types, and even within any one sub-type there are different profiles and considerable individual differences in the pattern of symptoms.

A neuropsychological assessment involves asking the person, where possible, to complete a set of tasks that evaluate aspects of mental ability in order to identify the pattern of strengths and difficulties. These are likely to cover memory, reasoning, problem-solving, decision-making, planning, attention, language and visual perception. It also involves gathering a comprehensive account of the way in which the person is functioning in

daily life and how this may have changed, as well as information about the person's circumstances, relationships and general health. The resulting information is used to determine the most likely reasons for any difficulties and ways in which these might be alleviated, particularly where the diagnosis is uncertain. Equally importantly, it contributes to a detailed formulation of the person's situation and needs, and makes it possible to identify opportunities for building on the person's strengths and thus to help with developing coping strategies.

What is formulation?

Formulation is the summation and integration of the knowledge that is acquired by assessment. This draws on psychological theory and research to provide a framework for describing a client's needs. What makes this activity unique to psychologists is the knowledge base, experience, and information on which they draw. The ability to access, review, critically evaluate, analyse and synthesise data and knowledge from a psychological perspective is one that is distinct to psychologists, both academic and applied.

Following assessment, communication of the diagnosis must be done sensitively, with sufficient time allowed for discussion and the opportunity for follow-up appointments. Knowledge gained through the processes of pre-diagnostic counselling and assessment can help to ensure that the discussion, and the explanations given, are individually-tailored, and that the person's wishes about how and what to be told are respected. Any ongoing support offered to facilitate adjustment to living with the condition should be appropriate to the needs of the individual and family. Communicating a diagnosis of dementia is challenging for health professionals, and staff engaged in this work benefit from psychological input in developing and maintaining an approach that is sensitive and person-centred.

As dementia progresses, further psychological assessment offers an important means of monitoring progression, identifying retained strengths and responding to changing needs, and ensuring timely and appropriate support. Detailed assessment is sometimes needed to help distinguish whether particular issues are due to dementia or result from other health needs. Psychologists can help families and care staff to understand that care must be adapted as the dementia progresses, so it is vital that there is input from psychologists throughout the trajectory of a person's experience of dementia.

Assessment

As part of the diagnostic process, access to timely and prompt psychological assessment, including specialist neuropsychological assessment, is essential.

Planning care

'I have personal choices and control or influence over decisions about me.'

Choice and control: What does good psychological care involve?

- Listening to what people with dementia want and making sure that their voices are heard.
- Ensuring through clinical leadership that the diagnostic pathway is based on good psychological care; for example, ensuring that pre-diagnostic assessment counselling is offered to everyone seeking a formal diagnosis.
- Contributing a detailed neuropsychological assessment to inform differential diagnosis.
- Ensuring that the expertise, input and involvement of family carers and other advocates is encouraged where the person with dementia needs additional support in exercising choice and control.

Each individual's experience of dementia is unique. Dementia affects people from all groups within society, and it is vital to ensure that all groups have equal access to high-quality services and care in a timely manner throughout the course of dementia. The experience of dementia is influenced both by the types of changes that characterise the person's dementia and by the person's life experience, personality, resources, and family and social context. Dementia is a progressive condition, and the nature of the experience, along with the resulting needs, will change over time. The trajectory and rate of change varies considerably and can be influenced for example by other physical health conditions. The care needs of people experiencing young-onset dementia, who may have young families, who are often physically fit and mobile, and who enjoy the kinds of interests and activities shared by people in their own age-group, can differ considerably from those of people who develop dementia in later life.

There is a need to consider models of service that can improve accessibility. Clinical services must be sensitive to people with a range of abilities, cultures and backgrounds and from different age-groups. Services are less accessible for people from black and minority ethnic groups, who are under-represented in memory clinics. Some groups may require services tailored to their particular needs; for example, specialist expertise is required to diagnose dementia in people whose first language is not English and those with intellectual disability in order to provide appropriate post-diagnostic support.⁶

People cope with dementia in different ways. Some acknowledge and accept the diagnosis, confront its implications, and actively make changes that can help them to manage the condition better. Others cope by trying to keep things the same and taking one day at a time. Some people may be unable to understand the diagnosis and its implications, and a small proportion of people diagnosed with early-stage dementia seem not to acknowledge that they are experiencing any particular difficulties or that there is anything wrong. This apparent lack of awareness may in some cases be caused by changes in the brain, but it can also reflect the way in which people respond to the emotional threat that dementia represents. These different ways of coping mean that psychological support must be based on a formulation of individual needs and circumstances.

Planning care

- Improving people's experience of dementia means ensuring that their care and treatment is individually tailored to their needs throughout the dementia journey.

Understanding dementia from a social and psychological perspective has had a major impact on how the condition is understood and how those experiencing it are viewed.⁷ There is now an increased focus on the importance of asserting and upholding the human rights of people affected by dementia, alongside people with other disabilities. Psychologists are instrumental in the growing move towards inclusion of people with dementia in decisions about their own care and in supporting their active and meaningful involvement in decision-making in their own lives and in service evaluation and planning.⁸ This movement actively contributes to the reduction of the stigma surrounding dementia and the development of dementia-friendly communities.

Maintaining a sense of control, identity and connection is a key focus as dementia progresses. When it becomes harder to remember and communicate important information or to access familiar and personally-meaningful experiences, there is a risk that the person will experience a sense of isolation and dislocation at a time when the emotional resources to protect against this threat are lacking. It is vital that health care staff, together with family and friends and all those in regular contact with a person affected by dementia, work to support and maintain links with key aspects of the person's individual, social and cultural identity, including personal preferences, wishes, memories and experiences, and that this kind of support is integral within different contexts of care. This support helps to engender trust, to establish a sense of security and comfort, and to provide a sense of social connection, and thus maintains wellbeing and self-esteem. Positive interactions and supportive contexts can help to mitigate the impact of particular difficulties or symptoms.

Planning care

- People with dementia should be supported in making their own decisions as far as possible. When this is not possible, their wishes, feelings, values and beliefs should be taken into account, in consultation with carers, to the greatest extent possible in making decisions in their best interests.

Treatment and support

Psychological support and interventions in the early stages of dementia

'I have the knowledge and know how to get what I need and so does my carer.'

Information and support: What does good psychological care involve?

- Promoting an understanding of how information can be communicated in a timely way.
- Signposting people to other sources of information and support along the dementia pathway.
- Working to remove barriers to accessing available support.
- Supporting people to draw up advance statements regarding their future care

Current Government policy emphasises the importance of timely diagnosis of dementia, and of diagnosing a greater proportion of people with the condition. However, a diagnosis is of questionable value if it does not result in access to appropriate information, treatment or support. Support immediately after diagnosis is vital if people are to live well with dementia. There is an urgent need for commissioners and service providers to address this gap in provision, and to identify ways of ensuring that people with dementia and carers receive appropriate psychological support.⁹

Provision of psychological support and access to evidence-based psychological and social interventions can help to promote adjustment, maintain everyday functioning and alleviate psychological distress and therefore reduce the need for medication. Insufficient attention has been paid to ensuring that people with dementia and carers can access these kinds of support, which are only available to a small percentage of those who might benefit.

Psychological interventions play a key role in improving the wellbeing of people with dementia and their carers.¹⁰ Therapeutic interventions such as systemic, cognitive-behavioural and other therapies provided individually or in groups can help people process some of the difficult emotions associated with a diagnosis of dementia and thus adjust and cope. Psychologists encourage family members and care staff to understand the importance of strategies that can help to maintain a sense of identity and connection when memory for important people, events and experiences fades, such as the timely development of life story books.

'I have a sense of belonging and of being a valued part of family, community and civic life.'

Belonging and being valued: What does good psychological care involve?

- Supporting the development of dementia-friendly communities.
- Actively involving people with dementia and their families in service evaluation and strategy development.
- Providing training for voluntary organisations working with people living with dementia.
- Involving people with dementia in training and interventions as 'experts by experience'.

Throughout the four UK nations, dementia-friendly and dementia-supportive communities are being created, where people have an awareness of what it is like to live with dementia and are therefore more likely to be supportive of a person with dementia in their community. The Dementia Friends initiative has energised this process with over 1.5 million recruited throughout the UK since 2014.^{11,12} People with dementia and carers have developed, and participate in, many formal and informal networks including support, self-help and advocacy initiatives.

As dementia progresses, psychological and psychosocial interventions, delivered by staff from a range of disciplines including psychologists, continue to offer important benefits. The selection of appropriate options is based on psychological assessment and formulation from a positive behaviour support perspective that considers all aspects of the person's life, including health, relationships, social networks, and the physical environment. As well as providing psychological interventions, psychologists also support access to a range of interventions offered by other staff groups. These include for example counselling, reminiscence, cognitive stimulation, creative activities, individually-tailored activities, and sensory stimulation. Appropriate interventions can promote wellbeing and increase the likelihood of people with dementia living full lives in their local communities.

Treatment and support:

People with dementia should have the opportunity to participate in meaningful activities, and be part of a local community that is dementia-friendly and fully supportive.

Psychological support and interventions as dementia progresses

'I have support that helps me live my life.'

Support to live a meaningful life: What does good psychological care involve?

- Advising on the development of services that are person-centred and recovery-focused, enabling people to live lives that are meaningful and satisfying.
- Encouraging the collection and use of life stories in clinical practice.
- Working to support the capacity of people with dementia to make their own decisions as far as possible, and identifying and promoting their best interests in areas where they are deemed to lack capacity.
- Providing evidence-based psychological interventions to people with dementia and their carers.
- Devising strategies for maintaining or improving a person's skills, interests and activities, based on a clear understanding of the person's strengths and difficulties and of what is important and meaningful to the person.

Some people with dementia will make the transition to living in a residential home or nursing home. About one-third of people with dementia live in care homes, and about 70 per cent of care home residents have dementia.² Psychological support for the person with dementia and any family members involved can help to ease the transition and allow a smooth adjustment in these very challenging circumstances. Psychologists and other health professionals provide training, psychological support and supervision for staff in residential settings that helps to develop their understanding about ways of providing person-centred, rather than institutional, care.

People with dementia, especially those living in residential care settings, may show high levels of distress or engage in behaviour that others find difficult to understand. Dementia can impact on a person's ability to communicate needs and wishes. Behaviour can be understood as a response to distress or as means of communicating or addressing an unmet need. Often the response to behaviour that is considered difficult is to prescribe anti-psychotic medication or major tranquillisers, despite evidence that this is frequently ineffective in many cases, and may have very harmful effects or even prove fatal in others.¹³ It is now recognised that such medication should not be used until the application of psychological and social interventions has been fully explored, and then only in the short term. An alternative, psychological approach is based on understanding the meaning and function of behaviour, rather than viewing it as an inevitable symptom of an underlying illness.¹⁴

This kind of positive behaviour support is founded on the premises that behaviour occurs for a reason or serves a particular function. It may occur in response to the individual's internal or external environment or reflect an underlying unmet need, pain or illness, and it is influenced by the person's pattern of cognitive strengths and weaknesses. Behavioural approaches involve developing an understanding of why the behaviour occurs, and what internal or external factors trigger or maintain it. This helps to identify ways of preventing the behaviour happening or of responding to it appropriately when it does occur. An acceptance of the importance of cultural and other values is integral to this approach, as is an emphasis on preventative strategies through the delivery of person-centred care.

Psychology and co-morbid health conditions

People with dementia often also have other physical and mental health conditions, with high levels of co-morbidity. For some people, these co-morbid conditions create more of a challenge, and are more disruptive to everyday life, than dementia. It is important that any concurrent health conditions are recognised and appropriate treatment offered. It is also important to accept that treatment for co-morbidities may be refused – either contemporaneously by people with the capacity to do so, or in advance via the mechanism of a legally-binding Advance Decision – (e.g. refusing a feeding tube with end-stage dementia). Treatment of co-morbidities should be provided if – and only if – it is in the person's best interests and has not been legitimately refused. People with dementia should be able to access mental and physical health services appropriate to their needs. Provision of effective psychological therapies for mental health issues such as depression or anxiety requires an understanding of changes in cognition, of the emotional impact of dementia, and of the context in which people experience and live with dementia, including their attachments and relationships. Psychological therapies often need to be adapted to compensate for the impact of cognitive changes and to ensure sensitivity to the individual's wider context. Management of physical health conditions is important to avoid hospital admission wherever possible.

Treatment and support

Dementia care plans must cover all the person's needs, including equal access to the right healthcare for other mental or physical health needs.

Psychology and end of life care

Good end of life care covers all aspects of wellbeing. The focus is on the quality, rather than the length, of life, relieving any discomfort and distress, and providing care that is underpinned by compassion and respect. While dementia itself shortens life expectancy, people living with dementia may also have other life-limiting illnesses which result in death while their dementia is at a relatively early stage.

The European Association for Palliative Care¹⁵ drew on expert evidence and consensus to describe an optimal approach to palliative dementia care. Palliative care should provide relief for the emotional, psychological, relational and physical challenges that face people with severe dementia. Untreated or undertreated pain is commonplace leading to distress, disturbed behaviour, depression, decreased functioning and increased dependency.

People with dementia have the right to make their own decisions about end of life care when they have the mental capacity to do so. This includes the right to consent to or to refuse treatment for other life-limiting illnesses. People in the earlier stages of dementia, who have the capacity to make treatment decisions for themselves, should also be offered the opportunity to make an Advance Decision and should be supported in doing this.

For someone with severe dementia, end of life care may last for weeks, months or even years, making planning uncertain and difficult. The emotional reactions of family and close friends before and after death may be complex, reflecting the long duration of the illness. People living with severe dementia often become isolated, which leads to depression, withdrawal and negative health outcomes. Although spoken language is

likely to be severely affected, the person with dementia will still be able to respond at an emotional level. Carers require the ability to sensitively attend to signs of wellbeing and ill-being and respond appropriately. For both staff and family members, caring for someone at the end of life can be very rewarding and a time of great closeness.

Psychologists are well-placed to contribute to policies aimed at providing co-ordinated and holistic support that responds to an individual's wishes and needs, so that people with dementia end their lives with dignity and free from pain.

Treatment and support

To ensure the best possible outcomes for people with dementia, multi-agency multi-disciplinary teams in health and social care should include psychologists, and those receiving care in hospitals and care homes should have access to multi-disciplinary teams which include psychologists.

Psychology and service delivery

The needs of people with dementia are best met when all services work closely together, alongside other community resources, to deliver integrated care. Psychologists are key contributors to this process. Through their detailed understanding of cognition, behaviour, emotions and social interactions, psychologists offer expertise in many aspects of dementia diagnosis, care and management, as well as prevention and risk reduction. Psychologists from a range of backgrounds and with varying types of expertise contribute to providing effective services and care. Practitioner psychologists are trained to doctoral level and may progress to consultant level, and a continuing commitment to training sufficient numbers of practitioner psychologists is vital. The largest group of practitioner psychologists involved in dementia care are clinical psychologists who work as part of multi-disciplinary teams in memory clinics, services for older people or other specialist services, but psychologists from a range of specialisms also play a vital role. Amongst these are clinical neuropsychologists, health psychologists and counselling psychologists. The nature of practitioner psychologists' training enables them to play a key role in undertaking detailed psychological assessments and interventions, training and supporting other staff groups, evaluating service provision and overseeing the provision of good psychological care.

Psychologists are at the forefront of developing and evaluating interventions, and train and supervise other staff groups to deliver these. These include, for example, information about practical strategies for dealing with memory problems, self-management groups, or individually-tailored cognitive rehabilitation to support engagement in everyday activities, promote independence and boost confidence.

Health and social care staff need training and support to provide high quality, person-centred care to maintain dignity and quality of life. Staff providing care for people with dementia face many challenges and, in addition to skills training, need effective support and supervision, with a focus on maintaining their own psychological wellbeing. Psychologists are vital for the provision of this form of work due to both their academic background and their training in providing therapeutic support at many different levels, including individual, group and systemic psychotherapy and neuropsychological rehabilitation. Psychologists contribute to training care staff in implementing positive behaviour support approaches and can provide specialist expertise where this is needed.

Where stays in acute hospitals are unavoidable, it is essential that staff members at all levels are supported and equipped to care for patients who have dementia. Psychologists are well-placed to contribute to training and supporting staff on general hospital wards to provide good-quality care for patients with dementia and support effective communication of personal needs and preferences.

Treatment and support

Psychologists should be involved in training and supporting a workforce able to deliver excellence in dementia care.

Increasing pressure on health care systems, resulting from financial constraints and the need to develop services that are more responsive to need, is likely to lead to the development of innovative methods of assessment and intervention. It is important that these services are evaluated appropriately and that any new service development continues to hear the voice of people affected by dementia. Psychologists are trained in service evaluation and are well-equipped to contribute to this process.

Families and carers

'I live in an enabling and supportive environment where I feel valued and understood.'

Enabling and supportive environments: What does good psychological care involve?

- Challenging ageist attitudes and reducing the stigma of dementia, and promoting social inclusion and involvement in valued roles and activities.
- Helping families, carers and care staff understand that behaviour that challenges communicates an unmet need.
- Training staff in the use of psychosocial approaches to meet the person's needs.
- Advising on environmental adaptations to promote independence and reduce risk.

Family members of people affected by dementia who take up the caring role cope with this in different ways. They may have other challenges to cope with, such as physical health problems of their own, and they may have to combine caregiving with other family and employment responsibilities. This is particularly the case for carers of younger people with dementia, who have higher levels of burden than their older counterparts, even when severity of dementia and levels of behavioural disturbance are the same. It is important to work with carers and involve them in the process of deciding what kinds of support will be most useful and when.

Providing information can help carers understand the condition and what to expect, and enable them to respond in a helpful way to the needs of the person with dementia. Sharing experiences with other carers in a similar situation can also be invaluable. Beyond this, carers often benefit from detailed advice and training in specific skills that can develop resilience and coping skills, support their own wellbeing and that of the person with dementia, and enable both to maintain a good quality of life. This kind of support may be needed at any stage of dementia, depending on individual needs and circumstances, but should always be available at the time of diagnosis and at key transition points such as a move to residential care. Where care is in danger of breaking down or either the person with dementia or the carer is at risk, skilled couple therapy may be needed.

Carers derive most benefit from structured multi-component psychological approaches provided by skilled and experienced practitioners over a defined period, followed up by ongoing contact. Key components of these interventions are

- **Emotional and psychological support** – encompassing emotional support, counselling or psychotherapy, and development of stress management and self-care strategies.
- **Information** – including developing knowledge about dementia and the support services available, and understanding the behaviour of the person with dementia.
- **Skills training** – focusing on, for example, how to communicate effectively with the person with dementia, how to respond to distress, how to engage a person who has become inactive or withdrawn, and how to support meaningful activity and occupation.
- **Increasing social support** – for some carers, involving the wider family or otherwise strengthening networks of social support is an important consideration.

Families and carers

Families and carers play an important role in improving people's experience of dementia. They should be included in care planning and should have access to psychological support themselves.

Training and research

'I know there is research going on which delivers a better life for me now and hope for the future.'

Participating in research: What does good psychological care involve?

- Promoting engagement of people with dementia and their supporters in setting the research agenda and development of research ideas and protocols.
- Ensuring research opportunities are communicated at a helpful point in the pathway.
- Promoting appropriate research to add to the evidence base on psychosocial interventions.
- Providing smaller scale, qualitative and interview based approaches to researching the experience of people with dementia and their supporters.
- Ensuring that participation in research is a constructive and positive experience for people with dementia and carers.

Research on dementia can help people living with dementia now and help prevent dementia in the future. The Join Dementia Research initiative has been set up to encourage people with dementia and carers to participate in research.¹⁶ Academic psychologists, who may also hold practitioner qualifications, work with colleagues from a range of disciplines to conduct research aimed at understanding aspects of dementia, developing and evaluating interventions, identifying better ways of measuring outcomes, and enhancing the provision of services and care.

Psychologists have made a major contribution to identifying the different sub-types of dementia and outlining their characteristics, and have been at the forefront of attempts to better understand and respond to the experiences of people with dementia and carers. Psychological research has led to, or contributed to, many of the approaches and interventions used regularly to support people with dementia and carers, as well as the development of preventive interventions, and a continuing commitment to funding psychological research is essential. Psychological researchers will continue to work with people with dementia, carers, and colleagues from many disciplines to tackle the ongoing challenge of dementia.

Training and research

Inspiring the change needed to deliver excellence in dementia care means investing in psychological research to improve practice.

Expanded recommendations

Prevention/risk reduction

As lifestyle factors contribute significantly to the risk of developing dementia a psychological approach is needed to enable people to make sustainable changes in behaviour and adopt healthier lifestyles.

- Interventions aimed at reducing the risk of dementia that are most likely to prove effective are those based on psychological theories of motivation and behaviour change.
- Helping people adopt healthy behaviours and lifestyle could reduce their risk of developing Alzheimer's disease or vascular dementia in later life.

Assessment

As part of the diagnostic process, access to timely and prompt psychological assessment, including specialist neuropsychological assessment, is essential.

- Psychologists are the only professionals with specialised and accredited training in conducting neuropsychological assessment as well as the necessary skills to undertake the complex therapeutic interventions that may be required following diagnosis.
- Early diagnosis is of questionable value unless it results in access to appropriate information, treatment or support.
- A neuropsychological assessment contributes to a detailed formulation of the person's situation and needs, and makes it possible to identify opportunities for building on the person's strengths and helping to develop coping strategies.
- As dementia progresses, further psychological assessment offers an important means of monitoring progression, identifying retained strengths and responding to changing needs, and ensuring timely and appropriate support.

Planning care

Improving people's experience of dementia means ensuring that their care and treatment is individually tailored to their needs throughout the dementia journey.

- Dementia is experienced differently by each person. This experience is shaped both by the changes that characterise the specific type of dementia and by the person's life experience, personality, resources, and family and social context.
- Focusing on the person rather than the disease leads to an emphasis on what helps people to live well with dementia.

People with dementia should be supported in making their own decisions as far as possible. When this is not possible, their wishes, feelings, values and beliefs should be taken into account, in consultation with carers, to the greatest extent possible in making decisions in their best interests.

- Maintaining a sense of control, identity and connection is a key focus as dementia progresses. Without it, there is a risk that the person will experience a sense of isolation and dislocation at a time when the resources to protect against this threat are lacking.
- Positive interactions and supportive contexts can help to mitigate the impact of particular difficulties or symptoms.

Treatment and support

People with dementia should have the opportunity to participate in meaningful activities, and be part of a local community that is dementia-friendly and fully supportive.

- Appropriate psychological and psychosocial interventions can promote wellbeing and increase the likelihood of people with dementia living full lives in their local communities.

Dementia care plans must cover all the person's needs, including equal access to the right healthcare for other mental or physical health needs.

- People with dementia often also have other mental and physical health conditions, with high levels of co-morbidity. For some people, these co-morbid conditions create more of a challenge, and are more disruptive to everyday life, than dementia.
- Management of physical health conditions is important to avoid hospital admission wherever possible, and psychologists support the provision of high-quality community-based health care.
- Provision of effective psychological therapies for mental health issues such as depression or anxiety requires an understanding of changes in cognition, of the emotional impact of dementia, and of the context in which people experience and live with dementia, including their attachments and relationships.

To ensure the best possible outcomes for people with dementia, multi-agency multi-disciplinary teams in health and social care should include psychologists, and those receiving care in hospitals and care homes should have access to multi-disciplinary teams which include psychologists.

- Provision of psychological support and access to evidence-based psychological and social interventions can help to promote adjustment, maintain everyday functioning and alleviate psychological distress.
- Psychologists can help to identify ways of preventing distressing or difficult behaviour happening or of responding to it appropriately when it does occur, resulting in reduced prescription of anti-psychotic and neuroleptic medication.
- Psychological support for both the person with dementia and any family members involved can help to ease the transition into a care home.
- Psychologists are well-placed to understand the individual experience of dying and death and to support the individual, the family and others in this and the resultant grief process.

Psychologists should be involved in training and supporting a workforce able to deliver excellence in dementia care.

- Staff providing care for people with dementia face many challenges and, in addition to skills training, need effective support and supervision, with a focus on maintaining their own psychological wellbeing.

Families and carers

Families and carers play an important role in improving people's experience of dementia. They should be included in care planning at all times and have access to psychological support.

- Carers derive most benefit from structured multi-component psychological approaches provided by skilled and experienced practitioners over a defined period, followed up by ongoing contact.
- Carers who are well-supported are better able to provide support over a longer period.

Training and research

Inspiring the change needed to deliver excellence in dementia care means investing in psychological research to improve practice.

- Psychologists have made a major contribution to identifying the different sub-types of dementia and outlining their characteristics, and have been at the forefront of attempts to better understand and respond to the experiences of people with dementia and carers.
- Psychological research has led to, or contributed to, many of the approaches and interventions used regularly to support people with dementia and carers, as well as the development of preventive interventions.

About the authors

The British Psychological Society (BPS) has highlighted dementia as part of its thematic priority of Health and Wellbeing, reflecting the increasing emphasis on dementia as a social, political and economic priority in all four nations of the United Kingdom. The Dementia Advisory Group was formed in 2014. It consists of psychological experts in dementia, both practitioners and academics, and a retired clinical psychologist with a diagnosis of Alzheimer's disease. This advisory group provides expert advice to the Policy Team within the BPS, and has collaboratively produced this position statement on dementia.

The members of the working party are:

Professor Linda Clare (Chair)

Professor Richard Cheston

Professor Robin Morris

Professor Bob Woods

Dr Nicola Bradbury

Reinhard Guss

Professor Matt Lambon Ralph

Professor Marjan Jahanshahi

Professor Elizabeth Warrington

Professor Dawn Brooker

Dr Karen Dodd

Dr Sebastian Crutch

Professor Peter Mittler

Dr Frances Duffy

Dr Lisa Morrison Coulthard (Lead Policy Advisor)

Hannah Farndon (Policy Advisor)

References (extended)

- Aguirre, E., Woods, R.T., Spector, A. & Orrell, M. (2012). Cognitive Stimulation for dementia: A systematic review of the evidence of effectiveness from randomized controlled trials. *Ageing Research Reviews* 12(1): 253–262.
- Alzheimer's Society (2014). *Dementia UK report* (2nd edition). London: Alzheimer's Society.
- Bahar-Fuchs, A., Clare, L. & Woods, R.T. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews, Issue 6*, Art. No.: CD003260.
- Ballard C, Howard R. (2006). Neuroleptic drugs in dementia: Benefits and harm. *Nature Reviews Neuroscience*, 7, 492–500.
- Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London: Department of Health.
- Beattie, A.M., Daker-White, G., Gilliard, J. & Means, R. (2002). Younger people in dementia care: A review of service needs, service provision and models of good practice. *Ageing & Mental Health*, 6(3), 205–212.
- Beck, C., Auer, S., Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J.M., Collins, H., Teri, L., Mittelman, M., Orrell, M., Feldman, H. & Muñiz, R. (2010). Non-pharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, 30, 161–178.
- Brechin, D., Murphy, G., James, I.A. & Codner, J. (2013) *Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester: British Psychological Society.
- British Psychological Society & Royal College of Psychiatrists. (2015) *Dementia and people with intellectual disabilities: Guidance on assessment, diagnosis, interventions and support for people with intellectual disabilities and dementia*. Leicester: British Psychological Society.
- Brodaty H, Green A and Koschera A. (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatric Society*, 51(5), 657–64.
- Brooker, D. (2004) What is person centred care for people with dementia? *Reviews in Clinical Gerontology*, 13(3), 215–222.
- Brooker, D., La Fontaine, J., Evans, S., Bray, J. & Saad, K., (2014) Public health guidance to facilitate timely diagnosis of dementia: Alzheimer's Cooperative Valuation in Europe (ALCOVE) Recommendations. *International Journal of Geriatric Psychiatry*, 29: 682–693.
- Brooker, D. & Latham, I. (2015) *Person Centred Dementia Care (2nd Edition): Making services better with the VIPS framework*. London: Jessica Kingsley Publications.
- Brooker, D., Latham, I., Evans, S., Jacobson, N, Perry, W., Bray, J. Ballard, C., Fossey, J. & Pickett, J (2016) FITS into Practice: Translating research into practice in reducing the use of anti-psychotic medication for people living with dementia in care homes. *Ageing and Mental Health*, 20(7),709–18.
- Chan, D., Livingston, G., Jones, L. & Sampson, E.L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry*, 28(1), 1–17.
- Cherry, M.G., Salmon, P., Dickson, J.M., Powell, D., Sikdar, S. & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology*, 23(04), 251–266.

- Cheston, R (2013) Dementia as a problematic experience: Using the Assimilation Model as a framework for psychotherapeutic work with people with dementia. *Neurodisability and Psychotherapy*, 1(1), 70–95
- Chu, H., Yang, C.Y., Liao, Y.H., Chang, L.I., Chen, C.H., Lin, C.C. & Chou, K.R. (2011). The effects of a support group on dementia caregivers' burden and depression. *Journal of Aging Health*, 23(2), 228–41.
- Clare, L. (2008). *Neuropsychological rehabilitation and people with dementia*. Hove: Psychology Press.
- Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H., van Paasschen, J., Nelis, S.M., Hoare, Z., Yuen, K.S. & Rugg, M.D. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: A single-blind randomized controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry*, 18, 928–939.
- Clare, L., Nelis S.M., Martyr A., Roberts, J., Whitaker, C.J., Markova, I.S., Roth, I., Woods, R.T. & Morris, R.G. (2012). The influence of psychological, social and contextual factors on the expression and measurement of awareness in early-stage dementia: testing a biopsychosocial model. *International Journal of Geriatric Psychiatry*, 27, 161–177.
- Clare, L., Whitaker, R., Woods, R.T., Quinn, C., Jelley, H., Hoare, Z., Woods, J., Downs, M. & Wilson, B.A. (2013). AwareCare: A pilot randomized controlled trial of an awareness-based staff training intervention to improve quality of life for residents with severe dementia in long-term care settings. *International Psychogeriatrics*, 25, 128–139.
- Clemerson, G., Walsh, S. & Isaac, C. (2013). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia*, 13(4), 451–66.
- Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D. & Ballard, C. (2012). Assessment and treatment of pain in people with dementia. *Nature Reviews Neurology*, 8(5), 264–274.
- Dodd, E., Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R. and Gray, R. (2014) An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Services Research*, 14, 592
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomised trial. *British Medical Journal*, 332(7544), 756–761.
- Freyne, A., Kidd, N., Coen, R., Lawlor, B.A. (1999) Burden in carers of dementia patients: Higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry*, 14(9), 784–8.
- Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, J.C., Baker, P.A., Hastings, R.P., Noone, S.J. & Denne, L.D. (2013). Definition and scope for positive behavioural support. *International Journal of Positive Behavioural Support*, 3(2), 14–23.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press
- Lecouturier, J., Bamford, C., Hughes, J.C., Francis, J.J., Foy, R., Johnston, M. & Eccles, M. (2008). Appropriate disclosure of a diagnosis of dementia: Identifying the key behaviours of 'best practice'. *BMC Health Services Research*, 8(95).
- Lincoln, P. et al. (2014) The Blackfriars Consensus on brain health and dementia. *The Lancet*, 383(9931), 1805–1806

- Lishman, E., Cheston, R. and Smithson, J. (2014) The paradox of dementia: Meaning making before and after receiving a diagnosis of dementia. *Dementia: The International Journal of Social Research and Policy*, 15(2), 181–203.
- Lockeridge, S. & Simpson, J., (2012) The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, 12(5), 635–51.
- Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L. & Teri, L. (2010). Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 65B, 691–697.
- Marshall, A., Spreadbury, J., Cheston, R., Coleman, P., Ballinger, C., Mullee, M., Pritchard, J., Russell, C. and Bartlett, E. (2015). A pilot randomised control trial to compare changes in quality of life for participants with early diagnosis dementia who attend a ‘Living Well with Dementia’ group compared to waiting list control. *Aging and Mental Health*, 19(6), 526–535.
- Matthews, F., Arthur, A., Barnes, L.E., Bond, J., Jagger, C., Robinson, L., Brayne, C. and Medical Research Council Cognitive Function and Ageing Collaboration. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the Cognitive Function and Ageing Study I and II. *The Lancet*, 26: 382 (9902), 1405–12.
- Mental Health Foundation (2015) *Dementia, rights and the social model of disability*. London: MHF. Retrieved 18 October 2015 from <http://www.mentalhealth.org.uk/publications/dementia-rights-report/>
- Moniz-Cook, E. & and Manthorpe, J. (Eds) (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley.
- Moriarty, J., Sharif, N. & Robinson, J. (2011). *SCIE Research briefing 35: Black and minority ethnic people with dementia and their access to support and services. (Research Briefings)*. Social Care Institute for Excellence.
- National Dementia Declaration (2016). (Note: While the National Dementia Declaration was developed in England, the ‘I Statements’ represent important aspects of the experience of living with dementia that are equally relevant for people with dementia and carers in all four UK nations – www.dementiaaction.org.uk/nationaldementiadeclaration
- Nelis, S.M., Clare, L., Martyr, A., Markova, I., Roth, I., Woods, R.T., Whitaker, C.J. & Morris, R.G. (2011). Awareness of social and emotional functioning in people with early-stage dementia and implications for carers. *Aging and Mental Health*, 15(8), 961–969.
- Norton, S., Matthews, F.E., Barnes, D.E., Yaffe, K. & Brayne, C. (2014). Potential for primary prevention of Alzheimer’s disease: An analysis of population-based data. *The Lancet Neurology*, 13(8), 788–794.
- Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., del Ser, T., Woods, B., Rossor, M.N., Fox, N.C., Mummery, C.J., Schott, J.M. & Warren, J.D. (2010). The diagnosis of young-onset dementia. *Lancet Neurology*, 9(8):793–806.
- Selwood, A., Johnston, K., Katona, C., Lyketsos, C. and Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101, 75–89.
- Sheppard, C.L., McArthur, C. & Hitzig, S.L. (2015). A systematic review of Montessori-based activities for persons with dementia. *Journal of the American Medical Directors Association*, 17(2), 117–22.

- Sommerlad, A., Manela, M., Cooper, C., Rapaport, P. & Livingston, G. (2014). START (StrAtegies for RelaTive) coping strategy for family carers of adults with dementia: Qualitative study of participants' views about the intervention. *British Medical Journal Open*, 4(6). Available from: <http://bmjopen.bmj.com/content/4/6/e005273.full>.
- Spector, A., Charlesworth, G., King, M., Hoe, J., Lattimer, M., Sadek, S., Marston, L., Rehill, A., Qazi, A., Knapp, M. & Orrell, M. (2015). Cognitive Behavioural therapy (CBT) for anxiety in dementia: A pilot randomised controlled trial. *British Journal of Psychiatry*, 206(6), 509–16.
- Strydom, A., Chan, T., Fenton, C., Jamieson-Craig, R., Livingston, G. & Hassiotis, A. (2013). Validity of criteria for dementia in older people with intellectual disability. *The American Journal of Geriatric Psychiatry*, 21(3), 279–288.
- Subramaniam, P., Woods, B., Whitaker, C. (2013) Life review and life story books for people with mild to moderate dementia: A randomised controlled trial. *Aging & Mental Health*, 18, 363–375.
- Svanberg, E., Spector, A. & Stott, J. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics*, 23(3), 356–71.
- van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans, R.T.C.M. & Verhey, F.R.J. (2011) Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry*, 25, 1091–100.
- Volicer, L. & Simard, J. (2015) Palliative care and quality of life for people with dementia: Medical and psychosocial interventions. *International Psychogeriatrics*, 27:10, 1623–1634.
- Watts, S., Cheston, R., Moniz-Cook, E. Burley, C. & Guss, R. (2014). Post-diagnostic support for people living with dementia. In R. Guss, et al. (2014). *Clinical psychology in the early stage dementia care pathway*. Leicester: British Psychological Society.
- Woods, R.T. & Clare, L. (Eds). (2008) *Handbook of the Clinical Psychology of Ageing*. London: Wiley.
- Woods, B., Clare, L. & Windle, G. (2012). Dementia and related cognitive disorders. In Sturmey, P. & Hersen, M. (eds) *The handbook of evidence-based practice in clinical psychology – Volume 2: Adult disorders*. (pp.97–131). New York: Wiley.
- Woods, B. & Lamers, C. (2016). Psychological problems of older people. In: Carr, A. & McNulty, M. (eds) *The handbook of clinical psychology: An evidence-based practice approach* (2nd edition). London: Routledge.



The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Tel: 0116 254 9568 Fax 0116 227 1314 Email: mail@bps.org.uk Website: www.bps.org.uk



The British
Psychological Society
Promoting excellence in psychology



Division of
Clinical Psychology
Faculty of the Psychology
of Older People

Clinical Psychology in the Early Stage Dementia Care Pathway

Reinhard Guss and colleagues

Collated on behalf of the Faculty of the Psychology of Older People.

*A collaboration of people living with dementia and the
Dementia Workstream Expert Reference Group.*

November 2014



© The British Psychological Society 2014

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Telephone 0116 254 9568 Facsimile 0116 247 0787

E-mail mail@bps.org.uk Website www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

This publication has been produced by the Division of Clinical Psychology Faculty of the Psychology of Older People and represents the views and expert contributions of the members of that Division only.

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.

Contents

Foreword.....	2
Clinical Psychology in the Early Stage Dementia Care Pathway.....	3
Early and timely intervention in dementia: Pre-assessment counselling	6
Cognitive assessment of people who may be developing dementia.....	31
Communicating a diagnosis of dementia.....	39
Post-diagnostic support for people living with dementia	40
FPOP consultation with people living with dementia in the UK:	52
A position paper	
Glossary of terms	61

Foreword

Dementia Challenge and the recent G7 summit have acted as catalysts for renewed energy and commitment. There are growing calls for action regarding timely diagnosis and post-diagnosis support, with the Alzheimer's Society calling for all areas of the UK to achieve a 75 per cent rate of diagnosis by 2017 and suggesting that minimum standards should be set for integrated post-diagnosis advice and support. These are important goals.

Making a diagnosis of dementia, however, can be a very complex process. Receiving a diagnosis of dementia is a life-changing event, and post-diagnosis support must be tailored to individual needs rather than taking a one-size-fits-all approach. All of these activities demand great skill from clinicians and carefully designed service models. Recognising the challenges inherent in responding effectively to the needs of people developing dementia and living with early-stage dementia, members of the Dementia Workstream of the British Psychological Society Faculty of the Psychology of Older People (FPOP) recently embarked on an initiative to provide evidence-based guidelines to support clinicians and clinical services.

FPOP identified four key areas of psychological practice where guidance would be useful – pre-diagnostic counselling, diagnostic assessment, communicating the diagnosis, and post-diagnosis support – and focused on these to develop the guidelines in this set of documents. These guidelines, which clearly demonstrate the contribution clinical psychologists make to the care of people with early-stage dementia, will encourage and stimulate good practice and provide an important basis for new developments that will enhance the services available.

As a result of consultation with people who have dementia and carers, a fifth strand of work was identified, leading to the development of a Guide to Psychosocial Interventions for people in the early stages of dementia. This accessible and informative guide is an exceptionally valuable resource for people with dementia and carers, and will also be useful for clinicians, service providers and service commissioners.

I would like to thank everyone who has contributed to the development of these documents, and especially Reinhard Guss for leading the Dementia Workstream initiative.

Linda Clare

Professor of Clinical Psychology and Neuropsychology, Bangor University and
Chair of the British Psychological Society Dementia Advisory Group.

Clinical Psychology in the Early Stage Dementia Care Pathway

Introduction

The Dementia Strategies of the four Nations stress the importance of early diagnosis of dementia (Department for Health, Social Services and Public Safety, 2011; Department of Health, 2009; Scottish Government, 2010; Welsh Government, 2011), a policy priority further emphasised by the report of the All-Party Parliamentary Group on Dementia (All-Party Parliamentary Group on Dementia, 2012) and the Prime Minister's Dementia Challenge (Department of Health, 2012)) to increase diagnosis rate. Key advantages of diagnosing and treating dementia early are seen as better adjustment, slowing of progression, planning ahead and, ultimately, savings to the health economy due to prolonged independence and delayed need for care home or hospital admission.

The Faculty of the Psychology of Older People (FPOP) is responding to this agenda by publishing, in the form of four linked papers, good practice guidance for clinicians and recommendations for commissioning across the key components of care pathways in early stage dementia. Writing groups consisting of experts from the profession have examined pre-diagnostic counselling and informed consent, cognitive and neuropsychological assessment in memory clinics, communicating about a dementia diagnosis with those affected, and psychosocial post-diagnostic support and interventions.

The writing process was accompanied by extensive consultation with groups of people living with dementia, which has led to an additional position paper summarising the views expressed by service users and an overview of psychosocial interventions that provides information on types of treatments available, their evidence base and for whom they might be helpful. These consultations have influenced the content of the professional papers and quotes from participating service users are included throughout.

Executive summary

Each of the four professionals' papers provides a more detailed summary of findings and recommendations.

- Across the four papers and the service user consultation there is agreement that any care pathway in early dementia has to consider the wide variation in the needs and preferences of people who are developing dementia. Care pathways should offer choices in the type and intensity of treatment and interaction with services. In turn, services should respond by assessing the individual patterns of need and meeting these in different ways and at varying points in the course of the development of the illness.
- Good practice in **pre-diagnostic counselling** and establishing **informed consent** sets the scene for successful future engagement with services and enables people to adapt in such a way that the advantages of early diagnosis are maximised.
 - While some people are keen to be assessed and have a diagnosis as soon as possible, for example, in a 'one stop shop' diagnostic clinic, several sessions of pre-diagnostic work are needed by others to feel confident to engage with the diagnostic process.

- While in later stages of dementia, and for those lacking capacity to make decisions about their assessment and treatment, the provisions of the Mental Capacity Act regarding best interest guidance come to bear. People in the early stages of dementia usually have capacity and are, therefore, entitled to decline further assessment following discussion of the advantages and possible disadvantages.
- The earlier in the development of dementia a diagnosis is attempted, the more likely it is that there will be a need for a complex **assessment of cognitive functioning**. This should involve a Clinical Psychologist with training and expertise in the neuropsychological assessment of people with suspected dementia.
 - Screening tests developed for use in Primary Care are effective in alerting staff to the presence of a more advanced dementia, particularly where this takes the form of Alzheimer’s disease or vascular dementia. Psychologists’ or Clinical Neuropsychologists’ role in situations where the decision is not complex is one of training provision, for example, on the use of standardised clinical screening instruments, clinical supervision and quality control.
 - Early-stage dementia and rarer forms of dementias such as Fronto-temporal dementia or Lewy-body dementia may not be detected by standard screening tests. This emphasises the need for specialist assessment services, including comprehensive neuropsychological assessment by a trained Psychologist.
 - It is essential for Clinical Psychologists to contribute to team discussions when decisions are being made about the level of testing needed to clarify whether dementia is present and if so which type of dementia is indicated.
- Clinical Psychologists are well placed to support teams with the difficult task of **communication about a diagnosis of dementia** and, where appropriate, undertake this, due to their background knowledge of cognitive difficulties and communication processes.
 - Factors such as previous personality and coping styles, cognitive profile, current appraisal of nature and extent of difficulties and a person’s personal preferences all affect how a diagnosis is discussed. This includes at which point in the assessment process the diagnosis is named, and what is required to support a person with cognitive impairment to process the information and adjust well.
 - Sharing and communicating a diagnosis of dementia requires a range of individualised approaches along the early dementia care pathway; recommendations are outlined and a checklist is provided to assist professionals.
- Successful **adjustment to a diagnosis of dementia** is key to the envisaged health and economic benefits of receiving a diagnosis early. However, whether successful adjustment takes place and how it can be maintained is dependent upon the availability of **post-diagnostic psychosocial interventions** and support, particularly for people who do not benefit from currently available medication.
 - There is a range of psychologically-based post-diagnostic interventions. However, due to limited resources availability is variable across the country. This leads referrers and people affected to doubt the helpfulness of referral and undermines the ability of early diagnosis to deliver the hoped for benefits.
 - An overview is given of good practice examples in psychosocial interventions and a model for matching complexity of intervention to needs is outlined.

- This forms a starting point to address the Psychosocial Intervention Gap. It identifies practical ways of ensuring that people who are living with dementia and their families receive adequate support through structured, evidence-based pathways into psychosocial interventions.
- Extensive consultation has been undertaken with people living with the early to moderate stages of dementia. Workshops and focus groups were held in collaboration with DEEP (the Dementia Engagement and Empowerment Project), including groups from the South East, the Midlands, the North West and Scotland. People with dementia commented on each stage of the pathway stating that:
 - One size does not fit all – service responses need to be individualised.
 - Pre-diagnostic counselling is essential for many, and helpful for most.
 - Preferences for how diagnosis is shared vary greatly.
 - Post-diagnostic support and psychosocial interventions are essential, and choices need to be available about the type of intervention and whether it is delivered individually or in groups.
 - Insufficient information is available about the range of psychosocial interventions that have been shown to benefit people affected by dementia.
- In response to the views of service users, a **‘Guide to Psychosocial Interventions’** was developed, describing post-diagnostic support and interventions that have a significant psychological component and apply to the early stage dementia pathway. This excludes medication, physical exercise and purely activity-based interventions and those mainly used in care home environments and in later stages of dementia.
 - The Guide to Psychosocial Interventions can be used as a catalogue with interventions listed alphabetically.
 - The Guide to Psychosocial Interventions is also designed to be useful to people with a diagnosis of early stage dementia and their families, who can inform themselves about interventions to address specific needs.
 - The Guide to Psychosocial Interventions will need to be updated as new evidence and new interventions become available, and a web-based resource is under development to facilitate this.

Reinhard Guss

FPOP Dementia Workstream Lead.

References

- All-Party Parliamentary Group on Dementia (2012). *Unlocking Diagnosis: The key to improving the lives of people with dementia*.
- Department for Health, Social Services and Public Safety (DHSSPS) (2011). *Improving dementia services in Northern Ireland: A regional strategy*. Belfast: DHSSPS.
- Department of Health (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.
- Department of Health (2012). *Prime Minister’s challenge on dementia: Delivering major improvements in dementia care and research by 2015*. London: Department of Health.
- Scottish Government (2010). *Scotland’s National Dementia Strategy*. Edinburgh: Scottish Government.
- Welsh Government (2011). *National Dementia Vision for Wales*. Cardiff: Welsh Government.

Early and timely intervention in dementia: Pre-assessment counselling

Authors

Jenny La Fontaine, Young Onset Dementia Development Officer, Worcestershire Health and Care NHS Trust and Honorary Senior Lecturer, Association for Dementia Studies, University of Worcester.

Anna Buckell, Clinical Psychologist, Early Intervention Dementia Service, Worcestershire Health and Care NHS Trust.

Tanya Knibbs, Mental Health Nurse, Early Intervention Dementia Service, Worcestershire Health and Care NHS Trust.

Mel Palfrey, Mental Health Nurse, Early Intervention Dementia Service, Worcestershire Health and Care NHS Trust.

Introduction

An important aspect of living well with dementia involves the provision of a timely diagnosis and intervention to enable people and their families to make appropriate choices; to access support in order to live well with dementia and to make decisions about the future (Banerjee et al., 2009; Prince et al., 2011). However, in spite of the recognition of the need for effective interventions in dementia, it is suggested that services have often failed to provide adequate support (Alzheimer's Society, 2012; National Audit Office, 2007). The considerable economic and personal costs of dementia combined with evidence of patchy service provision have provided a powerful argument for the need for services to do more, including the need to raise awareness and reduce the stigma associated with dementia (Alzheimer's Society, 2012; National Audit Office, 2007, 2010). In this context National Dementia Strategies for England, Wales, Scotland and Northern Ireland were launched between 2009 and 2011, identifying a range of key objectives (Department of Health, 2009; Department of Health, Social Services and Public Safety, 2011; NHS Wales, 2010; The Scottish Government, 2010). These objectives included raising awareness of dementia; providing early assessment and diagnosis for people with suspected dementia; approaching diagnosis in a sensitive manner and providing high quality, accessible information to people with dementia and their families about the illness. Subsequently, further policy objectives have set out the need for good quality, early diagnosis and intervention (c.f. Department of Health, 2012). Given that it is recognised that an earlier and timely diagnosis has not been the norm within the UK, an important area of research and practice development has sought to understand the factors influencing the journey to help-seeking for people with suspected dementia and the practice of professionals when delivering an assessment and diagnosis. This has included considering the way in which a diagnosis of dementia is shared.

Werner et al. (2013) suggest that research in this area has progressed through a number of stages, beginning with whether people with dementia wanted to know their diagnosis, which included considering whether they should be told (c.f. Bamford et al., 2004;

Husband, 2009; Pratt & Wilkinson, 2003). Subsequently research has considered what best practice in a diagnosis of dementia should be and what influences the experience. Such research has culminated in the recognition of the diagnosis of dementia as a journey, which begins when the person and/or their family notice changes and seek help (Derksen et al., 2006a, 2006b; Lecouturier et al., 2008; Werner et al., 2013). The majority of this research has indicated that many people with dementia want to know their diagnosis and do have the potential to live well with dementia (Bamford et al., 2004; Pratt & Wilkinson, 2003). Nevertheless, it is also clear that for many, a difficult emotional journey occurs alongside assessment and diagnosis. This journey is influenced by many factors, including the considerable stigma associated with dementia, all of which need to be addressed if we are to achieve a timely and earlier diagnosis (Batsch & Mittelman, 2012; Gibson & Anderson, 2011; Moniz Cook et al., 2006; Moniz Cook & Manthorpe, 2009; Vernooij-Dassen et al., 2006).

Consequently in considering what can enable people and their families to live well with dementia, recent research and practice has begun to address how a diagnosis of dementia should be shared, considering the methods of delivery, what should happen following diagnosis, the skills of practitioners involved and the processes required to facilitate adjustment (Karneili-Miller et al., 2012a, 2012b; Manthorpe et al., 2011; Robinson et al., 2012; Werner et al., 2013).

Throughout these three phases, a growing body of evidence has highlighted the need to place the perspectives and experiences of people with suspected cognitive difficulties and their families at the centre of the process. This is particularly important because significant psychological and social adjustment is needed to manage the transition to living well with dementia beyond the diagnosis and also to challenge the stigma associated with dementia (Bunn et al., 2012; Cheston, 2013; Manthorpe et al., 2011; Prince et al., 2011; Robinson et al., 2012). This evidence highlights that people living with dementia and their families have experienced shock, stigma and distress when a diagnosis has been disclosed and were often unprepared for the outcome of an assessment (Bamford et al., 2004; Karneili-Miller et al., 2012a, 2012b; Manthorpe et al., 2011; Robinson et al., 2012). It is also important because the outcome for some may not be a diagnosis of dementia. Therefore, a number of authors have argued for the provision of pre-assessment counselling prior to assessment and diagnosis which can facilitate preparation for possible outcomes and offer choice about assessment (Derksen, 2006b; Lecouturier et al., 2008; Williams, 2004).

This briefing paper reviews current opinion, emerging research and practice on pre-assessment counselling, offered prior to the commencement of assessment and diagnosis. This begins by considering the factors influencing the journey from first noticing symptoms to help seeking, the impact this may have on the way in which people present for assessment and the implications of this for practice. The processes, principles of practice and theoretical frameworks informing pre-assessment counselling are then described. This includes discussion of a number of key issues arising in the initial contact with persons with cognitive difficulties and their family members, including openness and honesty, achieving informed consent, managing expectations and family involvement.

Limitations

Although literature concerning diagnostic disclosure has increased over the past decade, limited evidence concerning interventions and practice in the period prior to assessment and diagnosis exists. Furthermore, this evidence base uses a range of methodologies including reviews, small scale qualitative research and some quantitative studies, thus it is only possible to provide a narrative review at this time. Of those references included in this briefing paper few explicitly address the perspectives of minority communities, such as people from migrant communities. Furthermore, many of the early studies concerning the experiences and perspectives of people receiving diagnostic disclosure were studies of family members in care-giving roles, thus the perspective of people with cognitive symptoms or a diagnosis of dementia are less well represented.

Recognising Early Signs: The journey to help seeking

In recent years, a wide range of research and auto-biographical literature documenting the experience of living with dementia has emerged (c.f. Christine Bryden, 2006; Lucy Whitman, 2009). These narratives have presented a nuanced understanding of the person and family members' experiences, highlighting that while there are considerable difficulties associated with dementia, there is also room for hope, wellbeing, maintenance of identity and continued success. Furthermore, they emphasise that the journey through dementia involves considerable changes and challenges, and that each family's journey is unique, for them as a whole and for each person within that family. The changes and challenges brought about by dementia require that the person with dementia and their family engage in an on-going process of assimilation, adaptation and adjustment (Cheston, 2013; Hellström et al., 2007; Keady & Nolan, 2003; La Fontaine & Oyebode, 2013; Manthorpe et al., 2011).

Recent research has highlighted that people commonly experience changes for at least two years before presenting concerns about cognitive difficulties to a health care professional. Thus in considering the pre-assessment phase, it is necessary for us to understand the factors influencing the journey to help seeking as these will impact upon when, whether and how people seek help and the expectations they have when approaching services (Chrisp et al., 2011). These authors indicate that the process may begin by the person with symptoms recognising something might be wrong. However, it may be some time before the person discusses their concerns with a family member (Chrisp et al., 2011). During this time changes may also be recognised by family members (Chrisp, Taberer & Thomas. 2013; Chrisp et al., 2011; Koppel & Dallos, 2007; Leung et al., 2010; Manthorpe et al., 2011). However, the decision to seek help, and who does this will be strongly influenced by a range of factors including:

- The gradual progression of symptoms and attribution of changes to normal ageing (Boustani et al., 2006; Chrisp et al., 2012; Jones et al., 2010; Leung et al., 2010).;
- Viewing changes as associated with other health problems (Chrisp et al., 2012; Jones et al., 2010; Leung et al., 2010).;
- Unwillingness to recognise the severity of the difficulties by the person with symptoms and/or their family members (Chrisp et al., 2012; Jones et al., 2010).;
- Stigma (Batsch & Mittelman, 2012; Boustani et al., 2006; Iliffe & Manthorpe, 2004; Leung et al., 2010).

- Relationships with health care professionals (Chrisp et al., 2012; Jones et al., 2010).;
- Knowledge, understanding and previous experience of dementia in family members (Jones et al., 2010; Leung et al., 2010).;
- Cultural conceptualisations of dementia, including the presence of the word in different languages (La Fontaine et al., 2007; Seabrooke & Milne, 2009; Tilki et al., 2010).

Research emphasises the difficult emotional and psychological processes occurring for the person and their family members during this period, which may involve distress, disagreement and conflict, fear for the future, concerns about loss of self and identity and the experience of stress (Chrisp et al., 2011; Chrisp et al., 2012; Manthorpe et al., 2011; Moniz-Cook et al., 2006; Rosness, Ulstein & Engedal, 2009). This complex emotional journey can result in considerable challenges within the family context. While some families are able to work together to achieve a way forward, it is evident that such challenges can also result in the person with symptoms and their family members working apart or separately (Chrisp et al., 2012; Keady & Nolan, 2003).

It is evident then, that the initial contact with health care professionals may be made by family members rather than the person with cognitive symptoms, particularly where the person has been experiencing symptoms for some considerable time. While people with cognitive symptoms may seek help, this is often with prompting from family members who were concerned and had noticed changes (Chrisp et al., 2013; Koppel & Dallos, 2007; Leung et al., 2010; Manthorpe et al., 2011).

The first contact is generally with the family doctor or other primary health care professional whose response to the concerns is of critical importance. Evidence suggests that the knowledge, attitudes and skills of health care professionals can act as a barrier to timely help seeking. Consequently improving knowledge and skills among family doctors, primary health care professionals and others who may be in a position to recognise early and timely cognitive changes is of particular importance if people are to come forward for assessment and diagnosis (Belmin et al., 2012, Hansen et al., 2008, Koch & Iliffe, 2010, Martinez-Lage et al. 2010, Mitchell et al., 2011).

The complexities involved in the journey to initial assessment as highlighted above would suggest that when people finally present for assessment, it is likely that they and their families will have a range of concerns, expectations and fears and may be more or less willing to undergo assessment. Accordingly, the need for pre-assessment counselling is of fundamental importance in addressing these issues. Intervention at this stage would seek to ensure that the person is empowered and enabled to make an informed decision concerning further assessment and diagnosis; make decisions about the involvement of their family in this process and begin to address the psychological and social implications of the difficulties they are experiencing. The principles of pre-assessment counselling are now discussed.

Principles of practice in pre-assessment counselling

Pre-assessment counselling involves providing the opportunity for the person with suspected dementia and their families or significant others to fully understand:

- The reasons for referral;
- What assessment will involve;
- The possible outcomes of an assessment; and
- Implications for other areas of life including, driving, work and insurance.

These are necessary steps to achieving an informed decision about undergoing an assessment that may lead to a diagnosis of dementia (Cheston & Bender, 1999; De Lepeleire et al., 2008; Derksen et al., 2006b; Doncaster, Hodge & Orrell, 2012; Moniz-Cook et al., 2006; Williams, 2004).

Pre-assessment counselling generally involves meetings between the person with cognitive difficulties and (with their permission) family members or significant others prior to the commencement of assessment (Aminzadeh et al., 2007; Derksen et al., 2006b; Manthorpe et al., 2011; Moniz-Cook et al., 2006). It will also frequently include providing information and education, which also has the goal of challenging stigma. While this process frequently facilitates significant information about the person and their family that can inform assessment, it is not intended that formal assessment of cognitive function should take place at this stage, unless the person indicates a desire for this to take place.

Given the complex psycho-social processes taking place for the person and their family, pre-assessment interventions should also include the opportunity for the person and their family/significant others to discuss their experiences, concerns and fears. Creating the space for articulation of these concerns is critical to enabling the person and their family to make an informed decision and begin the process of understanding and adjustment. Furthermore, such discussions can assist practitioners in tailoring assessment and diagnosis, understanding the strengths and well-being needs of the person and their family, providing tailored information and education and can inform future planning.

The complexity of this process requires that practice is informed by appropriate theoretical frameworks. Commonly, person-centred care (Brooker, 2008; Kitwood, 1997) informs practice within dementia care. The principles of person centred care have recently been applied to early and timely diagnosis, and emphasise the necessity of timely diagnosis which:

- Places the rights and wishes of the person with cognitive symptoms as paramount in engaging with the process of assessment and diagnosis;
- Emphasises the importance of assessment and diagnosis as key interventions in adjustment to living with dementia, thus the needs of the person and their family should be central to the whole process; and
- Creates opportunities to challenge the stigma and discrimination associated with dementia (Brooker et al., 2013).

These authors further describe the principles that underpin person centred practice in timely diagnosis, including pre-assessment counselling.

Other theoretical frameworks can also usefully inform practice in this area. Cheston (2013) and Betts and Cheston (2012) have recently discussed the assimilation of problematic voices model of change (Stiles, 1999) and describe its potential value in working with people living with dementia. This framework describes three tasks:

1. Helping the person to acknowledge the experience of dementia without becoming emotionally overwhelmed. The person is described as progressing from warding off, to achieving vague awareness;
2. Identifying dementia as the problem while gaining distance and perspective, which is described as enabling the person to understand the impact that dementia is having upon themselves;
3. Working through and trying out problem solutions, which involves the person's active engagement in the development and assimilation of new strategies and ways of being (Betts & Cheston, 2012).

The assimilation model can be appropriately applied to understand the experience of people who present with cognitive symptoms in the pre-assessment phase. Many of the early experiences identified in the literature, such as attributing difficulties to physical health or normal ageing could be understood in part as attempts to 'ward off' the emerging concerns and the associated emotional trauma this brings. Therefore, a key task in pre-assessment intervention is to begin the process described in stage 1, of helping the person to acknowledge the experience of cognitive change and what this might mean for them, and importantly, assisting them to contain the emotions associated with this experience. It would appear that this process could equally be applied to the experience of family members, who as a consequence of the changes in the person with cognitive symptoms may also be undergoing considerable challenges to their own identity and the relationships between family members.

Finally, given the relationship challenges brought about by the experience of dementia, application of family theories may also inform interventions at this stage. Rolland (1994) describes a family systems illness model, which articulates:

1. The impact of chronic illness upon the normal developmental life cycle of the family;
2. A psychosocial typology of illness including the onset, course, outcome and level of incapacitation experienced;
3. The time phases of the illness, including an articulation of the crisis phase occurring prior to assessment, through to initial adjustment following diagnosis; and finally
4. How family adaptation and resilience can be supported in order that they can manage the impact and experience of chronic illness.

In the pre-assessment phase, the application of this model is helpful in assisting practitioners to understand how the cognitive changes are impacting upon family functioning, and furthermore to identify how the family have responded to challenges such as ill health in the past. This can facilitate an exploration of how and in what way family involvement in the process of assessment and diagnosis can be supported, while retaining the rights of the person with cognitive difficulties to make decisions about whether to go forward for assessment and diagnosis. Furthermore, learning about family experiences and strategies for managing ill health and other transitions can support post-diagnostic interventions.

A number of challenges are known to exist in engaging in pre-assessment counselling, including:

- Honesty and openness, including using the word dementia;
- Expectations, fears and coping strategies;
- Facilitating informed consent;
- The involvement of family members.

Each of these issues are now addressed in detail.

Honesty and openness, including using the word 'dementia'

Dementia is among the most feared diseases associated with getting older (Batsch & Mittelman, 2012). Stigma can influence the meanings associated with dementia and can discourage people from seeking help or pursuing an assessment of cognitive difficulties (Batsch & Mittelman, 2012; Boustani et al., 2006; Bunn et al., 2012; Chrisp et al., 2011, 2013; Moniz-Cook et al., 2006). In addition to this, once diagnosed, people can feel stigmatised by the label of dementia (Robinson et al., 2011).

Despite this, research with people with dementia suggests that they want to know their diagnosis (have it named), or to have a choice about whether or not they receive this information (Harman & Clare, 2006; Manthorpe et al., 2011). It has been suggested that the majority of people with dementia wish to be told their diagnosis (Manthorpe et al., 2011; Robinson et al., 2011), however, people with cognitive symptoms and their families can also experience ambivalence and conflict in this respect. People with symptoms may experience a dilemma between wanting to find out more and a wish to avoid thinking about the future or having 'too much' information (Harman & Clare, 2006). Research has also highlighted that differences can exist between the view of the person and their family about whether they should be told about their diagnosis (Robinson et al., 2011).

The pre-assessment process allows these issues (where appropriate) to be identified, named and discussed and allows people to decide whether or not they wish to progress with an assessment and receive the results of this.

This requires a willingness to be open on the part of professionals. However, research identifies considerable difficulties associated with honesty and openness, and disclosing a diagnosis has been rated by professionals as amongst the most difficult aspects of dementia management (Bamford et al., 2004). This is thought to be challenging because of the incurable and stigmatised nature of the illness, along with the emotional aspects, familial and personal costs (Werner et al., 2013). Professionals report difficulty in discussing the diagnosis openly with persons (Bamford et al., 2004; Kaduszkiewicz et al., 2008).

Furthermore, some studies with health professionals (primarily doctors) have specifically identified how clinicians may be reluctant to use the word 'dementia' during their conversations with persons and their families (Lecouturier et al., 2008b). While some report using terms such as 'dementia' or 'Alzheimer's disease', others prefer to use more vague descriptions such as 'confusion' or 'memory problems' (Bamford et al., 2004; Kaduszkiewicz et al., 2008). It is suggested that these euphemisms may be a way of professionals 'dulling the negative understanding' of a diagnosis of dementia (Karnieli-Miller et al., 2007).

While professionals may report positive views about honesty, they also sometimes report conflicting approaches to this in their clinical practice (Kaduszkiewicz et al., 2008; Werner et al., 2013). Lecouturier et al. (2008b, p.95) highlighted that while professionals identify the importance of explicitly naming dementia and avoiding euphemisms, they also reported *'using terminology carefully as a way of getting information across without telling patients what they don't want to hear'*. Maguire (2002) summarise the dilemma often felt by health professionals of being truthful, but at the same time not causing harm.

However, the implications of avoidance or use of euphemisms is significant for the person with cognitive symptoms. People with dementia have reported vague terms to be upsetting, confusing and difficult to interpret (Bamford et al., 2004). Ultimately, if the word dementia is not used by professionals, people with cognitive symptoms are rendered unable to make an informed decision about whether they wish to pursue an assessment (Kaduszkiewicz et al., 2008). There is also the danger that if professionals avoid using the word dementia, this may exacerbate the stigma surrounding the diagnosis. By using the word dementia at the pre-assessment stage, professionals allow people to discuss their thoughts and fears and make the best decisions for them and their situation at that time.

It should be noted, however, that despite research highlighting the importance of honesty and clarity when discussing dementia, this is not necessarily implemented in practice, and evidence suggests that avoidance or inappropriate practice in this regard has been found to induce additional stress on the person and reduce trust in the professional (Karnieli-Miller et al., 2007; Street et al., 2009).

For example, Phillips et al. (2012) draw attention to the fact that whether or not the word dementia is used by professionals, being referred to a specialist service may itself indicate that a diagnosis of dementia is a possibility. This has implications for services, few of which have the word 'dementia' in their title, with many called Memory Clinics or Services.

In terms of 'introducing the idea of dementia', Cheston (2013) provides a framework which discusses how this might be raised, as described earlier. It is suggested that this should take place at the pace a person can manage; that symptoms are discussed before syndromes; and that taking an indirect approach ('some people worry they may have an illness like dementia, is that something that has ever worried you?') might be helpful in allowing a person to explore this as a possibility for themselves.

Some authors identify the importance of retaining a focus on positives and skills within these discussions, which can often draw attention to limitations, losses and difficulties. The process of assessment can be stressful because it uncovers limitations and cognitive deficits (Derksen et al., 2006b) and it is, therefore, suggested that it may be important to also focus on positive aspects of life within the context of the process (Robinson et al., 2011).

While reinforcing the strengths of the person with dementia appears to be beneficial for the relationship between the person and their family (Vernooij-Dassen et al., 2006) and hope can be important for quality of life, Lecouturier et al. (2008) warn against minimising the seriousness of dementia and avoiding detailed discussions if that is what the person requires.

It therefore appears that balancing honesty and hope, or 'fostering a (realistic) sense of hope' (Lecouturier et al., 2008, p.4) is an important (and difficult) balance within these

interactions (Fisk et al., 2007; Milne, 2010). ‘The move between truth telling and being honest while being sensitive and showing concern to persons’ abilities and needs and fear of doing no harm is a continuing struggle that no simple guideline can resolve’ (Werner et al., 2013, p.82).

This is evidently skilled and emotional work, which presents challenges for the person with cognitive symptoms and their families. Gomes Martins and Palmares Carvalho (2013, p.67) also highlight the potential impact of this on professionals, noting that if staff feel insufficiently trained in communication skills, they are more likely to experience distress ‘when faced with patient’s suffering’.

Exploring expectations and experiences, fears and previous ways of coping with difficulties

Significant factors influence a person’s willingness to seek help regarding their cognitive problems and to consent to an assessment (which may result in a diagnosis of a dementia) including their expectations, fears and previous ways of coping with difficult life events. People have different expectations and fears which may influence whether they choose to pursue an assessment, how they experience this and subsequently how they respond to a diagnosis of dementia should this be the outcome. Chrisp et al. (2011) highlight how people may have low expectations about what can be achieved by seeking a diagnosis (that the situation is hopeless and nothing can be done). It is possible that in these circumstances, people may be more likely to decline an assessment, or not seek help in the first place, and experience low mood.

Meanings attached to dementia and beliefs about this are likely to be influenced by a person’s current situation, past experiences and exposure to others with dementia (Bunn et al., 2012; Manthorpe et al., 2011; Moniz-Cook et al., 2006). Societal, familial and personal experience, expectations of normal aging and current health status (Moniz-Cook et al., 2006; Robinson et al., 2011) have all been implicated in influencing expectations and fears about dementia, whether a person wishes to know their diagnosis and how this is processed (Chrisp et al., 2012; Manthorpe et al., 2011; Robinson et al., 2011). The influence of information from the media has also been highlighted as an important factor in this regard, especially when people do not have personal experience of dementia (Manthorpe et al., 2011; Moniz-Cook et al., 2006).

It is necessary, therefore, to know what a person’s expectations about a diagnosis of dementia are before they are given this information (Derksen et al., 2006a, 2006b; Karnieli-Miller et al., 2012; Milne, 2010). Lecouturier et al. (2008b) note that some of the distress caused by a dementia diagnosis relates to a person’s negative attitudes and preconceptions. It has therefore been recommended that ‘Before disclosing a diagnosis of dementia, health professionals should explore the concerns of both the person and their family as to what they think the cause of their cognitive difficulties may be and identify any particular individual concerns around diagnosis’ (Robinson et al., 2011, p.1041). It is also suggested that health professionals need to not only identify concerns and expectations, but also offer a more balanced or realistic view where appropriate (Karnieli-Miller et al., 2012; Lecouturier et al., 2008b).

Exploring a person’s point of view in this way also allows any explanations to be linked to their personal experience, which may enhance their understanding of a diagnosis of dementia should they receive one (Lecouturier et al., 2008b). Pre-assessment counselling,

therefore, provides the opportunity for people to talk about expectations, express their fears and potentially address inaccurate beliefs (Moniz-Cook et al., 2006). These may differ in families (Fisk et al., 2007; Karnieli-Miller et al., 2012). For example, Moniz-Cook et al. (2006) identified fears around losses for both the person receiving an assessment and their carer, with a slightly different emphasis for each. It also allows these conversations to start at the person's understanding so that further discussions are at their pace and are meaningful to them.

In addition, this pre-assessment process allows professionals to use the information and understanding gained at this stage to plan their approach to assessment and sharing of the diagnosis and to start to identify possible needs for the person and their family where appropriate (Derksen, 2006; Lecouturier, 2008). This allows their care throughout this process to be based on actual rather than perceived needs (Wilkinson, 2002), or a 'one-size-fits-all' approach. Pre-assessment counselling further raises the diagnosis of dementia as a possibility and, therefore, allows a process of disclosure (Manthorpe et al., 2011). Involving people in pre-assessment discussions about expectations regarding possible outcomes of assessment can reduce feelings of shock if a diagnosis of dementia is received (Beattie et al., 2004; Derksen et al., 2006; Lecouturier et al., 2008; Manthorpe et al., 2011; Robinson et al., 2011, Vernooij-Dassen et al., 2006) and research indicates that people who receive informal feedback about the possible diagnosis before the formal disclosure were less anxious (Carpenter et al., 2008; Lecouturier et al., 2008, 2008b; Manthorpe et al., 2011).

In addition to this it can be helpful to identify a person's expectations, hopes and fears about the assessment itself and prepare them for the reality of what this might involve. Several difficulties with the assessment and diagnosis process have been identified and prior discussion about expectations and what will happen when, may avoid these problems.

- Manthorpe et al. (2011) note that waiting can be a time of great uncertainty and worry for people, commenting that for participants in their research it was not generally the waiting that caused distress but the 'lack of information about why that was occurring'. People sometimes felt that the pathway was fragmented and feared never getting a conclusion (Manthorpe et al., 2011). This is echoed by Koppell et al. (2007) who found that people often expected that clarification of memory problems would happen at assessment and that how far they felt they had an explanation at this time influenced their satisfaction, along with how much they felt involved in the process. Robinson et al. (2010) found high levels of anxiety regarding what to expect and when and that participants wanted to be informed about what was happening at every stage, highlighting the relationship between uncertainty and anxiety.
- Inaccurate expectations of scans as diagnostic tools may also be present (Manthorpe et al., 2011) and research has also identified that people are often not prepared for the possibility of diagnostic uncertainty. Many people seek assessment because they believe there will be an answer and experience disappointment when this is not provided (Karnieli-Miller et al., 2012; Manthorpe et al., 2011).
- Research also suggests that people may have unrealistic expectations regarding 'solutions' such as medication or other treatments (Bunn et al., 2012; Karnieli-Miller et al., 2012; Manthorpe et al., 2011; Milne, 2010; Moniz-Cook et al., 2006).

Discussions at the pre-assessment stage therefore enable these expectations to be identified and explored. People frequently experience anxiety and frustration when their expectations are not met (Manthorpe et al., 2011) and this process may, therefore, aim to 'reduce or manage the gap between the information to be disclosed and [the person's] beliefs and expectations' (Lecouturier et al., 2008, p.4). This in turn may facilitate engagement, adjustment and coping and reduce anxiety and distress.

In terms of the impact of a diagnosis of dementia, coming to terms with loss on multiple levels (psychologically, socially and functionally) may be the greatest difficulty people with dementia face (Manthorpe et al., 2011; Robinson et al., 2011). It is, therefore, possible that previous experience of loss may influence this experience. In addition to this, family members in caring roles may also increasingly have to cope with greater responsibility while maintaining 'emotional status quo' (Robinson et al., 2011).

Dementia can represent 'a profound existential threat' (Cheston, 2013) and a range of ways of coping with these experiences and feelings has been identified in the literature, including feeling empowered, experiencing difficulty accepting the diagnosis, ambivalence in this respect and active denial (Cheston, 2013; Manthorpe et al., 2011; Robinson et al., 2011). These ways of coping may be conducted individually, in couples or wider systems (Hellstrom et al., 2005).

Taking notice of a person's awareness of their cognitive problems prior to diagnosis (Derksen et al., 2006) might be beneficial in supporting them following this. Working with people at the pre-assessment stage may help to identify how people might cope with a diagnosis of dementia (and build on their natural strategies), and also to highlight those who may experience greater difficulty adjusting. Previous ways of coping may indicate how a person might cope with this news (Cheston, 2013). If it is possible to understand how people naturally cope and adjust we may, therefore, be able to build on these strategies to support them in adjusting to a dementia diagnosis (Clare, 2002). It has also been noted that people sometimes develop ways of coping with dementia prior to diagnosis (Moniz-Cook et al., 2006) and describe how they might cope or 'achieve positive outcome for the 'self' in the face of the threat [of dementia]' (Moniz-Cook et al., 2006, p.387), again supporting the possible benefits of an awareness of these issues at the pre-assessment stage.

Different ways of coping may, of course, be helpful in different circumstances, for different people and at different times (for example, problem solving versus reframing (Ducharme et al., 2009)). Research has identified people, couples and systems that may be more likely to experience greater difficulty in adjusting to, or coping with, a diagnosis of dementia. In particular, those whose worth depends on what they do, rather than who they are (Cheston, 2013; Manthorpe et al., 2011) and those with a family history of conflict (Manthorpe et al., 2011). In addition to this it has been suggested that those with poor previous marital relationships might experience increased fear about the future of the relationship (Manthorpe et al., 2011).

It may, therefore, be beneficial to assess the 'potential for adverse psychological consequences [which] may be avoided or moderated through educational interventions early in the diagnosis process' (Fisk et al., 2007, p.408). Therefore, pre-assessment may offer the opportunity to provide people and families time for support with recognition and change (Moniz-Cook et al., 2006) and facilitate the timely identification of those who need

specialist psychological support as has been recommended (Manthorpe et al., 2011; Milne, 2010; Robinson et al., 2011).

Informed Consent

A fundamental aspect of pre-assessment counselling is providing the person with cognitive symptoms with the opportunity to make an informed decision about going forward with assessment and diagnosis. The Mental Capacity Act (MCA) (2005), Adults with Incapacity (AWI) (Scotland) Act (2000) and Human Rights Legislation (1998), therefore, have particular relevance to the provision of pre-assessment counselling. Human Rights Legislation indicates that the rights of the person must be respected when delivering care and that professionals are morally and legally bound to ensure that the person is able to express their opinion and have choice and control over their lives. Furthermore, both the MCA and the AWI provide a structure for working with people to maximise their involvement in decision making concerning their own lives. These acts are underpinned by the following five key principles:

- A presumption of capacity;
- The right for people to be supported to make their own decisions;
- Retain the right to make what may be seen as unwise or eccentric decisions;
- Best interests; and
- Least restrictive interventions (Mental Capacity Act 2005; Adults with Incapacity, Scotland, 2000).

A person must give their permission before they receive any type of intervention, regardless of what intervention is required. These acts provide a statutory framework for working with people to support their involvement in making specific decisions, and to assess the person's ability to make the particular decision. They also ensure good practice when a decision must be made on a person's behalf due to loss of capacity.

Legislation, therefore, provides a foundation for the professional when delivering pre-assessment counselling, firstly that professionals should begin with an assumption that capacity is present and secondly to ensure that the person with cognitive difficulties is assisted to make an informed choice about whether they wish to pursue an assessment of their cognitive abilities. The process of informed consent should be an ongoing process which begins when the person with cognitive symptoms makes contact with a primary care health professional, as it is at this point that a person may give consent to a referral for assessment.

Seeking valid consent during pre-assessment counselling involves a discussion which ensures that the person understands that any further involvement with the service is with their consent and that they understand the options available to them. To provide valid consent the person must understand what they are consenting to, which requires that good quality, personalised information is provided.

Therefore, the pre-assessment appointment begins with a discussion of their concerns which led them to seek support from their GP. This provides the opportunity to sensitively explore the person's understanding of the word dementia and conditions that can cause dementia. Evidence suggests that people who refuse a clinical diagnostic assessment for dementia after screening do so, in part, because of the stigma associated with mental health (Boustani et al., 2006). Therefore, in addressing informed consent within

pre-assessment counselling, it is important that information giving incorporates explanations about the physical changes that occur in the brain with conditions such as Alzheimer's disease and vascular dementia, which can help to address the stigma and fears associated with dementia including pre-conceived beliefs about losing one's mind.

Information should be provided on what will be offered should a diagnosis of dementia be confirmed. This includes information concerning treatments, interventions, information and support available and discussing the advantages of future planning. It is also important that people understand that at times diagnostic uncertainty is a possibility. The person is also encouraged to consider whether they wish to be informed of their diagnosis and with whom this information can be shared, where they wish to receive the outcome of their assessment and who they want to be present when outcomes of assessment are disclosed. This information should be shared with colleagues involved in assessment and diagnosis to ensure all are aware of the person's wishes.

Facilitating informed consent involves considerable skill, as professionals are involved in emotionally charged communication about an incurable and stigmatised condition that is associated with personal, familial and societal costs (Karnieli-Miller et al., 2007; Werner et al., 2013). Studies in other chronic disease showed that interpersonal ability and the professional skill of the professional involved in 'disclosing the news' had a profound effect on the level of hope and anxiety in adapting to the condition identified. The nature of pre-assessment counselling may hold considerable fear for people and may in itself be misconstrued as 'the beginning of the end'. It may be that more than one appointment will be required, to sensitively explore, for example, concerns about loss of a driving licence or the impact on travel and independence before the person is ready to make a decision. A person may change their decision at any point in this process.

Nevertheless, for some people, the appointment can be a difficult experience (Keady & Gillard, 2002) and for their own reasons the person may choose to not continue with the assessment process. Professionals at this stage may need to explore reasons including for example, an inability to recognise the symptoms others have observed or the potential implications of receiving a diagnosis of a dementia, such as having to inform the DVLA and increased holiday insurance premiums.

As autonomy is easily compromised by cognitive difficulties, a loss of personal freedom can be encountered, particularly when the referred person is facing an increased need to be dependent on others. In these circumstances, there are risks that other people may take over in talking for that person, thus their rights and autonomy can be denied. A skill for professionals involved in the pre-assessment phase is therefore to ensure a person's autonomy is respected and that their decision making ability is supported. It is important that the professional treats consent as an ongoing process and ensures that the person is aware that they can withdraw from the assessment process at any stage. Following pre-assessment counselling, as long as the person has the capacity to consent, their right to refuse to continue with assessment should be respected. Where their decision to refuse is in conflict with those supporting them, opportunities should be given to explore ways of providing information and support to family members/significant others.

Providing information for people with cognitive symptoms where they have refused assessment following pre-assessment counselling will be necessary. It is important to enable

people to realise that they can come back to the service at a later date. Indeed, evidence from service evaluation in one area suggests that those people who initially refused assessment following pre-assessment counselling, do return when the time is right for them to undertake assessment and diagnosis (La Fontaine et al., 2011).

Involvement of Families or Significant Others

As highlighted previously, family members also experience difficulties associated with the onset of cognitive difficulties (Manthorpe et al., 2011; Robinson et al., 2012). They experience considerable changes in relationships and roles, including the transition to becoming a carer; all of which can negatively impact upon their own health and wellbeing (Gallagher-Thompson et al., 2012; Prince et al., 2011). Close family members may notice changes before or at the same time as the person and may also have difficulty in exploring these for similar reasons to those impacting upon the person's help seeking. Family members may also seek help at a point when the person with cognitive symptoms is not ready in an effort to make sense of the changes, with the resulting risks to personal autonomy (Chrisp et al., 2012). While it is important to support the autonomy of the person with cognitive symptoms, as dementia impacts upon relationships and remaining at home is largely predicated on family care and support (Brooker et al., 2013; La Fontaine & Oyebode, 2013), including family members in the process of assessment and diagnosis is an important consideration in the provision of pre-assessment counselling.

To engage family members in the pre-diagnostic stage of an assessment requires consent from the person with cognitive difficulties. However, there is frequently a family member present at initial contact with services, indeed family are regularly called upon for collateral history (Tuffrey-Wijn, 2012). This is often invaluable, as the nature of cognitive difficulties may mean that the person themselves is not aware of subtle changes (Chrisp et al., 2011; Koppel & Dallos, 2007). Their involvement in the pre-assessment counselling process also provides family members with the opportunity to discuss their concerns, express their expectations of the service (Williams, 2004) and highlight their agenda, which may or may not be similar to the person with cognitive difficulties. However, family members can find it very difficult to talk about their concerns and what they have observed in front of the person with the symptoms or vice versa. Therefore, it may be necessary to provide space to talk separately.

It is not uncommon for family to encourage an assessment, the reasons for which include wanting clarity and understanding (Lecouturier et al., 2008), access to treatment (Fisk et al., 2007), planning for later life (Lecouturier et al., 2008) and to provide guidance for suitable care provision (Connell et al., 2004). Some family members may not wish to proceed with assessment, often through fear or previous experience (Vernooij-Dassen et al., 2005), denial of difficulties or due to the geographical distance lived from the person with cognitive difficulties (Teel, 2004). Some relatives fear the change of a relationship from being a spouse, a son or a daughter to a 'carer' and the implications this carries regarding shift in decision making and responsibilities (Adams, 2008; Robinson et al., 2011). On occasions family members will encourage a person with cognitive difficulties to decline an assessment when they realise there is no cure and view this negatively as a service's inability to meet their expectations. This has at times been due to a drive by the media which has produced unrealistic expectations (Bunn et al., 2012) and treatments being symptomatic rather than curative (Moniz-Cook et al., 2006).

During the pre-assessment counselling appointment, it is not uncommon to experience a family member who is anxious to 'protect' the referred person and will rationalise the symptoms that led to the referral. Chrisp et al. (2012) suggests this to be 'normalising the problem' and Moniz-Cook (2008) refers to this as 'protective care giving', where the spouse is protecting the self image of their partner developing a dementia. Subsequently at a post diagnostic stage Bunn et al. (2012) observed carers continuing to balance protection and independence. Where such reactions are occurring, it is helpful to consider strategies which may assist both parties to acknowledge the difficulties occurring, and on occasions, it may be helpful to carry out an initial assessment such as the ACE III in order that the person and their family member supporter are able to move towards acknowledgement of the cognitive changes (Chrisp et al., 2012), as well as highlighting the strengths of the person in order that meaningful discussions can take place about a way forward.

It is necessary to acknowledge that all present will have a personal agenda and varied levels of knowledge (Williams, 2004), which may also include children. Managing expectations, frustrations and emotional distress of the family members (Bamford et al., 2004) can be a challenging service to deliver. This is best met with open dialogue, partnership approaches and continual assessment of the dialogue between the person, their family members and the professional.

Conclusion

Adjustment to a diagnosis of dementia (for the person and their family) is a process which is likely to be influenced by many factors including societal and cultural perspectives, individual expectations, previous experiences and fears and a person's current situation, including whether they present early or later in the disease process. (Manthorpe et al., 2011). A person's experience of adjustment is likely to change over time and will influence their needs and facilitating transitions (particularly role transitions) has been indicated as being potentially one of the key roles played by nurses and other professionals (Ducharme et al., 2009).

This adjustment process begins before people come into contact with specialist services. People, couples and families have been through a process of becoming aware of difficulties, discussing these and seeking help, before being referred for assessment (Bunn et al., 2012; Chrisp et al., 2011, 2012; Moniz-Cook et al., 2006). There may be two-and-a-half years from noticing changes to seeking help, a period of time which may involve psychological, practical and relational processes (Chrisp et al., 2011; Derksen et al., 2006) and may influence what each person needs from services.

It is important to note that the person and their family may have different needs, which could be in conflict with each other and consequently difficult to manage. This may require support from two or more professionals over more than a single encounter (Karnieli-Miller et al., 2012). For example, it may not be the person with the possible dementia who has sought a referral (Chrisp et al., 2012) and it may, therefore, be that they and their family members have different perspectives, hopes and expectations and, therefore, needs (Bunn et al., 2012; Chrisp et al., 2012; Derksen et al., 2006b; Ducharme et al., 2009; Gibson & Anderson, 2011; Lecouturier et al., 2008; Manthorpe et al., 2011). These may also be influenced by wider cultural factors (Bunn et al., 2012; Fisk et al., 2007; Koppell et al., 2008; Manthorpe et al., 2011; Robinson et al., 2011; Werner et al., 2013).

Some people will seek information and others will reject this (Bunn et al., 2012), preferring little or no information (Milne, 2010), and giving information at the wrong time may be unhelpful. For example, Boustani et al. (2006) reported that 48 per cent of those screened refused further assessment for dementia. Not all of these people had presented with concerns about their cognitive function, suggesting that this may not have been a concern to them at this stage, or they were not ready to engage in this process.

More generally research has highlighted the need for personally tailored, timely information as critical and noted that needs are likely to evolve over time (Bunn et al., 2012; Ducharme, 2009; Koppell et al., 2008; Lecouturier et al., 2008, 2008b; Manthorpe et al., 2011; Moniz-Cook et al., 2006; Robinson et al., 2011; Werner et al., 2013).

The process of adjustment is supported by delivering pre-assessment counselling, which allows for the opportunity to:

- Explore the perspectives and views of the person with cognitive difficulties and their family prior to disclosure in order to determine how best to communicate the diagnosis (Connell et al., 2004; Karnieli-Miller et al., 2007; Robinson et al., 2011);
- Enable people with cognitive symptoms to retain autonomy and be in control of the process, including the pace of information, assessment and disclosure of the diagnosis should this be relevant (Manthorpe et al., 2011, Werner et al., 2013);
- Enable the process to be personally tailored to the person and their family members' needs, including, for example, written information (Carpenter et al., 2008; Derksen et al., 2006b; Gibson & Anderson, 2011; Lecouturier et al., 2008b; Milne, 2010; Robinson et al., 2011; Werner et al., 2013);
- Avoid the negative outcomes associated with unmet need at diagnosis (such as feeling that information and support were inadequate) (Bamford et al., 2004; Werner et al., 2013); and
- Provide specifically tailored information to meet needs (Robinson et al., 2010).

Successful diagnosis giving and post-diagnostic support may be facilitated by good quality pre-assessment counselling, which highlights the person's needs and engages people in this process (Fisk et al., 2007), which it appears must be integrated in order that services can respond flexibly to needs from referral to discharge (Jha et al., 2013; Werner et al., 2013).

It is evident that in order to sensitively deliver pre-assessment counselling, the skills of the professionals will need to be addressed. The skills, attitudes and knowledge required of professionals working in this way are considerable, and evidence suggests that professionals working in primary and secondary mental health care do not necessarily feel prepared to deliver such interventions or to manage the emotional impact of such work (Buckell, 2007; Burgers et al., 2012; Kaduskiewicz et al., 2008; Karnieli Miller et al., 2007; Lecouturier et al., 2008; Werner et al., 2013). Supervision and appropriate exploration of personal beliefs concerning dementia are likely to be a necessary part of enabling professionals to work in this way.

Person-centred approaches to enhance control and dignity (Zaleta & Carpenter, 2010) and the benefits of a person- and family-centred approach in disclosing 'grave medical conditions' has long been advocated along with the importance of communication skills and ability to respond to potential differences in needs among family members (Karnieli-Miller et al., 2012). Werner et al. (2013) identifies the positive effects of communication

skills training for staff members (increasing their willingness and desire to discuss diagnosis and prognosis) and the potential need for training around communicating in triads (the person, carer and professional), which may enhance the ability of clinicians to take account of cognitive impairment in communication, build emotional rapport (Zaleta & Carpenter, 2010) and respond flexibly to need.

References

- Adams, K.B., McClendon, M.J. & Smyth, K.A. (2008). Personal losses and relationship quality in dementia caregiving. *Dementia*, 7(3), 301–319.
- Adults with Incapacity Act (Scotland). Act.
(http://www.opsi.gov.uk/legislation/scotland/acts2000/asp_20000004_en_1).
- Alzheimer's Society (2012). Dementia 2012: A national challenge. Accessed March 2012, from: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1389
- Aminzadeh, F., Byszewski, A., Molnar, F.J. & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregiver's perspectives. *Aging and Mental Health*, 11(3), 281–290.
- Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C. & Bond, J. (2004). Disclosing a diagnosis of dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 19, 151–169.
- Banerjee, S. & Wittenberg, R. (2009). Clinical and cost effectiveness of services for early diagnosis and intervention in dementia. *International Journal of Geriatric Psychiatry*, 24, 748–754.
- Batsch, N.L. & Mittelman, M.S. (2012). *World Alzheimer Report 2012, Overcoming the stigma of dementia*. Alzheimer's Disease International. Available online at: <http://www.alz.co.uk/research/world-report-2012>
- Beattie, A., Daker-White, G. & Gillard, J. (2004). 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. *Health and Social Care in the Community*, 12, 359–368.
- Belmin, J., Min, L., Roth, C., Reuben, D. & Wenger, N. (2012). Assessment and management of persons with cognitive impairment and dementia in primary care. *The Journal of Nutrition, Health & Aging*, 16(5), 462–467. (France & California). (QuR).
- Betts, N. & Cheston, R. (2012). From warding off to working through: Helping people facing a diagnosis of dementia to change their relationship with their memory problems. *PSIGE Newsletter*, 118, 35–42.
- Boustani, M., Perkins, A.J., Fox, C., Unverzagt, F., Austrom, M.G., Fultz, B., Hui, S., Callahan, C.M. & Hendrie, H.C. (2006). Who refuses the diagnostic assessment for dementia in primary care? *International Journal of Geriatric Psychiatry*, 21, 556–563.
- Brooker, D. (2007). *Person-centred dementia care: Making services better*. London: Jessica Kingsley Publishers.
- Brooker, D., La Fontaine, J., Evans, S., Bray, J. & Saad, K. (2013). *Timely diagnosis of dementia*. Alzheimer Co-operative Valuation in Europe Synthesis Report. Available online at: <http://www.alcove-project.eu> (WP5, timely diagnosis of dementia).
- Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia*. London... Jessica Kingsley Publishers.

- Buckell, A. (2007). *What is the experience of staff members of the assessment and diagnosis of people presenting with memory problems?* Unpublished Doctoral Thesis, University of Coventry and Warwickshire.
- Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E. & Iliffe, S. (2012). Psychosocial factors that shape person and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Med*, October 9(10), e1001331. doi: 10.1371/journal.pmed.1001331. Epub 2012 Oct 30. <http://www.ncbi.nlm.nih.gov/pubmed/23118618>
- Burgers, C., Beukeboom, C.J. & Sparks, L. (2012). How the doc should (not) talk: When breaking bad news with negations influences persons immediate responses and medical adherence intentions. *Person Education and Counselling*, 89, 267–273.
- Carpenter, B.D., Xiong, C., Porensky, E.K., Lee, M.M., Brown, P.J., Coats, M., Johnson, D. & Morris, J.C. (2008). Reaction to a dementia diagnosis in persons with Alzheimer's disease and mild cognitive impairment. *Journal of the American Geriatric Society*, 56, 405–412.
- Cheston, R. & Bender, M. (1999). *Understanding dementia; the man with the worried eyes*. London: Jessica Kingsley Publishers.
- Cheston, R (2013) Dementia as a problematic experience: using the Assimilation Model as a framework for psychotherapeutic work with people with dementia. *Neurodisability and Psychotherapy*, 1(1), 70–95.
- Chrisp, T.A.C., Thomas, B.D., Goddard, W.A. & Owens, A. (2011). Dementia timeline: Journeys, delays and decisions on the pathway to an early diagnosis. *Dementia*, 10(4), 555–570.
- Chrisp, T.A.C., Tabberer, S., Thomas, B.D. & Goddard, W.A. (2012). Dementia early diagnosis: Triggers, supports and constraints affecting the decision to engage with the health care system. *Aging & Mental Health*, 16(5), 559–565.
- Chrisp, T.A.C., Tabberer, S. & Thomas, B.D. (2013). Bounded autonomy in deciding to seek medical help: Carer role, the sick role and the case of dementia. *Journal of Health Psychology*, 18(2), 272–281.
- Clare, L., (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Ageing and Mental Health*, 6, 139–148.
- Connell, C.M., Boise, L., Stuckey, J.C., Holmes, S.B. & Hudson, M.L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist*, 44(4), 500–507.
- De Lepeleire, J., Wind, A.W., Iliffe, S., Moniz-Cook, E.D., Wilcock, J., Gonzalez, V.M., Derksen, E., Gianelli, M.V., Vernooij-Dassen, M. & Interdem Group (2008). The primary care diagnosis of dementia in Europe: An analysis using multidisciplinary, multinational expert groups. *Aging & Mental Health*, 12(5), 568–576.
- Department of Health (2009). *Living well with dementia: A National Dementia Strategy*. Available online at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
- Department of Health (2012). *Prime Minister's Challenge on Dementia – Delivering major improvements in dementia care and research by 2015*. Available online at: <http://www.dh.gov.uk/health/2012/03/pm-dementia-challenge/>

- Department of Health, Social Services and Public Safety (2011). *Improving Dementia Services in Northern Ireland; A regional strategy*. Available online at: <http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf>
- Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde Rikkert, M. & Scheltens, P. (2006a). Impact of diagnostic disclosure in dementia on persons and carers: Qualitative case series analysis. *Aging & Mental Health*, 10(5), 525–531.
- Derksen, E., Vernooij-Dassen, M., Scheltens & Olde-Rikkert, M. (2006b). A model for the disclosure of a diagnosis of dementia. *Dementia*, 5(3), 462–466.
- Doncaster, E., Hodge, S. & Orrell, M. (2012). *Memory Services National Accreditation Programme*. Royal College of Psychiatrists' Centre for Quality Improvement. Available online at: www.rcpsych.ac.uk/memory-network
- Ducharme, F., Beaudet, L., Legault, A., Kergoat, M-J., Levesque, L. & Caron, C. (2009). Development of an intervention programme for Alzheimer's caregivers following diagnostic disclosure. *Clinical Nursing Research*, 18(1), 44–67.
- Fisk, J.D., Beattie, B.L., Donnelly, M., Byszewski, A. & Molnar, F.J. (2007). Disclosure of the diagnosis of dementia. *Alzheimer's and Dementia*, 3, 404–410.
- Gallagher-Thompson, D., Tzuang, Y.M., Au, A., Brodaty, H., Charlesworth, G., Gupta, R., Lee, S.E., Losada, A. & Shyu, Y-I. (2012). International perspectives on non-pharmacological best practices for dementia family caregivers: A review. *Clinical Gerontologist*, 35(4), 316–355.
- Gibson, A.K. & Anderson, K.A. (2011). Difficult diagnoses: Family caregivers' experiences during and following the diagnostic process for dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 26(3), 212–217.
- Gomes Martins, R. & Palmares Carvalho, I. (2013). Breaking bad news: Persons preferences and health locus of control. *Person Education and Counselling*, 92, 67–73.
- Graham, C., Ballard, C. & Sham, P. (1998). Carer's knowledge of dementia and their expressed concerns. *International Journal of Geriatric Psychiatry*, 12(4), 470–473.
- Hansen, E.C., Hughes, C., Routley, G. & Robinson, A.L. (2008). General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science and Medicine*, 67, 1776–1783.
- Harman, G. & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research*, 16, 484–502.
- Hellström, I., Nolan, M. & Lundh, U. (2005). We do things together; A case study of couplehood in dementia. *Dementia*, 4(1), 7–22.
- Hellström, I., Nolan, M. & Lundh, U. (2007). Sustaining 'couplehood': Spouse' strategies for living positively with dementia. *Dementia*, 6(3), 383–409.
- Human Rights Act (1998). (c42). HMSO.
- Husband, H.J. (2009). What do we tell people with dementia about their diagnosis and how do we tell them? In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia*. London: Jessica Kingsley Publishers.
- Iliffe, S. & Manthorpe, J. (2004). The hazards of early recognition of dementia: A risk assessment. *Aging & Mental Health*, 8(2), 99–105.

- Jha, A., Jan, F., Gale, T. & Newman, C. (2013). Effectiveness of a recovery oriented psychiatric intervention package on the well-being of people with early dementia: A preliminary randomised controlled trial. *International Journal of Geriatric Psychiatry*, 28, 589–596.
- Jones, R.W., Mackell, J., Berthet, K. & Knox, S. (2010). Assessing attitudes and behaviours surrounding Alzheimer's disease in Europe: Key findings of the Important Perspectives on Alzheimer's Care and Treatment (IMPACT) survey. *The Journal of Nutrition, Health & Aging*, 14(7), 525–530.
- Kaduszkiewicz, H., Bachmann, C. & van den Bussche, H. (2008). Telling the truth in dementia: Do attitude and approach of general practitioners and specialists differ? *Person Education and Counselling*, 70, 220–226.
- Karneili-Miller, O., Werner, P., Aaron-Peretz, J., Sinoff, G. & Eidelman, S. (2012a). Expectations, experiences, and tensions in the memory clinic: The process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics*, 24(11), 1756–1770.
- Karneili-Miller, O., Werner, P., Neufeld-Krozyński, G. & Eidelman, S. (2012b). Are you talking to me? An exploration of the triadic physician-person-companion communication within memory clinics encounters. *Person Education and Counselling*, 88, 381–390.
- Karneili-Miller, O., Werner, P., Aaron-Peretz, J. & Eidelman, S. (2007). Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: Walking an ethical and professional tight rope. *Person Education and Counselling*, 67, 307–314.
- Keady, J. & Nolan, M. (2003). The dynamics of dementia: Working together, working separately or working alone? In M. Nolan, U. Lundh, G. Grant & J. Keady (Eds.), *Partnerships in family care: Understanding the caregiving career*. Buckingham: Open University Press.
- Keady, J. & Gilliard, J., (2002). Testing times: The experience of neuropsychological assessment for people with suspected Alzheimer's. In P. Harris (Ed.), *The person with Alzheimer's disease: Pathways to understanding the experience*. Maryland: John Hopkins Press.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Koch, T. & Iliffe, S. (2010). Rapid appraisal of barriers to the diagnosis and management of persons with dementia in primary care: A systematic review. *BMC Family Practice*, 11, 52.
- Koppel, O.S.B. & Dallos, R. (2007). The development of memory difficulties: A journey into the unknown. *Dementia*, 6(2), 193–213.
- La Fontaine, J. & Oyebode, J.R. (2013). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing and Society*. Available on CJO 2013 doi:10.1017/S0144686X13000056
- La Fontaine, J., Brooker, D., Wallcraft, J. & Vickers, H. (2011). *Evaluation Report, Early Intervention Dementia Service, Executive Summary*. Association for Dementia Studies, University of Worcester. Available at: <http://www.worcester.ac.uk/discover/dementia-early-interventions.html>

- La Fontaine, J., Ahuja, J., Bradbury, N., Phillips, S. & Oyeboode, J. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing*, 60(6), 605–614.
- Lecouturier, J., Bamford, C., Hughes, J.C., Francis, J.J., Foy, R., Johnston, M. & Eccles, M.P. (2008). Appropriate disclosure of a diagnosis of dementia: Identifying the key behaviours of best practice. *BMC Health Service Research*, 1(8), 95.
doi: 10.1186/1472-6963-8-95.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2408568/>
- Leung, K.K., Finlay, J., Silvius, J.L., Koehn, S., McCleary, L., Cohen, C.A., Hum, S., Garcia, L., Dalziel, W., Emerson, V.F., Pimlott, N.J.G., Persaud, M., Kozak, J. & Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health and Social Care in the Community*, 19(4), 372–381.
- Maguire, C.P. (2002). Telling the diagnosis of dementia; consider each person individually. *International Psychogeriatrics*, 14(2), 123–126.
- Manthorpe, J., Iliffe, S. & Eden, A. (2003). Testing Twigg and Atkin’s typology of caring: A study of primary care professionals’ perceptions of dementia care using a modified focus group method. *Health and Social Care in the Community*, 11(6), 477–485.
- Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J., Watts, S., Robinson, L., Gemski, A., Warner, J., Goodman, C., Drennan, V. & Iliffe, S. (2011). *The transition from cognitive impairment to dementia: Older people’s experiences*. NIHR Service Delivery and Organisation Programme. Available online at:
<http://eprints.kingston.ac.uk/18322/>
- Martinez-Lage, P., Frolich, L., Knox, S. & Berthet, K. (2010). Assessing physician attitudes and perceptions of Alzheimer’s disease across Europe. *The Journal of Nutrition, Health & Aging*, 14(7), 537–544.
- Mental Capacity Act (2005). (c9). London: HMSO.
- Milne, A. (2010). Dementia screening and early diagnosis: The case for and against. *Health, Risk & Society*, 12(1), 65–76.
- Mitchell, A.J., Meader, N. & Pentzek, M. (2011). Clinical recognition of dementia and cognitive impairment in primary care: A meta-analysis of physician accuracy. *Acta Psychiatrica Scandinavica*, 124(3), 165–183. (Systematic Review, USA, Europe, UK). (SR).
- Moniz-Cook, E. & Manthorpe, J. (2009). Personalising psychosocial interventions to person needs and context. In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia*. London: Jessica Kingsley Publishers.
- Moniz-Cook, E. (2008). Assessment and psychosocial intervention for older people with suspected dementia: A memory clinic handbook perspective. In K. Laidlow & B. Knight (Eds.), *Handbook of emotional disorders in later life: Assessment and treatment* (pp.424–450). Oxford: Oxford University Press.
- Moniz-Cook, E., Manthorpe, J., Carr, I., Gibson, G. & Vernooij-Dassen, M. (2006). Facing the future: A qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia*, 5(3), 375–395.
- National Audit Office (2007). *Improving services and support for people with dementia*. London: The Stationery Office.

- National Audit Office (2010). *Improving dementia services in England – an interim report*. London: The Stationery Office.
- NHS Wales (2010). *1000 Lives plus, improving care, delivering quality: Improving dementia care*. Cardiff: NHS Wales.
- National Institute for Clinical Excellence (2011). *Technology appraisal Donepezil, Galantamine, Rivastigmine and Memantine for the treatment of Alzheimer’s disease, TA217*. Available online at: <http://www.nice.org.uk/guidance/index.jsp?action=byID&o=13419>
- Pratt, R. & Wilkinson, H. (2003). A psychosocial model understanding the experience of receiving a diagnosis of dementia. *Dementia*, 2(1), 181–199.
- Phillips, J., Pond, C.D., Patterson, N.E., Howell, C., Shell, A. et al. (2012). Difficulties in disclosing the diagnosis of dementia: A qualitative study in general practice. *British Journal of General Practice*, 62(601), 546–553.
- Prince, M., Bryce, R. & Ferri, C. (2011). *World Alzheimer Report 2011: The benefits of early diagnosis and intervention*. Alzheimer’s Disease International. Available online at: <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>
- Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K. & Manthorpe, J. (2012). The transition to dementia – person and family experiences of receiving a diagnosis: A review. *International Psychogeriatrics*, 23(7), 1026–1043.
- Rolland, J., (1994). *Families, illness and disability: An integrative treatment model*. New York: Basic Books.
- Rosness, T.A., Ulstein, I. & Engedal, K. (2009). Stress affects carers before person’s first visit to a memory clinic. *International Journal of Geriatric Psychiatry*, 24, 1143–1150.
- Seabrooke, R. & Milne, A. (2009). Early intervention in dementia care in an Asian community: Lessons from a dementia project. *Quality in Ageing*, 10(4), 29–36.
- Stiles, W. (1999). Signs and voices in psychotherapy. *Psychotherapy Research*, 9(1), 1–21.
- Street, Jr. R.L., Makoul, G., Arora, N.K. & Epstein, R.M. (2009). How does communication heal? Pathways linking clinician-person communication to health outcomes. *Person Educ Couns*, 2009, 74, 295–301.
- Teel, C.S. (2005). Rural practitioners’ experiences in dementia diagnosis and treatment. *Ageing and Mental Health*, 8(5), 422–429.
- The Scottish Government (2010). *Scotland’s National Dementia Strategy*. Available online at: <http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf>
- Tilki, M., Mulligan, E., Pratt, E., Halley, E. & Taylor, E. (2010). Older Irish people with dementia in England. *Advances in Mental Health*, 9(3), 219–230.
- Tuffrey-Wijne, I. (2012). A new model for breaking bad news to people with intellectual disabilities. *Palliative Medicine*, 27(1), 5–12.
- Vernooij Dassen, M., Derksen, E., Scheltens, P. & Moniz-Cook, E. (2006). Receiving a diagnosis of dementia: The experience over time. *Dementia*, 5(3), 397–410.
- Werner, P., Karneili-Miller, O. & Eidelman, S. (2013). Current knowledge and future directions about the disclosure of dementia: A systematic review of the first decade of the 21st century. *Alzheimer and Dementia*, 9, e74–88.
- Whitman, L. (Ed.) (2009). *Telling tales about dementia, experiences of caring*. London: Jessica Kingsley Publishers.
- Wilkinson, H. (2002). Including people with dementia in research: Methods and motivations. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations*. London: Jessica Kingsley Publishers.

- Williams, C. (2004). Pre-assessment counselling with people with memory problems: What can we learn from HIV/GUM services? *PSIGE Newsletter*, 87, 11–16.
- Woods, R.T., Moniz-Cook, E., Iliffe, S., Champion, P., Vernooij-Dassen, M., Zanetti, O. & Franco, M. (2003). Dementia: Issues in early recognition and intervention in primary care. *Journal of the Royal Society of Medicine*, 96, 320–324.
- Zaleta, A.K. & Carpenter, B.D. (2010). Person-centred communication during the disclosure of a dementia diagnosis. *American Journal of Alzheimer's disease and other dementias*, 25(6), 513–520.

Appendix 1: Service user quotes around pre-diagnostic counselling and informed consent (from FPOP and DEEP service user consultation, 2014).

1.1 First contact with clinicians

'You go to the GP when you're ill or injured... you only bring up your memory as an afterthought.'

Several points highlighted in discussions concern how people were first referred to memory or diagnostic services, in most cases being referred by a GP:

- Many felt that GPs needed training in dementia, as some seemed to lack knowledge on the subject. *'We need specialist GPs in dementia... And all staff need training really, including receptionists!'*
- Some felt that many clinicians were behind an impenetrable wall of professionalism. Empathy was highlighted as an important factor in positive experiences with health care professionals. *'It's important that professionals are good at just being human... it makes a difference being a human being.'*
- Certain GPs were praised for their knowledge and understanding. *'My GP was fantastic. He said he knew exactly what was wrong with me and would pass me onto people who could help me even more.'*
- It helps to stay with the same clinician throughout the process, rather than being transferred repeatedly. *'I didn't always have the same GP every time I visited, so I didn't really have any time to build up a relationship with anyone.'*

'I think everybody's different. I think there needs to be an understanding by the GPs that people are different.'

1.2 Pre-diagnostic information and consent

'We had no information given to us before testing. We just went and they asked us questions. They didn't mention dementia.'

Informed consent was highlighted as ethically imperative as it allows people to assess whether or not they wish to continue, and whether or not they would wish to know that they have a dementia. The following points are important in allowing informed consent:

- Provide time and space to absorb pre-diagnostic information. It is important not only that information is provided, but also that it is made easy to absorb and that time is given to do so. *'Because of the dementia, there was trouble absorbing verbal information. You need written information to take away.'*
- Give information about types of dementia other than dementia in Alzheimer's disease, including the possibility that memory may not initially be the most pressing issue. *'...all professionals seem to just emphasise memory! I was doing my own research. In the end I was informing my GP about dementia!'*
- Consent must be given at every diagnostic and pre-diagnostic appointment. *'[The psychologist] was constantly giving me a 'get out of jail free card'. I think that's very important.'*

- Ensure that the diagnostic process is collaborative and clients know what the purpose of each test is, and what the final diagnosis might be. *[Carer] 'We went through the GP who referred us. He [husband] was sent for a brain scan. I never saw this and the consultant never explained the scan or the process, but just diagnosed Alzheimer's.'*
- Highlight the possibility of diagnostic uncertainty. *'The consultant warned me. That helped me because when the scans came back not showing anything wrong, I was prepared for the possibility it was still dementia.'*

'The sooner you use the word [dementia], the better. If a medical person avoids using the word, it puts it way up there.'

Cognitive assessment of people who may be developing dementia

Authors

Daniel Collerton, Consultant Clinical Psychologist, Northumberland, Tyne and Wear NHS Foundation Trust, Associate Clinical Teacher, Newcastle University.

Dr Rachel Domone, Consultant Clinical Neuropsychologist, Memory Assessment Service, Burnley, Lancashire Care NHS Foundation Trust.

Key messages

- Cognitive assessment of people at risk of dementia should be a supportive and informative experience.
- A range of cognitive assessment tools are available, all with strengths and limitations.
- Training, experience, and supervision are needed at all levels of practice.
- Clinical Psychologists and Neuropsychologists have the highest levels of expertise in conducting comprehensive cognitive assessments.
- Good services have effective systems to ensure that people have the best level of assessment to meet their needs.
- Good services recognise the potential for harm through inaccurate cognitive assessment and act to minimise this.

Introduction

‘When you have a test you automatically think, ‘Well I want to pass this test!’... You’re constantly thinking, ‘Am I passing this test or am I failing?’... I thought about what they asked me last time... so I revised and practised!’

‘I fought it to the end because I didn’t believe it. No one pressured me into doing the tests though, and I came to terms with it.’

Cognitive assessment should be a supportive and informative experience for the person being assessed. As well as a route to a diagnosis, it should be able to answer questions that people may have about their cognitive abilities and provide them with an account of their strengths and potential (Borson, S. et al., 2006; Galton et al., 2005; Samsi et al., 2014; The National Collaborating Centre for Mental Health, 2007; National Institute for Health Research, 2011; Woodford & George, 2007).

This will give them the best chance of making the most of their abilities, irrespective of the type or stage of dementia they may be facing (Bahar-Fuchs et al., 2013; Clare, 1999, 2008; Clare & Woods, 2004; Clare et al., 2010, 2013). Whilst this paper is focused on assessment, the timely, accurate and sensitive feedback of findings from cognitive assessment is an intervention in itself. It has the potential to help people and their families adjust to changes, as well as direct them to the best post-diagnostic and/or rehabilitation strategies to enable them to live well with whatever cognitive difficulties they may face.

Types of cognitive assessment

There is a hierarchy of assessments from short simple tests which can quickly identify marked cognitive impairment to long complex neuropsychological assessments which give the most comprehensive indication of a person's cognitive abilities [2, 4]. Every test needs specific training to administer and interpret.

All cognitive tests have strengths and limitations. Tests need to be selected to be good measures of the cognitive abilities affected by dementia; they should be given consistently and carefully, and scored and interpreted correctly. Poor quality assessments are costly for the person being assessed, services, and society.

All cognitive assessments should be carried out alongside other investigations such as medical screening and brain imaging in order to create an accurate formulation of a person's strengths and difficulties and, where applicable, a diagnosis. Detailed cognitive assessments describe a person's abilities, and contribute significantly to a holistic, accurate, and informative assessment process and outcome.

Good quality basic cognitive assessment

Brief tests are often in the public domain and may be administered by staff from different disciplines following training (Alzheimer's Society, 2014; Ashford, 2008; Brodaty et al., 2002; Brooke & Bullock, 1999). Tests such as the Six Item Cognitive Impairment Test (6-CIT) can typically be carried out by health care professionals such as Practice Nurses or General Practitioners with small amounts of training.

Other tests such as the Montreal Cognitive Assessment (MoCA) or Addenbrooke's Cognitive Examination (ACE-III) are usually carried out as part of a more comprehensive assessment by specialist services¹. They require higher levels of training and regular supervision and monitoring of standards.

Tests at this level are essential initial assessments, but have limited ability to distinguish between dementia and other causes of poor cognitive performance, or between different forms of dementia, particularly unusual initial presentations. Cognitive decline can be overestimated in people who have sensory impairments, a limited education, a learning disability, poor physical or mental health, or past or current substance misuse, or in those from a different culture or with a different language. Conversely, in a person of very high lifelong intellectual ability, change may be underestimated. Accurate classification can be particularly difficult in the early stages of dementia when pressure for a quick diagnosis can lead to error (Cullen et al., 2007; Stoppe et al., 2007; Varma et al., 1999; Wood et al., 2006). These cases should be referred to specialist services for an in-depth individual cognitive assessment by a Clinical Psychologist or equivalent specialist.

Avoidable errors in the use of these tasks can be reduced by regular training, supervision and audit from experienced Clinical Psychologists. Training should include the technical aspects of test administration, including scoring and interpretation, how to set up the test

¹ Until recently, the Mini Mental State Examination (MMSE) was commonly used, falling somewhere between the most basic tests and more advanced individual tests such as the ACE-III in terms of length and domains covered. It has significant limitations with its psychometric properties and since it became subject to copyright it is less commonly used.

environment appropriately, how to introduce the test to the individual, and issues relating to informed consent, and the sensitive use of test results.

All users of cognitive tests should demonstrate competence in their use before assessing people for the first time. It is important that competence in administration is maintained, and as such, refresher training may be indicated on an annual basis.

In order to maintain best practice, it is desirable to have a specialised Clinical Psychologist or Neuropsychologist embedded within the Memory Assessment Team.

In-depth assessment

When basic cognitive assessments are inconclusive, people will need an advanced, hypothesis-driven neuropsychological assessment (Cox, 2011; Dimcovic, 2003; Diniz et al., 2008; Lonie et al., 2010; Morris et al., 2000; Seo et al., 2010). Such in-depth assessments will use reliable estimates of life long levels of intellectual ability, and a range of up to date assessments of memory, attention, executive function, perception, and language in order to clarify clinical uncertainty. Advanced assessments integrate quantitative and qualitative cognitive information with history, background, and knowledge of physical and mental health to improve validity. Assessments may need to be repeated after a number of months dependent upon rate of change, but usually six months or more, to determine whether cognition is changing and to clarify any remaining uncertainties. The specific cognitive tools used need to be suitable for the characteristics of the population being assessed, and of demonstrable reliability and validity.

Choosing the correct assessment level

Services must ensure that people do not undergo lengthy assessments unnecessarily. Protracted assessments with no justification are neither desirable for people using services or for services themselves. It is unlikely that an individual would start the assessment process with the highest (i.e. most advanced) level of assessment. More likely, people would progress from a more basic test to a more in-depth assessment once a need has been identified. Should specific needs be identified early on, it would be appropriate to instigate a full, hypothesis driven neuropsychological assessment.

Some services have attempted to operationalise guidelines indicating the level of assessment an individual may need, for example, by stating that people of very high or low premorbid levels of ability or those with complexities related to their mental health may need full neuropsychological assessment. However, whilst clinically helpful, there is no evidence base to support these decision making processes. A likely result may be more or less obvious at an early stage: ultimately, the level of assessment required should be dictated by sound clinical judgement informed by consideration of initial interview and test data.

The characteristics of various level of assessment are indicated in Table 1 below.

Table 1.

Name of Test	Potential Benefits	Potential Limitations
Test Your Memory	Good scores can rule out cognitive problems for most people.	Poor scores do not rule in cognitive problems.
Montreal Cognitive Assessment	Can distinguish between normality and dementia reasonably well in most people.	Cannot distinguish between normality and mild cognitive impairment or mild cognitive impairment and dementia.
Addenbrooke's Cognitive Examination	Can distinguish between normality, mild cognitive impairment, and dementia.	Can not reliably distinguish between these categories in the presence of poor health or mood disorders.
Neuropsychological Assessment	Can distinguish between categories in the presence of poor health and mood disorders, etc.	Takes time, training and specific expertise to administer and interpret.

High quality services

High quality services providing cognitive assessment have the following characteristics.

- Good services will ensure that basic cognitive assessments are carried out accurately, reliably and validly through effective monitoring by experienced and qualified cognitive assessors.
- Good services will contain staff capable of conducting advanced cognitive assessments, and clear methods for accessing those assessments appropriately.
- All staff carrying out cognitive assessments will be aware of the uses and limitations of the tests they use, their own competence regarding which tests to use and when, and when to seek advice and support from experienced colleagues with specific qualifications in advanced neuropsychological assessment.
- Good quality services will ensure that assessments undertaken are person-centred and individualised to ensure that the appropriate level of assessment is carried out for each individual.
- Good quality services will ensure assessments are chosen and adapted where necessary to ensure that they are not unduly aversive for people, and provide the least experience of failure.
- Good services will be able to monitor the quality of cognitive assessments and make sure that poor quality practice does not result from pressures to increase the number of assessments carried out.
- Good services recognise the potential for error in assessing cognitive abilities and actively seek out and correct errors.

Some services use stepped care models, in which the response systematically varies depending upon the level of cognitive impairment suspected. Such approaches need to take account of the differing base rates of dementia in different parts of the health care system, and how these interact with the results of cognitive assessment. Routine screening for dementia is not recommended, but changes in personality, behaviour, or ability to manage everyday activities, particularly in older people who are at risk of dementia, and particularly in the absence of low mood or poor health, can suggest a developing dementia.

Whilst some individuals with mild cognitive complaints can be appropriately reassured without the need for specialist assessment, it is important to recognise that in a small number of cases, assessment of relatively mild complaints may prove very challenging and require the highest level of assessment. There should be clear guidelines to help identify when more comprehensive assessments will add most value to the care of an individual. These guides should not become barriers to accessing services through overly rigid application.

Qualifications and training

Differing types of assessment require varying levels of expertise as shown in Table 2 overleaf.

Conclusions and recommendations

‘Assessment should be collaborative. They should tell us what tests they’re doing and why they are doing these tests.’

Assessing cognition is a key part of the experience of people receiving a diagnosis of dementia. Services should be mindful of the potential for benefit and harm when assessing cognition and should strive to maximise the positive outcomes for the people being assessed by the judicious selection of assessment tools, and their careful application by properly trained and supervised workers.

Table 2.

Level	Who can administer?	Level of training required	Training delivered by	Examples of tests
Brief test	GPs, Practice Nurses and equivalent professionally trained staff.	Instruction in the basics of test administration and scoring (1–2 hours).	Professionally qualified staff, currently working in Memory Assessment services, experienced in assessing cognition.	6-CIT
Basic cognitive measure	Professionally qualified staff experienced in assessing cognition, e.g. Mental Health Nurses, Occupational Therapists.	Specific training in all aspects of setting up, administering & scoring a cognitive assessment (half to full day). Ongoing supervision and annual refresher training. Ability to carry out assessments with sufficient regularity to ensure competence is developed & maintained.	Clinical Psychologist/ Neuropsychologist.	ACE-III, MoCA
Hypothesis driven neuro-psychological assessment	Clinical Psychologist/ Neuropsychologist experienced in Memory Assessment work. Testing can also be carried out by Assistant Psychologists working under the direct supervision of the above.	Clinical Psychology training. May also have additional training in neuropsychology (post-graduate diploma or Masters degree and/or professional Qualification in Clinical Neuropsychology).	Recognised University courses in Clinical Psychology (doctorate) and Clinical Neuropsychology (postgraduate diploma or MSc).	Variety of tests including those assessing general ability, attention, memory and executive functioning as required (e.g. Wechsler tests of intellectual ability and memory).

References

- Ashford, J.W. (2008). Screening for memory disorders, dementia and Alzheimer's disease. *Aging Health, 4*, 399–432.
- Alzheimer's Society. *Assessing cognition in older people: A practical toolkit for health professionals*.
- Bahar-Fuchs, A., Clare, L. & Woods, R.T. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews, Issue 6, Art. No. CD003260*. doi: 10.1002/14651858.CD003260.
- Borson, S., Scanlan, J.M., Watanabe, J., Shin-Ping, T. & Lessig, M. (2006). Improving identification of cognitive impairment in primary care. *International Journal of Geriatric Psychiatry, 21*, 349–355.
- Brodaty, H., Pond, D., Kemp, N.M. et al. (2002). The GPCOG: A new screening test for dementia designed for general practice. *J Am Geriatr Soc, 50*, 530–534.
- Brooke, P. & Bullock, R. (1999). Validation of a six-item cognitive impairment test with a view to primary care usage. *Int. J. Geriatr. Psychiatry, 14*, 936–940.
- Clare, L. & Woods, R.T. (2004). Cognitive training and cognitive rehabilitation for people with early stage Alzheimer's disease: A review. *Neuropsychological Rehabilitation: An International Journal, 14*(4) 385–401.
- Clare, L. (1999). Intervening with everyday memory problems in early Alzheimer's disease. *PSIGE Newsletter, 70*, 37–42.
- Clare, L. (2008). *Neuropsychological rehabilitation and people with dementia*. Hove: Psychology Press.
- Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M., Kopelman, M., Kudlicka, A., Leroi, I., Oyebode, J., Pool, J., Woods, B. & Whitaker, R. (2013). Goal-oriented cognitive rehabilitation in early-stage dementia: Study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials, 14*, 152. doi: 10.1186/1745-6215-14-152
- Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H., van Paasschen, J., Nelis, S.M., Hoare, Z., Yuen, K.S. & Rugg, M.D. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry, 18*, 928–939. doi: 10.1097/JGP.0b013e3181d5792a
- Cox, D. (2011). The role of neuropsychological testing in the care of older adults. *BC Medical Journal, 52*, 416–420.
- Cullen, B., O'Neill, B., Evans, J.J., Coen, R.F. & Lawlor, B.A. (2007). A review of screening tests for cognitive impairment. *J. Neurol. Neurosurg. Psychiatr., 78*, 790–779.
- Dimcovic, N. (2003). Mild Cognitive Impairment (MCI) age-related decline or an early stage of dementia? *PSIGE Newsletter, 84*, 31–36.
- Diniz, B.S., Nunes, P.V., Yassuda, M.S., Pereira, F.S., Flaks, M.K., Viola, L.F. & Forlenza, O.V. (2008). Mild cognitive impairment: Cognitive screening or neuropsychological assessment? *Revista Brasileira de Psiquiatria, 30*, 316–321.

- Galton, J.C., Erzinçlioglu, S., Sahakian, J.B., Antoun, N. & Hodges, R.J. (2005). A comparison of the Addenbrooke's Cognitive Examination (ACE), conventional neuropsychological assessment, and simple MRI-based medial temporal lobe evaluation in the early diagnosis of Alzheimer's disease. *Cognitive and Behavioural Neurology*, *18*, 144–150.
- Lonie, J.A., Parra-Rodriguez, M.A., Tierney, K.M., Herrmann, L.L., Donaghey, C., O'Carroll, R.E. & Ebmeier, K.P. (2010). Predicting outcome in mild cognitive impairment: Four-year follow-up study. *British J. Psychiatry*, *197*, 135–140.
- Morris, R.G., Worsley, C. & Matthews, D. (2000). Neuropsychological assessments in older people: Old principles and new directions. *Advances in Psychiatric Treatment*, *6*, 362–372.
- National Institute for Health Research (2011). *The transition from cognitive impairment to dementia: Older people's experiences*.
- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., Watts, S. & Bond, J. (2014). Negotiating a labyrinth: Experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry*, *29*, 58–67.
- Seo, E.H., Lee, D.Y., Lee, J.H., Choo, I.H., Kim, J.W., Kim, S.G. & Woo, J.I. (2010). Total scores of the CERAD neuropsychological assessment battery: Validation for mild cognitive impairment and dementia patients with diverse etiologies. *Am. J. Geriat. Psych.*, *18*, 801–809.
- Stoppe, G., Haak, S., Knoblauch, A. & Maeck, L. (2007). Diagnosis of dementia in primary care: A representative survey of family physicians and neuropsychiatrists in Germany. *Dementia and Geriatric Cognitive Disorders*, *23*, 207–214.
- The National Collaborating Centre for Mental Health (2007). *A NICE-SCIE guideline on supporting people with dementia and their carer in health and social care*. British Psychological Society and Gaskell.
- Varma A.R., Snowdon, J.S., Lloyd, J.J. et al. (1999). Evaluation of the NINCDS-ADRDA criteria in the differentiation of Alzheimer's disease and frontotemporal dementia. *J. Neurol. Neurosurg. Psychiat.*, *66*, 184–188.
- Wood, R.Y., Giuliano, K.K., Bignell, C.U. & Pritham, W.W. (2006). Assessing cognitive ability in research: Use of MMSE with minority populations and elderly adults with low education levels. *Journal of Gerontological Nursing*, *32*(4), 45–54.
- Woodford, H.J. & George, J. (2007). Cognitive assessment in the elderly: A review of clinical methods. *QJM*, *100*, 469–484.

Communicating a diagnosis of dementia

Developing evidence from research, and surveys of people with dementia and their families, show that sharing a dementia diagnosis can be immensely useful, when this is done well, but that significant numbers of people are reporting problems with how this is currently undertaken. This has been underlined by findings from the Alzheimer's Society, the Dementia Engagement and Empowerment Project, and the Dementia Service User consultation undertaken by FPOP alongside the development of these papers. A subsequent BPS/FPOP paper, 'Communicating a diagnosis of dementia' is in preparation and will appear in early 2015.

This paper will address:

- the complex nature of the ethical issues arising from dementia diagnosis and disclosure; the 'right to know' and the 'right to not know';
- the problem of uncertainty in dementia diagnosis;
- potential benefits and disadvantages of sharing the diagnosis;
- psychosocial models integrating the meaning of diagnosis for the individual and family, their wishes and capacity to know and understand the diagnosis, and their wider social context; these models can help professionals understand and work with the emotional responses arising throughout the process of assessment and diagnosis sharing;
- the importance of separating issues around neurological impairments from quality of life and placing an emphasis on hope in the face of a difficult diagnosis;
- the need to manage positive and negative expectations about treatment options;
- where appropriate the use of progressive disclosure to allow the person (and caregivers) time to prepare and adjust;
- practical considerations about dementia disclosure, including skills, training and supervision needed for memory clinic staff;
- the contribution psychologists can make to support this work.

Post-diagnostic support for people living with dementia

Authors

Sue Watts, Consultant Clinical Psychologist, Head of Psychology of Older People, Greater Manchester West Mental Health Foundation Trust.

Professor Richard Cheston, Professor of Mental Health (Dementia) Research, Department of Health and Social Sciences, University of the West of England, Bristol.

Professor Esme Moniz-Cook, Consultant Clinical Psychologist, Humber NHS Foundation Trust, Honorary Professor of Dementia Research, University of Hull.

Cath Burley, Clinical Psychologist, Outgoing Chair for the Faculty of the Psychology of Older People.

Reinhard Guss, Consultant Clinical Psychologist, Kent and Medway NHS and Social Care Partnership Trust, Dementia Workstream Lead, Faculty of the Psychology of Older People.

‘When they told me [the dementia diagnosis] it felt hopeless. [The advice] just seemed to be about getting your affairs in order... I could hardly talk afterwards! I locked myself away for a while, I was withdrawn...’

‘... they shouldn’t be focused on what pills to give us; they should be focused on feelings! They should ask, ‘Are you coping?’’

Key messages

1. Currently, the policy across NHS Services is to make diagnoses of dementia earlier, and for more people, to maximise opportunities for adjustment and to deliver savings to the health and social care economy.
2. This policy focus has not been matched by attention to the need for adequate post-diagnostic support. Available support services are variable in content and frequently limited to a small percentage of the people accessing services.
3. In the absence of more effective preventative or curative treatments, concerns about the limitations of post diagnostic support will impact on referrals from general practitioners, and on participants’ engagement with services.
4. There are particular implications for people with dementia for whom pharmacological intervention is not an option. In the absence of psychosocial support, diagnosis may be experienced particularly negatively.
5. Adjustment to diagnosis is complex and an important stage in offering help to live well with the condition. While many people are able to adjust, the impact of the diagnosis is often profound and underestimated, but with good clinical practice, a diagnosis of dementia should not be experienced as coming ‘out of the blue’.
6. Adjustment to dementia diagnosis is an emerging area of research. However, the available evidence has also contributed to the international consensus, that timely dementia diagnosis is beneficial.

7. Psychosocial interventions promote psychological well-being by minimising and alleviating psychological distress and facilitating adjustment. Interventions can also enable people with dementia and families to improve self-management. Currently, the evidence base indicates the effectiveness of, and demand for, a range of interventions which address:
 - Adjustment to diagnosis and therapies for the person with dementia;
 - Rehabilitation work;
 - Help for families to adjust.
8. In order to balance the need for individualised interventions with the finite resources available, services should develop pathways to enable individuals and families to be directed to appropriate options and to choose between them.
9. It is essential that this Psychosocial Intervention Gap is addressed. Services should identify and deliver practical ways of ensuring that people who are living with dementia and their families receive adequate psychosocial support.

Aims

The aim of this document is to provide an overview of the range of psychosocial interventions available and good clinical practice in supporting people with dementia, their families and carers, commencing as soon as possible after diagnosis.

The focus is on the needs of people who are still at home, and in a relatively early stage of dementia. This excludes the specific needs of people with late diagnoses, and as such, this document does not address needs relating to significant levels of challenging behavior, which have been addressed by the Faculty's Dementia Workstream in an earlier document (Brechin et al., 2013). However, because the paper focuses on facilitating adjustment to the diagnosis of dementia, it is likely that such interventions will prevent or reduce the possible development of challenging behaviour in the future.

Introduction

Nationally a broad range of consumer groups, voluntary and statutory organisations and a cross-party consensus all support a drive towards the early identification of dementia for as many people as possible. This has been influenced by:

- individual accounts of difficulties arising from delays to diagnosis;
- attempts to improve prompt access to medication for people with dementias such as Alzheimer's disease;
- evidence of potential savings to the health and social care economy arising from early diagnosis (Banerjee & Wittenberg, 2009).

Commissioning Guidance has been issued to assist Clinical Commissioning Groups, NHS Trusts and other providers in developing services that can deliver early diagnosis. However, the Department of Health Service Specification for Dementia (2011), and in many cases the services themselves, have a focus on just that: early diagnosis. While there is detailed guidance on referring, timescales for different stages of assessment and number targets, it is less clear what services should be available after diagnosis. The post-diagnostic support stages lack clear guidance around content, especially in relation to non-pharmacological approaches. This is especially problematic for the many people with dementias for which non-pharmacological approaches are the only available treatments.

Unfortunately, many hard-pressed services discharge those people with dementia for whom prescribing is not an option, which also means that they do not receive follow up and on-going contact with specialist services. This is despite the fact that adjustment to diagnosis is a process – as recognised by the Payment by Results Cluster 18 pathway (Department of Health Payment by Results team, 2013) – that may take up to two years.

'My GP misdiagnosed me. They took me off my medication... There was no support. My only support was from Alzheimer's Scotland. There was no counselling or anything.'

'Once I'd accepted it, life became much easier. I didn't have to be super-efficient any longer.'

The original research projects which inspired the movement towards early diagnosis included a broad range of post-diagnostic support for people with dementia and their carers, together with the prescription of medication for people with Alzheimer's disease. Banerjee and Wittenberg (2009) analysed this information and, in addition to the more immediate clinical benefits of early diagnosis, identified significant scope for economic savings to the wider health and social care system, as a result of delayed admission to institutional care. The failure to offer the comprehensive packages of care offered in the original research and service trials may limit the calculated economic benefits. This not only represents a missed opportunity to provide support for people living with dementia and their families, but also has potential economic costs. Thus the Commissioning Guidance neither incorporates a realistic model of the support needed post diagnostically, nor provides the time and resources required to realise these potential savings.

Early diagnosis with little psychosocial support

There is evidence that the main focus of many assessment services is on the process of achieving a diagnosis, and that limited staff training and resources are available for post-diagnostic support. There are a number of possible explanations for this, including the increase in referrals, and an emphasis on the perceived benefits of pharmacological treatment. However, with only limited time available and a restricted range of support options, there is little scope for such services to be tailored to the needs of individuals and their families. This situation has led to recent concerns being raised (Illiffe & Manthorpe, 2010; Manthorpe et al., 2011) that diagnosis without adequate support may not be beneficial, and in some respects be detrimental.

'It felt hopeless. It just seemed about getting your affairs in order. Then, after some time, I was offered peer support. That worked for me. It changed my life.'

Good quality psychosocial support

This term reflects a broad range of individual and group approaches with diverse therapeutic style and focus, and covers different aspects of memory service provision. Interventions need to be timely and provided at a pace that is acceptable for the person living with dementia. It includes working at different levels, such as:

- sharing the diagnosis with the family in a sensitive and thoughtful manner;
- providing opportunities for rehabilitation and adjustment, possibly through the provision of psychotherapy or peer support groups;
- working with the person who is living with dementia, and his/her carer.

Initially, after being given a diagnosis, many people with dementia often describe moving from frustration and embarrassment, through feelings of shock and grief, and then to a wish to withdraw. For some people, there may also be a sense of relief as they at last have an explanation from which to make sense of their problems. Despite the emotional threat inherent in receiving a diagnosis, research suggests that, if given the choice, most people would want to know if they had dementia. This seems to be true both of people who attend a memory clinic and of the population in general. In a Canadian study, 98 per cent of people over the age of 65 would want disclosure for themselves if they were diagnosed with dementia (Ouimet et al., 2004). Similarly, most people who attend a memory clinic want to know the outcome of their assessment (Elson, 2006; Johnson, Pinner & Bouman, 2003; Jha, Tabet & Orrell, 2001), although a minority are clear that they don't want to know. A fundamental part of this wish to know is that gaining this understanding helps enable people to prepare for the future. For some people, the process of receiving a diagnosis, although difficult, can lead to significant changes in their lives. Thus, James McKillop, quoted in Mountain (2006), says:

'Being told I had dementia was like a door re-opening after a difficult time in my life – new challenges, new opportunities... I want people to understand that dementia isn't an end, it's a new beginning where you do things differently. While some things change forever there is a lot you still can do.'

The importance of skilled communication between people with dementia, carers and professionals is a unifying theme throughout the process of receiving a dementia diagnosis and the series of transitions that follow. Talking to people effectively about what is happening from assessment, through diagnosis and into the future is crucial. However, effective communication about such sensitive issues is often difficult.

At present the limited range of post-diagnostic support that is available is fragmented and provided by multiple organisations. There is no national standard or mapping of this. The National Service Framework for Dementia (2001) recognised the need for an individual who knows the family and their circumstances to provide continuity of support and to assist people in making choices about the appropriate services for their needs at the right time.

'After diagnosis I was put in touch with a dementia advisor. I don't remember who referred me, or what happened before, but I remember her.'

There is an evolving literature describing effective psychosocial interventions for the early stages of dementia. Moniz-Cook and Manthorpe (2009) provide a comprehensive overview of evidence based early interventions with people with dementia and their carers, targeting the range of emotional, cognitive and behavioural issues arising at this stage. The FPOP *A Guide to Psychosocial Interventions in Early Stages of Dementia* (2014), produced in conjunction with this document, provides descriptions of what these involve and summarises the current evidence supporting each one. Table 1 summarises the main types of intervention and key references.

Although Table 1 indicates that there are many potential examples of good practice, there is evidence that this support is not consistently available across the country. Every family and every person with dementia is unique in their experience, preferences and needs, and therefore a menu of intervention choices can help to empower people to engage with their treatment process.

Table 1: Examples of good practice.

Type of intervention	Summary of good practice	Selected references
Guidelines for sharing the diagnosis.	Good practice for sharing the diagnosis, includes preparing for this throughout the assessment, considering family involvement, exploring the patient's perspective and responding to their reactions.	Lecouturier et al., 2008.
Mild Cognitive Impairment (MCI) interventions.	Although people affected by MCI do not have a diagnosis, they live with cognitive disabilities, and can benefit from monitoring and help with adjustment to these difficulties.	Tuokko & Hultsch, 2006; Cantegreil-Kallen et al., 2009.
Therapeutic interventions, to help the person with dementia adjust to their diagnosis and forthcoming life changes, including use of peer support groups.	Therapeutic groups combine practical information with an opportunity to share experiences of dementia in a safe, emotionally-containing environment.	Logsdon et al., 2010; Marshall et al, 2014; Sorensen, Waldorff & Waldemar, 2008; Sadek et al., 2011.
Education about the symptoms of dementia and coping strategies.		Moniz-Cook et al, 2006, 2008.
Specific psychological therapies for distress, depression and anxiety in the person with dementia (e.g. Cognitive Behaviour Therapy (CBT) in the early stages of dementia).	A range of psychological and counselling therapies can be used to work individually with the person with dementia. For example, CBT addresses the interaction between thoughts feelings and behaviour, based on the needs of the individual.	Spector et al., 2014; Lipinska, 2009; Miller & Reynolds, 2006.
Life Story and Reminiscence.	Using personal history and long term memories in a range of approaches and activities, designed to increase social engagement and well-being.	Young, Howard & Keetch, 2013. Cochrane Collaboration Review: Woods et al., 2009. www.lifestorynetwork.org.uk
Dementia cafés.	Open events for people with dementia and their families to meet in informal settings, to exchange information and social support.	Jones, 2010.
Group and individual adjustment work with carers.	May use a variety of psychological techniques, including CBT and cognitive reframing. For example, in dementia care, cognitive reframing interventions focus on family carers' possible maladaptive, self-defeating or distressing thoughts about their relatives' behaviours and their own caring role.	Cochrane Collaboration Review: Vernooij Dassen et al., 2011; Charlesworth et al., 2009; Selwood et al., 2007.
Coping strategies and stress management for carers.	These interventions involve working with carers to identify individual difficulties and implement strategies to overcome these.	Cooper et al., 2012; Sommerlad et al., 2014.
Cognitive Stimulation Therapy (CST), individual CST (iCST), Maintenance CST.	CST is an intervention for people with dementia which offers a range of enjoyable activities providing general stimulation for thinking, concentration and memory usually in a social setting, such as a small group. Individual approaches are also being developed.	Cochrane Collaboration Review: Woods et al., 2012; Orrell et al., 2012, 2014.
Cognitive rehabilitation in early dementia.	Cognitive training and cognitive rehabilitation are specific approaches designed to address difficulties with memory and other aspects of cognitive functioning.	Clare et al., 2010, 2013; Bahar-Fuchs , Clare & Woods, 2013; Clare, 2008.
Interventions to support maintenance of activities of daily living/lifestyle e.g. Occupational Therapy.	Aim to improve patients' ability to perform activities of daily living, promote independence and participation in social activities. Also reduce the burden on the care giver by increasing their sense of competence and ability to handle problems.	Graff et al., 2006, 2008.

'Everyone's diagnosis is different, there's got to be something that suits everyone.'

'There is a lot going on that I just don't know about... Why isn't something being done to bring it all together and raise people's awareness of what is out there?'

Perhaps the most basic form of advice involves telling people about their diagnosis. While the manner and sensitivity with which their diagnosis is shared is important, unfortunately people with dementia and their family carers give a mixed picture about how well this is done (Lecouturier et al., 2008). Often health professionals either ignore or underestimate the emotional impact of the diagnosis. Connell et al. (2004) carried out focus groups with both care givers and doctors. The caregivers recounted a highly negative emotional response to the disclosure, whereas many physicians reported that families handled the information well. Similarly, even when people are informed about the diagnosis in an appropriate manner, there remains concern about the quality and amount of information with which they are subsequently provided. The National Audit Office Report of 2007 found that roughly half of the community services they surveyed had no policies regarding discussion with people with dementia and their carers about the likely progression of the illness, or options for support and care.

Equality of access to post-diagnostic support

Some specific groups may be more disadvantaged in terms of support provided than others. Significant numbers of people are identified with Mild Cognitive Impairment (MCI) through Memory Services. These people are usually seen as being a low priority for support, and yet many may remain for some years in a state of uncertainty as to whether their condition will convert to dementia. At the same time they are still living with the consequences of changed memory and thinking abilities. Between 10 and 15 per cent of people with MCI will progress to a diagnosis of dementia within a twelve month period (Ward et al., 2012). The National Service Framework (2001) recommended monitoring people with MCI. This would help these people adjust to their cognitive changes and to cope with the uncertainty over diagnosis.

People not in receipt of medication and with rarer diagnoses may also be at risk of being discharged from memory services, or of being excluded from support aimed at people with Alzheimer's disease or vascular dementia. This may have a particular impact on younger people, including those with a diagnosis of fronto-temporal dementia, or people with a learning disability. Similarly, the limited services for people from Black and Ethnic minorities may be less likely to meet their needs.

When adequate support is provided, this not only improves quality of life, but also enables people to make choices about their lives, reduces stress for their families, and means that people are less likely to require long term residential or hospital care (Brodaty et al., 2003; Spijker et al., 2008).

Matched Care Model for post-diagnostic support

In meeting the needs and preferences of people with dementia and their families there has to be a balance of evidence-based clinical good practice and cost-effectiveness. It is not only a question of what is offered by Memory Services but also the pacing and timing of what is offered. Services need to take into account the importance of relationships and continuity

in staff delivering this aspect of care. Adjustment is a process, not a set of boxes to be ticked at a pre-determined point. Services need to be able to work flexibly with families around the support they need. At the same time, memory services only have a finite amount of resources, and realistically will be able to provide only a limited range of interventions.

In order to meet the dilemma of how best to meet individual need within limited resources, Moniz-Cook and Manthorpe (2009) suggested a model of intervention spread across four tiers. More recent work in this area has proposed the development of pattern recognition to help match individual need and intervention. Within this matched care model, people would benefit from individualised (and/or family-centred) psychosocial profiling, leading to patterns of care interventions or ‘prescriptions’. Moniz-Cook describes up to eight groups of prescriptions to address psychological and social needs in the person and the family carer. These could be delivered within a planned pathway (Rewston & Moniz-Cook, 2013: personal communication).

Essential standards for supporting psychosocial adjustment in memory services

Memory services should not be assessed solely against the criteria of speed, accuracy and volume of diagnosis. The National Dementia Strategy and other documents have acknowledged the need for improved experience of services for people with dementia and their families, but how this can be achieved has not been incorporated into the Service Specification Guidance. The MSNAP Psychosocial Interventions Module provides a first attempt at a set of quality standards to address the current gap in commissioning guidance (MSNAP, 2012). These standards and accompanying examples of practice should be integrated into the diagnostic pathway:

- Access to psychosocial interventions is based on the needs and preferences of the person with dementia and, where appropriate, their carer.
- The service provides access to psychosocial interventions for cognitive aspects of dementia.
- The service provides access to psychosocial interventions for emotional aspects of dementia.
- The service provides or can signpost/refer people and their carers on to interventions for more complex needs, if required.
- The service provides access to psychosocial interventions for carers of people with dementia.
- Staff delivering psychosocial interventions are appropriately trained and supervised.
- The service monitors people’s responses to psychosocial interventions.

Consideration should be given to the provision of access to dedicated care workers to support the psychosocial interventions pathway. Such workers would enable people affected by dementia and their families to understand and make choices between the post-diagnostic support options available to them. Dedicated dementia care workers will need to know the person with dementia well, and to understand the family, its circumstances and the progress made with adjustment for this to work effectively. They will also need to develop the practical and emotional support skills to encourage people to choose and take up these interventions.

The end result of post-diagnostic adjustment should be to help people reach a point at which they feel that having a diagnosis has been helpful. That is to say, if the process works effectively, they should be able to see a way forward in their lives once again, towards living well with dementia.

Recommendations

FPOP recommends that all services which are involved with the person with dementia and their family should:

1. Provide equal access to post-diagnostic psychosocial support for all, regardless of age, ethnicity or diagnosis.
2. Provide a detailed assessment process which enables the clinician and the person involved to understand preferences around receiving a diagnosis and their needs for subsequent information and support afterwards.
3. Provide access to a dedicated care worker who will enable people affected by dementia and their families to understand and make choices between the post-diagnostic support options available to them.
4. Commission and provide psychosocial interventions, including individual and group therapeutic approaches which are informed by evidence-based practice and will support people throughout the process of adjustment.
 - Base rehabilitation work around psychological principles and understanding of cognitive processes: Research consistently indicates both that people affected by dementia can learn to use more effective ways of remembering information and that use of these strategies reduces distress and improves quality of life.
 - Provide help for families to adjust through interventions which combine education, problem-solving and enhance the coping skills of family carers to aid adjustment and reduce the likelihood that the care they provide will break down.
 - Provide a choice of interventions: Models of post-diagnostic support need to move away from ‘one model fits all’ approaches as research suggests that people with dementia and families need to be provided with an opportunity to choose from a menu of options.
 - Ensure that psychosocial support is timely and provided at a pace that is acceptable for the person living with dementia.
5. Provide staff with training, supervision and support to develop the skilled communication which is essential throughout the post-diagnostic process to support negotiations about changing needs and possible interventions over time.

The psychologist’s contribution

A complex interaction of cognitive changes, psychological distress, and social and family circumstances determines how each individual who is affected by dementia responds to the illness. Clinical psychologists’ general and neuropsychological expertise and skills place them in a unique position to support people following a diagnosis of dementia, through:

- sensitive assessment of the person’s emotional reaction to the diagnosis;
- neuropsychological assessment that identifies areas of preserved ability;
- formulation of specific individualised communication and treatment plans;
- direct provision of therapy;
- development of communication skills within teams;

- training and supervision of family care workers and other staff;
- training for, and ongoing supervision of, the delivery of specific psychosocial interventions;
- further development of interventions;
- identification of gaps in the evidence base, and contribution to research.

Closing comment

Dementia is one of the most widely feared aspects of growing old – and evidence suggests that the older we are, the more likely we are to be worried about developing dementia. The National Health Service is prioritising early or timely diagnosis of dementia, however, all too often people affected by dementia and their families tell us about the gap in services for them after diagnosis. While medication is available for some people with dementia, many are left to cope on their own with the emotional and psychological impact of the diagnosis.

At the same time, there is growing evidence that the right psychological interventions have an important role to play in easing distress, providing support, aiding adaptation and reducing the need for long term care. The time seems right, therefore, to address the Psychosocial Intervention Gap, and to identify practical ways of ensuring that people who are living with dementia and their families receive adequate support, through structured pathways which give access to a choice between a range of evidence-based interventions.

References

- Bahar-Fuchs, A., Clare, L. & Woods, B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews*, 5(6). doi: 10.1002/14651858.CD003260.pub2
- Banerjee, S. & Wittenberg, R. (2009). Clinical and cost effectiveness of services for early diagnosis and intervention in dementia. *International Journal of Geriatric Psychiatry*, 24(7), 748–754. doi: 10.1002/gps.2191
- Brechin, D., Murphy, G., James, I.A. & Codner, J. (2013). *Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester: British Psychological Society.
- Brodsky, H., Green, A. & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 1–8.
- Charlesworth, G., Halford, J., Poland, F. and Vaughan, S. (2009). Carer interventions in the voluntary sector. In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.
- Cheston, R. & Jones, R. (2009). A small-scale study comparing the impact of psycho-education and exploratory psychotherapy groups on newcomers to a group for people with dementia. *Aging and Mental Health*, 13(3), 410–425.
- Clare, L. (2008). *Neuropsychological rehabilitation and people with dementia*. Hove: University Press.

- Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M. & Whitaker, R. (2013). Goal-oriented cognitive rehabilitation in early-stage dementia: Study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials*, *14*, 152. doi: 10.1186/1745-6215-14-152
- Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H. & Rugg, M.D. (2010). Goal-oriented cognitive rehabilitation for people with early stage Alzheimer disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry*, *18*, 928–939.
- Connell, C.M., Boise, L., Stuckey, J.C., Holmes, S.B. & Hudson, M.L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist*, *44*(4), 500–507. doi: 10.1093/geront/44.4.500
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C.G., Ames, D., Rabins, P. & Livingston, G. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, *24*(6), 856–870.
- Department of Health (2001). *National Service Framework for Older People, Standard 7: Mental Health in Older People – Dementia*. London: Crown Copyright.
- Department of Health (2011). *Service specification for dementia: Memory service for early diagnosis and intervention*. London: Crown Copyright.
- Department of Health Payment by Results team (2013). *Mental Health Payment by Results Guidance for 2013–1* Department of Health: Leeds. Gateway ref. 18768
- Elson, P. (2006). Do older adults presenting with memory complaints wish to be told if later diagnosed with Alzheimer’s disease? *International Journal of Geriatric Psychiatry*, *21*, 419–425.
- Graff M.J., Vernooij-Dassen M.J.M., Thijssen, M., Dekker, J., Hoefnagels, W.H.L. & Olde Rikkert, M.J. (2006). Community-based occupational therapy for patients with dementia and their caregivers: A randomised control trial. *British Medical Journal*, *333*(7580), 1196–1201.
- Graff M, J, Vernooij-Dassen, M.J.M., Adang, E.M.M., Thijssen, M., Dekker, J., Hoefnagels, W. H. L., Jonsson, L. & Olde Rikkert, M.J. (2008). Community occupational therapy for older patients with dementia and their caregivers: Cost effectiveness study. *British Medical Journal*, *336*(7636), 134–138.
- Guss, R., Middleton, J., Beanland, T., Slade, L., Moniz-Cook, E., Watts, S. & Bone, A. (2014). *A guide to psychosocial interventions in early stages of dementia*. Leicester: British Psychological Society.
- Iiffe, S. & Manthorpe, J. (2010). Evaluating memory clinics. *Journal of the Royal Society of Medicine*, *103*(3), 81.
- Jha, A., Tabet, N. & Orrell, M. (2001) To tell or not to tell: Comparison of older patients’ reaction to their diagnosis of dementia and depression. *International Journal of Geriatric Psychiatry*, *16*(9) 879–885.
- Johnson, H., Bouman, W. & Pinner, G. (2003). Dementia: On telling the truth in Alzheimer’s disease: A pilot study of current practice and attitudes. *International Psychogeriatrics*, *12*, 221–229.
- Jones, G. (2010). *The Alzheimer Café: Why it works*. Berks, UK: The Wide Spectrum Publications

- Kurz, A.F., Leucht, S. & Lautenschlager, N.T. (2011). The clinical significance of cognition-focused interventions for cognitively impaired older adults: A systematic review of randomised controlled trials. *International Psychogeriatrics*, 1–12.
- Lecouturier, J., Bamford, C., Hughes, J.C., Francis, J.J., Foy, R., Johnston, M. & Eccles, M.P. (2008). Appropriate disclosure of a diagnosis of dementia: Identifying the key behaviours of ‘best practice’. *BMC Health Services Research*, 8, 95.
- Lipinska, D. (2009). *Person-centred counselling for people with dementia: Making sense of self*. London: Jessica Kingsley Publishers.
- Logsdon, R.G., Pike, K.C., McCurry, S., Hunter, P., Maher J., Snyder, L. & Teri L. (2010). Early-stage memory loss support groups: Outcomes from a randomised controlled clinical trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65B(6), 691–697.
- Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J. Bond, J. & Iliffe, S. (2011). *The transition from cognitive impairment to dementia: Older people’s experiences: Final Report*. National Institute for Health Research: Service Delivery and Organisation Programme.
- Marshall, A., Spreadbury, J., Cheston, R., Coleman, P., Ballinger, C., Mullee, M., Pritchard, J., Russell, C. & Bartlett, E. (2014). A pilot randomised control trial to compare changes in quality of life for participants with early diagnosis dementia who attend a ‘Living Well with Dementia’ group compared to waiting list control. *Aging and Mental Health*. doi: 10.1080/13607863.2014.954527.
- Miller, M.D. & Reynolds, C.F. (2006). Expanding the usefulness of interpersonal psychotherapy (IPT) for depressed elders with co-morbid cognitive impairment. *International Journal of Geriatric Psychiatry*, 22(2), 101–105.
- Moniz-Cook, E. (2008). Assessment and psychosocial intervention for older people with suspected dementia: A memory clinic handbook perspective. In K. Laidlow & B. Knight (Eds.), *Handbook of emotional disorders in later life: Assessment and treatment* (pp.424–450). Oxford: Oxford University Press,
- Moniz-Cook, E. & Manthorpe, J. (Eds.) (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.
- Moniz-Cook, E., Manthorpe, J., Carr, I. Gibson, G. & Vernooij-Dassen, M. (2006). Facing the future: A qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia*, 5(3), 375–395.
- Mountain, G. (2006). Self-management for people with early dementia: An exploration of concepts and supporting evidence. *Dementia*, 5, 429–446.
- National Audit Office (2007). *Improving services and support for people with dementia*. London: The Stationery Office.
- Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A. & Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: A single-blind, multi-centre, pragmatic, randomised controlled trial. *British Journal of Psychiatry*, 204(6), 454–461. doi: 10.1192/bjp.bp.113.137414
- Orrell, M., Spector, A. & Woods, B. (2012). Should we use individual cognitive stimulation therapy to improve cognitive function in people with dementia? *British Journal of Psychiatry*, 344(7844), 46–47. doi: 10.1136/bmj.e633

- Ouimet, M.A., Dion D., Élie M., Dendukuri N. & Belzile E. (2004). Disclosure of Alzheimer's disease: Senior citizens' opinions. *Canadian Family Physician*, 50(12), 1671–1677.
- Royal College of Psychiatrists (2012). *Memory Services National Accreditation Programme* (3rd ed.). London: Royal College of Psychiatrists.
- Sadek, S., Charlesworth, G., Orrell, M. & Spector, A. (2011). The development of a Cognitive behaviour therapy (CBT) manual: A pilot randomised control trial of CBT for anxiety in people with dementia anxiety. *International Psychogeriatrics*, 23, S383–S384.
- Selwood, A., Johnston, K., Katona, C., Lyketsos, C. & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101, 75–89.
- Sommorlad, A., Manela, M., Cooper, C., Rapaport, P. & Livingston, G. (2014). START (StrAtegies for RelaTive) coping strategy for family carers of adults with dementia: Qualitative study of participants' views about the intervention. *British Medical Journal Open*. Retrieved from: <http://bmjopen.bmj.com/content/4/6/e005273.full>. doi: 10.1136/bmjopen-2014-005273
- Sorensen, L., Waldorff, F. & Waldemar, G. (2008). Early counselling and support for patients with mild Alzheimer's disease and their caregivers: A qualitative study on outcome. *Aging and Mental Health*, 12(4), 444–450.
- Spector, A., Charlesworth, G., King, M., Hoe, J., Lattimer, M., Sadek, S. & Orrell, M. (2014). Cognitive behavioural therapy (CBT) for anxiety in dementia: A pilot randomised controlled trial. *British Journal of Psychiatry* (in press).
- Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R. & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalisation of patients with dementia: A meta-analysis. *Journal of the American Geriatrics Society*, 56(6), 1116–1128.
- Vernooij-Dassen, M., Draskovi, C.I., McCleery, J. & Downs, M. (2011). Cognitive reframing for carers of people with dementia. *Cochrane Database of Systematic Reviews*, 11. doi: 10.1002/14651858.CD005318.pub2
- Ward, A, Arrighi, H.M., Michels, S. et al. (2012). Mild cognitive impairment: Disparity of incidence and prevalence estimated. *Alzheimer's Dement.*, 8,14–21.
- Woods, B., Aguirre, E., Spector, A.E. & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, 2.
- Woods, B., Spector, A.E., Jones, C.A., Orrell, M. & Davies, S.P. (2009). Reminiscence therapy for dementia: Review. *Cochrane Database of Systematic Reviews*, 2. Retrieved from: <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001120.pub2/pdf>
- Young, L., Howard, J. & Keetch, K. (2013.) Once you start writing you remember more. *Journal of Dementia Care*, 21(2), 20–23.

FPOP consultation with people living with dementia in the UK: A position paper

Authors

Reinhard Guss, Consultant Clinical Psychologist, Kent and Medway NHS and Social Care Partnership Trust, Dementia Workstream Lead, Faculty of the Psychology of Older People.

Lewis Slade, Psychology Student, University of Kent.

Rachael Litherland, Director, Innovations in Dementia.

‘Perhaps at one stage, we don’t just want to understand... What we want is to live a normal life.’

Introduction

This document has been created in conjunction with several groups of people with dementia: The Forget Me Nots, based in East Kent, Al’s Café and Friends Together, based in Redditch, the Scottish Dementia Working Group, based in Glasgow, and EDUCATE, based in Stockport. Workshops and focus groups of this consultation were co-facilitated by the Dementia Engagement and Empowerment Project (DEEP) and the Dementia Workstream of the Faculty.

This document summarises the consultation with people living with dementia and informs the FPOP suite of papers on the early dementia care pathway.

It includes comments on each section of the FPOP suite of papers (pre-diagnostic counselling, cognitive assessment, communicating diagnosis and post-diagnostic support) gathered from involvement groups of people with dementia from across the UK. It also contains comments on *A Guide to Psychosocial Interventions in Early Stages of Dementia*, which was researched and compiled as a direct result of the early stages of this consultation.

This document is for:

- Members of FPOP and the wider BPS with an interest in the views of people living with dementia.
- People living with dementia, and their families and friends.
- GPs, commissioners and other professionals who are planning and providing dementia services.

Section 1: Pre-diagnostic Counselling and Informed Consent

1.1 First contact with clinicians

‘You go to the GP when you’re ill or injured... you only bring up your memory as an afterthought.’

Several points highlighted in discussions concern how people were first referred to memory or diagnostic services, in most cases being referred by a GP:

- Many felt that GPs needed training in dementia, as some seemed to lack knowledge on the subject. *‘We need specialist GPs in dementia... And all staff need training really, including receptionists!’*

- Some felt that many clinicians were behind an impenetrable wall of professionalism. Empathy was highlighted as an important factor in positive experiences with health care professionals. *'It's important that professionals are good at just being human... it makes a difference being a human being.'*
- Some GPs were praised for their knowledge and understanding. *'My GP was fantastic. He said he knew exactly what was wrong with me and would pass me onto people who could help me even more.'*
- It helps to stay with the same clinician throughout the process, rather than being transferred repeatedly. *'I didn't always have the same GP every time I visited, so I didn't really have any time to build up a relationship with anyone.'*

'I think everybody's different. I think there needs to be an understanding by the GPs that people are different.'

1.2 Pre-diagnostic information and consent

'We had no information given to us before testing. We just went and they asked us questions. They didn't mention dementia.'

Informed consent was highlighted as ethically imperative as it allows people to assess whether or not they wish to continue, and whether or not they would wish to know that they have a dementia. The following points are important in allowing informed consent:

- Provide time and space to absorb pre-diagnostic information. It is important not only that information is provided, but also that it is made easy to absorb and that time is given to do so. *'Because of the dementia, there was trouble absorbing verbal information. You need written information to take away.'*
- Give information about types of dementia other than dementia in Alzheimer's disease, including the possibility that memory may not initially be the most pressing issue. *'...all professionals seem to just emphasise memory! I was doing my own research. In the end I was informing my GP about dementia!'*
- Consent must be given at every diagnostic and pre-diagnostic appointment. *'[The psychologist] was constantly giving me a 'get out of jail free card'. I think that's very important.'*
- Ensure that the diagnostic process is collaborative and clients know what the purpose of each test is, and what the final diagnosis might be. *[Carer] 'We went through the GP who referred us. He [husband] was sent for a brain scan. I never saw this and the consultant never explained the scan or the process, but just diagnosed Alzheimer's.'*
- Highlight the possibility of diagnostic uncertainty. *'The consultant warned me. That helped me because when the scans came back not showing anything wrong, I was prepared for the possibility it was still dementia.'*

'The sooner you use the word [dementia], the better. If a medical person avoids using the word, it puts it way up there.'

Section 2: Cognitive assessment

2.1 The assessment itself

'When you have a test you automatically think, 'Well I want to pass this test!'... You're constantly thinking, 'Am I passing this test or am I failing?'... I thought about what they asked me last time... so I revised and practised!'

- Transient emotional and cognitive states can play a huge role in determining cognitive performance. *'Assessments are very tiring. Psychologists need to be aware of this.'* *'My psychiatrist noticed this, how stressful the tests were to me... they talked to me and conveyed that they wanted me to be relaxed.'*
- The environment needs to be appropriate. *'Hospitals aren't suitable because you go there for so many other things. You also need time. You should be offered the chance to ask questions later, perhaps even two hours after your meeting.'*
- Some highlighted that, before the appointment, they knew what was likely to come up in the test and so were able to prepare, thus giving inaccurate data. *'I think it's important to have different versions of cognitive tests, to make sure questions are different. Because I did learn the answers.'*
- It is important to think about which test would be appropriate: too easy, and difficulties might go undetected; too difficult, and self-esteem is needlessly damaged. *'Some tests are so easy that someone with early dementia could pass them and then not necessarily be referred, because there was no problem, as it were.'*

'Not seeing the same person every time was a problem. It probably stopped me knowing earlier about my dementia.'

2.2 Information

'I thought of recruitment selection psychometric testing. It wasn't until I started doing the tests that I realised it wasn't like that. But they did explain a bit.'

- It is important to consider how much information is appropriate for/desired by each individual. *'You can't have one rule for everyone – you're going to have to talk to people about what they want to know.'*
- Explanations about tests are important to many people. *'If you know in advance, if you are told, you are more prepared for the testing – but you don't want to prepare for it.'*
- Reports from cognitive testing need to be accurate. *'The report produced was inaccurate on two accounts; (the) medication I'd previously had was incorrect. Driving – it said my wife was not happy to drive with me. But she actually said that this was due to my cataracts, not my cognitive skills.'*
- Assessment should be collaborative. Information should be given to the person on the purpose of the tests, the results from each test, and how these results inform a possible diagnosis, if this information is desired by the person. *'There should be a better transition from assessment to the point of diagnosis. The professionals should communicate with us better; they should share what they're thinking during the process. Assessment should be collaborative. They should tell us what tests they're doing and why they are doing these tests. They should tell us if they are leaning towards one diagnosis or another.'*

'I fought it to the end because I didn't believe it. No one pressured me into doing the tests though, and I came to terms with it.'

Section 3: Communicating a diagnosis of dementia

3.1 Who shares the diagnosis?

‘Staff knew I was going to be told by a doctor I had never met before. They didn’t seem to realise how serious this was. It was horrific.’

The person most people would like to give the diagnosis is someone with whom they have built up a relationship. Ideally this would be the person who did the majority of the assessment.

- Sometimes the psychologist was identified. *‘The biggest relationship you build is actually with the psychologist.’*
- It was often the community psychiatric nurse who was identified. *‘My doctor could have explained the illness and its symptoms, the different types and what that means for me... I also would have preferred my community psychiatric nurse to give the diagnosis...’*
- Sometimes the person had a good relationship with the GP. *‘My GP texts me. We have a good relationship. He respects me.’*
- Others were happy with a psychiatrist sharing the diagnosis. *‘The psychiatrist was the central person who brings it all together, so it didn’t seem wrong to me.’*
- If the diagnosis is communicated by a lead clinician only, some identified that they would still like the clinician with whom they had the best relationship to be present at the appointment. *‘I had a good relationship with my community psychiatric nurse, but they weren’t allowed to be there. I would have liked him to be part of the process. My doctor’s first words were, ‘it’s dementia, it’s progressive, you can’t drive now’. I asked him ‘what kind of dementia?’ he said ‘does it matter?’ I went into denial after that... I think it was because of the way it was conveyed...’*

‘I got a long letter from my psychologist. It was very personal and human. This is what I needed.’

3.2 How the diagnosis is shared

‘There is no single answer.’

Many people stated that they would prefer whoever communicates a diagnosis to take time in doing so in order to do it in a sensitive manner.

- An abrupt diagnostic appointment can be distressing. *‘You have an incurable brain disease... Didn’t even say sorry. I was in the room for two minutes.’*
- The build up to the diagnosis affects how the diagnosis is received. *‘The delivery wasn’t a problem as we’d built up to it. Where I was let down was that there was no immediate follow-up. There was all this support up to this – it felt like ‘Go away and live with dementia’. It was like a vacuum, a cliff-edge.’*
- The diagnosis should be collaborative, with not just the diagnosis itself shared, but how clinicians came to this conclusion. *‘The psychiatrist gave a rationale for why he came to his conclusion.’*
- The diagnosis needs to be communicated sensitively and with empathy. *‘He didn’t introduce himself. He turned half way round in his seat. No name, he didn’t call me by my name. ‘I’ve been looking at your notes and you have got Alzheimer’s disease and you will never work again.’ He still didn’t look at me. I thought, ‘should I say something or should you?’ He just showed us the door, there was no one else waiting, no information.’*

- The importance of how a diagnosis is communicated was emphasised, as it has an effect on how people come to terms with it later. *‘If you [Health Care Professional] communicate this wrong, and the person goes on a downward spiral, resources are more to get them back to the surface. The cost would be greater to the individual and to society.’*

‘It was very neutral, not bad or positive. Many people would like positiveness, but not false positiveness.’

3.3 Language and terminology

‘Language should be challenged in the field of dementia care. There’s currently no challenge to the language that people still use. I still hear ‘demented’, ‘sufferers’, ‘pre-senile dementia’. We find it offensive!’

- Many of the terms that are sometimes used in the field of dementia care, including in diagnosis, people find unhelpful. *‘Don’t like the word ‘journey’ because the destination isn’t somewhere I want to get to. ‘Experience of dementia’ might be better.’ ‘Words are really important! We hate the word ‘sufferer’. It’s really important people know that.’*
- The language used around diagnosis is important. Many feel that the diagnostic process should be collaborative, and that the language should reflect this. *‘Disclosure’ feels like someone is hiding something from you.’ ‘Sharing’ is a better word. We [client and clinicians] have been through this process together.’*
- At the point of diagnosis, language use needs to be considerate and sensitive. *‘Be sensitive. Never be dramatic. For example, do not use terms like ‘I am afraid to tell you...’*

‘Think: How would you tell your mother?’

Section 4: Post-diagnostic support

4.1 Signposting and how post-diagnostic support is offered

‘We need a list of what is available, how to get hold of this kind of treatment, who it is suitable for and who I ask for advice.’

There is wide variation in the quality of signposting and the availability of post-diagnostic work.

- Some people were asked what they would like in terms of post-diagnostic work by clinicians. *‘They asked me what I was interested in. I joined service users – I’ve never had such a good social life.’*
- Post-diagnostic signposting, like the diagnosis itself, should be done with someone with whom the person has a good relationship. *‘The doctor asked me to come back after a visit and the Community Psychiatric Nurse was introduced to me soon after. The community psychiatric nurse then went on and talked to my wife rather than me! I kicked her out after that! It should have been a person who knew us that talked to us.’*

‘What is there? How are you supposed to find out about them?’

‘...they shouldn’t be focussed on what pills to give us; they should be focussed on feelings! They should ask, ‘Are you coping?’’

4.2 Post-diagnostic groups and courses

'Loneliness is your biggest enemy.'

- Post-diagnostic courses are often praised for the practical, emotional and social benefits that they provide. *'When I found I got dementia I didn't know what that meant. I didn't know anything about it... The post-diagnostic course was very helpful in getting all the information for my wife as a carer and myself. Very helpful.'*
- It was said that some individuals are put off by the idea of a group, and needed encouragement to go. *'My wife didn't tell me about the course, she just said 'we're going down to [local town]. I wouldn't have gone if I'd known it was a group. I wouldn't have been here otherwise.'*
- Some argued that groups have a downside. *'There is a downside to groups. You see someone sitting round a table, and you see someone who is obviously worse than you and you think oh God, that is yet to come. And I think that would put me off a bit.'*
- Others disagreed. *'No, I think it's good to have people at different stages because everyone has different problems and you adapt to that.'*
- While post-diagnostic support should be offered to families and carers, it is important to also offer support to the person living with dementia. *'Not everyone has a spouse or someone with them, they can often get forgotten.'*

'We did different things each week and there was plenty of information and leaflets there on how to get help. At the time it was quite new, I hope it's still going on.'

4.3 Good post-diagnostic support services are key to living well with dementia

'Families need support and time to adjust – these are big life changes for them as well.'

- Many people feel alone, confused and frightened after getting a diagnosis. Post-diagnostic support services can help people to adjust to living with dementia. *'I locked myself away for a while, I was withdrawn. Then, after some time, I was offered peer support. That worked for me. It changed my life.'*
- Post-diagnostic support should be available equally to everyone, regardless of time since diagnosis. *'Yes, everyone should have equal access to services and there should be no timescale on when they receive these.'*
- Support should be given according to the person's individual needs and circumstances. People offering services should recognise this. *'Our individual needs, they do change. Do we know what we need and when?'*
- Information on what is being offered should be communicated effectively to people. *'Services should think about communications systems so this information gets through and back to us.'*

'It felt hopeless. It just seemed to be about getting your affairs in order. I could hardly talk afterwards! Then I thought about giving something back. I thought I should do something positive. Giving support to other people gave me hope!'

4.4 There are barriers to getting post-diagnostic support

'If you are injured, then you go to a minor injuries unit. Where do you go if you've got dementia?'

- Many people with dementia and their families do not know what is available or how to access it. *'Where are these things happening? What about local information on local support?'*
- People with dementia and their families may be reluctant to seek support. *'We also need someone to encourage us to attend. This is really important. I didn't want to go to any of the groups or activities offered to me. Only with encouragement from my family did I end up going at all, and then I found it really good!'*
- Lack of accessibility is often a barrier to people getting the support that they need. *'How do you get there? If you are old and cannot drive and have no money or family nearby, how do you get to support groups, courses, etc.?''*

'We should be given support with transport and information... how can people get to any of these groups if there isn't someone to look out for them?'

4.5 Information about post-diagnostic support is vital

People with dementia need access to good quality, clear information about different types of post-diagnostic support.

GPs and other professionals who work with people with dementia need to know what support is available after their diagnosis.

Local information about what services are available, where they are available and how to access them is vital.

'There should be a leaflet or booklet out there that tells us – 'where do I go next'.' 'There is a lot going on that I just don't know about. There's a lot going on and why isn't something being done to bring it all together and raise people's awareness of what is out there.'

Section 5: The guide to psychosocial interventions

5.1 General comments and layout

'Will the guide be developed in simple terms, something everyone will understand?'

- Originally, the title was 'Compendium of Psychosocial Interventions', however, this consistently drew criticism due to its complex nature. *'The title [Compendium of Psychosocial Interventions] needs changing. It's too academic sounding.'* Other suggestions included 'Next Steps', 'Guide' and 'Catalogue'.
- Use of a signposting system within the guide that identifies specific needs and matches interventions to them (the 'What is My Need' section) was praised. *'The What is My Need section makes you think about things you might need but hadn't really thought about before.'*
- Comments were made regarding the general formatting of the document. *'Headings should be bigger, with more space in between sections.'* *'References should be put at the bottom of the same page, or if not, 'See appendix X for details of the full paper'.'*
- General wording was commented on. *'What are the possible downsides' could be changed to 'Are there any downsides?' A bit less pessimistic.'*

- Who is the guide addressed to? Some felt that directly addressing the reader was too direct. *'In a way it's better if it's more detached. 'You', 'you' all the time feels like you're singling me out.'*
- Comments were made on the general grammar of the document. *'Needs as many prompts and reminders as possible, so avoid using pronouns (it, they) and instead use the noun proper.'*

'Any guides that we have would need pictures.'

'If this is produced, it should be useable by professionals so that we can work together.'

5.2 Cognitive Behaviour Therapy (CBT) section

'Stress and anxiety is a big thing. It's very important to have a therapist every week.

We don't have this.'

- Some of the terminology was difficult to understand. *'Not sure what 'cognitive' means.'*
- Comments were made on specific wordings and phrases. *'Take out the phrase 'help you' and replace it with 'it aims to replace unhelpful...'. 'The phrase 'the severity of' is frightening.'*
- Use of technical abbreviations was criticised. *'Don't be so technical. Don't use abbreviations like 'CBT'. It's hard to distinguish all of these apart when you use abbreviations.'*

5.3 Cognitive Stimulation Therapy (CST) section

'It looks interesting. I would go for that.'

- People commented that the description of the intervention was clear and provided all the necessary information.
- Some commented that it was unhelpful to have information on CST and MCST simultaneously as this was confusing. *'Include MCST towards the end, in the 'How long does it take' section.'*
- Bullet points, where possible, would be useful. This also applies to other sections of the document.
- The 'What is the evidence' section (for all interventions) should be more accessible and summarised. While knowing if an intervention is evidence-based is useful, simply providing a list of references is inadequate in terms of information and accessibility.

'Make it more friendly and accessible sounding.'

5.4 Comments on other sections

'Is it possible that you need different things at different times?'

- Many felt that the Advanced Care Planning section was not accessible enough. *'This is awfully complicated.'* *'This was written for someone with brains!'*
- It was felt that the Stress and Anxiety management section was clearly distinguished from other similar interventions. *'This gives you examples about what it is.'* *'When your anxiety is higher, stress and anxiety management. When it is not serious, group.'*
- The downsides section in Counselling and Psychotherapy is useful. *'The downside in counselling and psychotherapy is big. It helps you decide between this and CST.'*

- It was felt that Life Review Therapy was clearly distinguished from CBT.
- The Assistive Technology section, while linguistically clear, needs to clarify what counts as assistive technology, for example, things like handrails which are not what one usually thinks of when thinking about technology. Also, the word ‘technology’ might put some people off.
- Pet Therapy needs a new ‘Possible Downside’. *‘Under ‘Possible Downsides’, note that hygiene is important in relation to pets.’*
- Many comments were made concerning the style of the Cognitive Training section. *‘This page is too wordy, it needs to be pruned, or broken up in some way.’ ‘Under ‘What does it do’, the second paragraph feels a bit like you’re talking down. Be careful not to become patronising!’*
- It needed clarifying that Music Therapy was a specific intervention using a specifically trained therapist to directly confront psychological difficulties.
- It was felt that the Life Story Work section, while well written, lacked ‘spark’ and sounded dull. *‘The section needs to express that sharing life stories can be an enjoyable and rewarding experience, and can have benefits for families later on.’*
- Wording of Personally Tailored Occupational Therapy needed rethinking. *‘This involves individualised goal setting – can put people off. It sounds as though you are being pushed, or forced to do things.’*
- There needs to be more direct reference to the appendix, as it contains useful information but was almost missed. *‘Perhaps have the information in the appendix in a fold-out sheet at the front so that people can refer to it while simultaneously reading the intervention entries.’*

‘Perhaps have a section on ‘How to use this compendium’ at the front.’

Authors’ Note

This consultation was an ongoing process throughout the period of compiling the suite of FPOP papers. Comments from service users were fed back to authors throughout the writing process and influenced the language used and informed the content. Comments also initiated *A Guide to Psychosocial Interventions in Early Stages of Dementia* and shaped the structure and presentation of the document.

We are very grateful to the service user groups and the organisations supporting them for sharing their expertise and enabling this collaboration between contributors.

Glossary of terms

Accuracy: In the context of cognitive assessment, accuracy refers to the likelihood of the findings of the assessment being correct.

Alzheimer's disease: A form of dementia associated with tangles and plaques in the brain. As the disease progresses, cognitive ability gradually declines.

Capacity: Mental capacity refers to an individual's ability to make an informed decision on a specific question.

Carer: One who cares for the needs of a person who is less able to manage independently.

Clinical Psychology: An area of psychology which uses psychological knowledge and research to promote psychological well-being.

Clinical Supervision: A space in which a health care professional discusses their clinical work with a supervisor with a view to improving quality.

Cognitive: To do with mental abilities and processes. Typically understood as thoughts, knowledge, language production, judgement and problem solving, among other thinking skills.

Commissioning: The act of buying services. In the United Kingdom, commissioners are responsible for deciding what services are provided in a specific area and how much funding these services receive.

Counselling: A type of talking therapy in which an individual discusses problems confidentially with a professional.

Dementia: A term which encompasses a range of medical conditions which cause ongoing decline in various thinking skills and abilities, for example, memory, planning, inhibition and being able to orient oneself to time and place.

Diagnostic uncertainty: It is sometimes difficult for people carrying out assessments to be certain that a dementia is present, or to distinguish between types of dementia. Diagnostic uncertainty refers to the possibility that the results of the assessment are inconclusive.

Discharge: Term used to describe the stage at which a client leaves a specific service, when the service is no longer deemed to be appropriate for the client.

Euphemism: A term that is used instead of another that might be considered offensive or distressing. An example would be the use of the phrase 'memory problems' instead of the word 'dementia'.

Frontotemporal dementia: A form of dementia which particularly involves the frontal and side regions of the outer brain. It is often associated with behavioural or personality change and/or difficulties with language.

Good practice: A term used to describe actions taken in health care that are seen as ideal for the well-being of the recipient of said care.

Holistic: Taking into account all aspects of a particular situation.

Hypothesis: A suggestion of fact made on limited evidence. Further testing is used to either support or disprove the hypothesis. In the context of cognitive assessment, for example, a psychologist might interpret existing evidence as suggesting a particular type of dementia before using in-depth tests to find evidence for or against this supposition.

Informed consent: According to best practice guidelines, no assessment or treatment should be undertaken unless the person receiving this is made fully aware of the processes and implications involved. In cognitive assessment, this means that the possibility of a diagnosis of dementia should be made clear before assessment is undertaken so that individuals can decide whether or not they would want to receive this information.

Intervention: A clinical term used to describe any treatment which aims to help people to adjust to changing circumstances or to improve quality of life.

Memory Clinic: A service which specialises in the diagnosis of neurological illnesses such as dementia, as well as early support for those with cognitive impairment and those closest to them.

Memory Services National Accreditation Programme (MSNAP): A programme which aims to evaluate services with the goal of improving their performance.

Mild Cognitive Impairment (MCI): A condition in which an individual's thinking skills are slightly but noticeably lessened, but not enough to impair day to day functioning. MCI may or may not indicate very early stage dementia.

Neuroimaging: The use of technology such as scans to provide an image of the brain.

Neurology: The study of the structure and function of the nervous system and the brain.

Neuropsychology: The study of the structure and function of the brain and how this relates to thinking and behaviour. Neuropsychological assessment involves testing specific thinking skills and using the results to gain an understanding of what might be physically happening in the brain.

Peer review: A process by which a piece of work is evaluated by a number of people knowledgeable on the subject matter of the work.

Person-centred: A style of health care which places the needs of the individual receiving said care as central to the process.

Pharmacology: The use of the active chemicals in medication to treat illness.

Prophylactic: A preventative measure.

Psychology: The academic study of the brain and how it relates to behaviour. In the context of clinical work with dementia, psychology focusses on the thinking skills which become more difficult to use and how one might compensate for these, as well as how individuals adjust to the life changes brought about by dementia.

Psychosocial: Relating to psychological (to do with the mind) as well as relating to social situations.

Psychotherapy: A form of therapy which aims to use psychological techniques and research to reduce psychological distress in an individual and promote good mental health.

Rehabilitation: The process of returning as much as possible to previous levels of functioning.

Referral: Term used to describe the allocation of a client to a service. For example, if an individual is referred by a GP to a memory clinic, the services of the memory clinic become available to the individual.

Qualitative research: Research that focusses on non-statistical data such as interviews. It is often used to study individuals in depth.

Quantitative research: Research that uses statistics to find general patterns in a population.

Stepped Care Model: An approach which seeks to treat service users at the lowest level required for their need, with intensity of care increasing with need.

Stigma: Negative views that are held by a large number of people about a specific subject or group of people. These views often come from inaccurate or exaggerated descriptions of real life.

Systematic review: The identification and analysis of all high quality research on a specific subject. Findings from systematic reviews carry great weight in terms of evidence.

Timely diagnosis: A term used to refer to a diagnosis given at a time most suitable for the service user receiving the diagnosis.

Vascular dementia: A form of dementia associated with repeated small strokes in the brain. As the disease progresses, cognitive ability gradually declines.

Notes

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Tel: 0116 254 9568 Fax 0116 247 0787 E-mail: mail@bps.org.uk Website: www.bps.org.uk



The British
Psychological Society
Promoting excellence in psychology



Division of
Clinical Psychology
Faculty of the Psychology
of Older People

A Guide to Psychosocial Interventions in Early Stages of Dementia

Reinhard Guss and colleagues

Collated on behalf of the Faculty of the Psychology of Older People.

*A collaboration of people living with dementia and the
Dementia Workstream Expert Reference Group.*

November 2014



© The British Psychological Society 2014

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Telephone 0116 254 9568 Facsimile 0116 247 0787

E-mail mail@bps.org.uk Website www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

This publication has been produced by the Division of Clinical Psychology Faculty of the Psychology of Older People and represents the views and expert contributions of the members of that Division only.

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.

Contents

Introduction	2
What is my need?	4
Advance Care Planning	6
Animal-Assisted Therapy	9
Assistive Technology	12
Cognitive Behaviour Therapy	15
Cognitive Rehabilitation	18
Cognitive Stimulation Therapy and Maintenance Cognitive Stimulation Therapy	20
Cognitive Training	23
Counselling and Psychotherapy	25
Creative Arts Therapies	28
Dementia Advisors (support from)	30
Dementia/Memory Cafés	32
Family/Systemic Therapy	34
Involvement Groups	36
Life Review Therapy	38
Life Story Work	40
Music Therapy	43
Peer Support Groups	46
Occupational Therapy	48
Post-Diagnostic Counselling	50
Post-Diagnostic Groups	52
Reminiscence	55
Signposting	57
Specialist Information	60
Stress/Anxiety Management	62
References	64
Appendix 1	69
Appendix 2	70

A Guide to Psychosocial Interventions in Early Stages of Dementia

Authors

Reinhard Guss, Consultant Clinical Psychologist, Kent & Medway NHS and Social Care Partnership Trust, Dementia Workstream Lead, Faculty of the Psychology of Older People.

James Middleton, Assistant Psychologist, Kent & Medway NHS and Social Care Partnership Trust, Dementia Home Treatment Service.

Tim Beanland, Knowledge Manager, Alzheimer's Society.

Lewis Slade, Psychology Student, Kent & Medway NHS and Social Care Partnership Trust, University of Kent.

Professor Esme Moniz-Cook, Consultant Clinical Psychologist, Humber NHS Foundation Trust, Honorary Professor of Dementia Research, University of Hull.

Sue Watts, Consultant Clinical Psychologist, Head of Psychology of Older People, Greater Manchester West Mental Health Foundation Trust.

Alex Bone, Psychology Student, Kent & Medway NHS and Social Care Partnership Trust, University of Kent.

Introduction

If you have recently received a diagnosis of dementia, you may want to know what support is available to you. Depending on your needs, there are a variety of treatments and interventions which can help you with coming to terms with your diagnosis and maintaining your well-being.

What is a Psychosocial Intervention?

A 'psychosocial intervention' is a broad term used to describe different ways to support people to overcome challenges and maintain good mental health. Psychosocial interventions do not involve the use of medication.

Psychosocial interventions are available to people who have received a diagnosis of dementia and their families. They are intended to help people to live well following diagnosis.

Psychosocial interventions can help with:

- coming to terms with a diagnosis of dementia
- maintaining your social life and relationships after diagnosis
- reducing stress and improving your mood, for example, if feeling worried, anxious, or depressed
- thinking and memory (cognitive function)
- living independently
- quality of life – maintaining health and happiness, and control over your life
- support for your partner and family

Deciding on the right psychosocial interventions for you depends on your needs and preferences.

We have outlined a list of different needs people may experience, and the psychosocial interventions that may be helpful in addressing these needs.

Psychosocial interventions are then described in alphabetical order from page 6 to 62.

What is my need?

General Information (and time to adjust)

Dementia Advisors.....	30
Dementia/Memory Cafés	32
Involvement Groups.....	36
Post-Diagnostic Groups	52
Signposting	57

Adjustment to diagnosis

Post-Diagnostic Counselling	50
Post-Diagnostic Groups	52

Specialist information (rare or unusual dementia, non-typical problems)

Specialist Information	60
------------------------------	----

Stress, anxiety or depression

Cognitive Behaviour Therapy.....	15
Counselling and Psychotherapy	25
Life Review Therapy.....	38
Stress/Anxiety Management.....	62
Reminiscence.....	55
Animal-Assisted therapy	9
Family/Systemic therapy.....	34

Improving and maintaining cognitive functioning

Assistive Technology.....	12
Cognitive Rehabilitation	18
Cognitive Stimulation Therapy.....	20
Cognitive Training.....	23
Occupational Therapy	48
Reminiscence.....	55
Specialist Information	60

Help for families and caregivers

Assistive Technology.....	12
Cognitive Behaviour Therapy.....	15
Counselling and Psychotherapy	25
Dementia/Memory Cafés	32
Family/Systemic Therapy	34
Peer Support Groups	46
Occupational Therapy	48
Post-Diagnostic Groups.....	52

Couples/families, relationships and communication

Dementia/Memory Cafés	32
Family/Systemic Therapy.....	34
Peer Support Groups	46
Post-Diagnostic Groups	52

Maintaining Independence

Assistive Technology.....	12
Dementia Advisors.....	30
Occupational Therapy	48
Involvement Groups.....	36
Cognitive Rehabilitation	18

Maintaining Quality of Life

Creative Art Therapies	28
Life Story Work.....	40
Music Therapy	43
Animal-Assisted Therapy.....	9
Reminiscence.....	55
Involvement Groups.....	36

Planning for the Future

Advance Care Planning.....	6
Dementia Advisors.....	30

Advance Care Planning

What is advance care planning?

Advance care planning is the process of discussing and then recording your future wishes and preferences for care and treatment. This record comes into effect if you lose mental capacity to make important decisions about your current or future care. It can include statements on how you wish to be treated at the end of your life.

Who is advance care planning for?

Anyone can start to plan for the future and think about their advance care plan. However, advance care planning is particularly important if you have been diagnosed with a long-term, life-changing, or life-limiting illness. It is recommended that you begin advance care planning if you have a diagnosis of dementia.

What does advance care planning involve?

Advance care planning involves discussing and recording your wishes and preferences, and making these known to nurses, doctors, and other family members. It includes anything that is important to you, no matter how trivial it seems. Advance care planning may include:

- an advance decision to refuse treatment. A legal document stating your feelings and beliefs about treatments, and your wishes to refuse specific treatment (e.g. resuscitation) or care in future should you lose mental capacity
- an advance statement of wishes and preferences. This is a summary of how you would like to be cared for in future
- setting up a Lasting Power of Attorney (LPA). This is a legal document naming the person or people whom you have chosen to speak for you, should you lose mental capacity to make certain decisions.

This care plan should be shared with the relevant people, such as family members and doctors. It is recommended that you seek advice from your GP and a solicitor in drafting an advance decision. Many people also see a solicitor to create an LPA.

When should I start advance care planning and how long does it take?

You choose when and if you want to record an advance care plan, but it is generally advised that you do so soon after finding out that you have a diagnosis of dementia. You can take time to think about your future care, and it is possible to update or change your advance care plan at any time you wish.

What benefits might I see from doing advance care planning?

Through advance care planning, you are documenting your preferences and wishes for future care. This should give you:

- some control over the future
- peace of mind
- help for your partner, family and professionals to act in your best interests when faced with decisions concerning your treatment, care or finances

What are the possible limitations to advance care planning?

Not all parts of your advance care plan will be legally binding.

Advance decision making requires you to plan for your care leading up to your death. This may be difficult for you, your partner and your family to talk about openly. You may need some time to come to terms with your diagnosis before you are able to make plans.

Some aspects of advance care planning might incur financial cost, as they require the involvement of legal professionals. You will also need to pay a fee to register a LPA.

Who can support me with advance care planning?

For your advance statement of wishes and preferences, you can discuss your plan with your partner and family, particularly if it involves them. You may have further questions about treatment and care and therefore you may want to speak to your GP or other health professionals before you make any decisions.

You may want to discuss the legal aspects of an advance care plan such as a LPA with a solicitor, who can guide you through the process.

As there are many aspects of advance care planning, you may want to speak to a number of professionals when making decisions about your future care, for example:

- wishes and preferences – family, friends, GP, carers, etc.
- health care decisions – to be made with the relevant professional
- advance decisions – doctor and solicitor
- LPA – discuss with your solicitor
- advice on advance care planning – most professionals, memory services, dementia advisor

Where can I find professional support with advance care planning?

Local charities, outreach workers from Age UK, dementia advisors, Alzheimer's Society, social services (social workers or case managers), and some memory services provide access to advance care planning. Your GP will also be able to direct you to someone who can help.

Where can I find more information on advance care planning?

There are a number of resources available on the internet.

NHS Choices has information on advance care planning, advance decision to refuse treatment and power of attorney:

<http://www.nhs.uk/conditions/dementia-guide/pages/dementia-diagnosis-plan.aspx>

<http://www.nhs.uk/carersdirect/moneyandlegal/legal/pages/advancedecisions.aspx>

<http://www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/Powerofattorney.aspx>

Alzheimer's Society factsheet 463 Advance decisions and advance statements:

www.alzheimers.org.uk/factsheet/463

Who approves/recommends advance care planning?

Advanced care planning is recommended by the British Psychological Society, The Royal College of Psychiatrists and the European Association for Palliative Care.

National Institute of Health and Care Excellence (NICE).

1.1.4.4 Ethics consent and advance decision making.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

4.2.14 Care Management – support with legal matters.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

European Association for Palliative Care. Standard 3.2. Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.

EAPC (2013). Recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias. *Palliative Medicine*, published online 4 July 2013. Retrieved 10 June 2014 from:

<http://www.eapcnet.eu/Corporate/AbouttheEAPC/EAPCpublications/EAPCrecommendations/tabid/1616/ctl/Details/ArticleID/612/mid/3090/Default.aspx>

Animal-Assisted Therapy and pets

What is animal-assisted therapy?

In this guide, we describe animal-assisted therapy as a type of therapy involving structured encounters with animals with the purpose of improving well-being and quality of life. It can involve therapeutic encounters with a range of animals, such as dogs, animals, fish, and also toy animals and robot animals.

Animal-assisted therapy has specific goals and outcomes and is different from just owning a pet or being in contact with animals, which can also make you feel good.

Animal-assisted therapy as a term has been used to describe a number of different interventions. Pets-as-therapy (PAT) animals are an example of an animal-assisted activity, and are not regarded as animal-assisted therapy. Similarly, being provided with an animal for practical support such as a Dementia Dog, or a guide dog is not animal-assisted therapy.

Who is animal assisted-therapy for?

Anyone with a diagnosis of dementia, and also their family or carers.

What does animal-assisted therapy involve? How does it work?

There is a wide range of approaches involving animals which have therapeutic value. Some animal-assisted therapy involves contact with an animal in the company of a trained handler. The therapist will facilitate your interaction with the animal with a specific goal or outcome in mind, for example, motivating you to exercise or improving your communication skills or confidence.

Sometimes animals are used to improve your well-being through bonding and companionship, or to help you maintain independence.

How long does animal-assisted therapy take?

The type of animal-assisted therapy you choose will determine the duration of treatment. Some animal-assisted therapy may involve making a long-term commitment to having an animal stay with you. You will co-operatively decide with your therapist if this is the therapy for you and how long you will be involved with the animal.

The responsibility and time-frame of having a pet should be considered. It may be more feasible to have short-term interactions with animals, for example offering to look after pets for friends and family.

What benefits might I see from having animal-assisted therapy?

Animal-assisted therapy can help to reduce loneliness, and may help alleviate depression and anxiety, or encourage you to engage in physical activity, leisure, and relaxation. Some studies suggest have suggested that time spent with animals can reduce blood pressure. Research has also suggested that spending time with animals can encourage people to be sociable.

What are the possible limitations to animal-assisted therapy?

- You may be allergic to some animals.
- Hygiene must be taken into account when around animals.

Who can provide me with animal-assisted therapy?

Depending on the type of animal-assisted therapy, this should be provided by an individual with the correct level of qualifications and experience in handling animals in a therapeutic setting.

If you want to spend time with animals without a therapist, you may be interested in an animal-assisted activity (such as from a PAT animal) or be interested in taking on your own animal as a companion.

Where can I ask for animal-assisted therapy?

You can request advice on animal-assisted therapy from your dementia advisor. You can also ask for information on an animal-assisted therapy provider at your memory clinic.

Where can I find more information?

Ask for information on animal-assisted therapy from a professional at your memory clinic. There are several private providers of animal-assisted therapy advertised on the internet, however, many of these advertise actually offer activities called animal-assisted interventions which are not animal-assisted therapy.

If you are interested in animal-assisted activities, or animals as practical support for your memory rather than animal-assisted therapy, these websites might be useful to you:

Pets as therapy: www.petsastherapy.org

Information on dementia dogs: www.dementiadog.org

What is the evidence for animal-assisted therapy?

There is limited evidence for animal-assisted therapy available in research literature at present, however small studies have shown that spending time with animals can benefit people living with dementia.

Filan S.L. & Llewellyn-Jones R.H. (2006). Animal-assisted therapy for dementia: A review of the literature. *International Psychogeriatrics*, 18(4), 597–611.

Who approves/recommends animal-assisted therapy?

Animal-assisted therapy is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.7.1.2 Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia.

1.8.1.3 Interventions for comorbid emotional disorders in people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.7.1 People with dementia and their carers are made aware of other non-pharmacological interventions that they may wish to consider.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Assistive Technology: Advice and support

What is Assistive Technology: Advice and support?

‘Assistive technology’ refers to devices and technology which help make life easier for you, and help you to cope with the changes that can come with having a diagnosis of dementia. They can help you to maintain independence, keep you and your family safe, and enable you to stay connected with your loved ones and your community.

As there is a range of assistive technology available, it is sometimes helpful to have specialist advice to help you choose and operate assistive technology.

Who is Assistive Technology: Advice and support for?

If you want some advice on what kind of assistive technology devices may help you now or in the future, you may wish to discuss your needs with an occupational therapist, or a professional who knows about assistive technology. If you have recently purchased or been given a new piece of equipment, it may be helpful to have guidance or training in using this effectively.

What does Assistive Technology: Advice and support involve?

Primarily, advice and support with assistive technology will involve a discussion about your specific needs. During this discussion the aim will be to see what kind of equipment can be helpful to you specifically.

There is equipment and devices which can help you in the following areas:

- speaking, for example, communication aids
- doing things independently at home
- keeping safe when going out, for example, satellite navigation to help you find places, or GPS trackers to help others to find you
- memory, for example, a medication monitor or alarm which reminds you to take your medication. An electronic dosage system can ensure you take the right quantity
- socialising and staying connected with others, such as tablet computers or video conferencing systems to help you keep in touch
- preparing food and drink, such as alarms which automatically shut off your gas supply should your cooker be left on
- keeping you and your family safe in the home, for example, against falls, or by helping to regulate the temperature

There are many devices available and it may be difficult thinking about which device will be the right one for you. Any combination of devices can be used depending on your own needs, and personalised professional advice can help you decide what will help you the most.

How long does it take to receive advice and support with assistive technology?

You may need time to think about the specific aspects of your life in which technology may help you; for example, you may wish to have a device that helps you remember tasks or appointments. A professional can provide you with information on these devices directly during a consultation. You may want them to show you how to use your chosen device so

you get the most out of it. You may want to have several sessions of learning with a professional, particularly if you want your family or partner to understand how it works as well.

Leaflets may also be provided so that you can go through options at your own pace.

What benefits might I see from having advice and support with assistive technology?

Assistive technology is designed to provide safety, peace of mind and increased independence, while causing as little disruption to your daily life as possible.

What are the limitations of advice and support with assistive technology?

Assistive technology may involve a significant financial cost. You will also need to learn how to use certain types of equipment. It may not fit with your lifestyle and you may have to change your routines.

Who can provide advice and support with assistive technology?

Some occupational therapists or other health and social care professionals can talk to you about assistive technology and how you and your family can use it effectively. They can also advise you on financial assistance, as many devices come at a cost. For a small charge, some disability living centres will loan you equipment so that you 'try before you buy'.

Where can I ask for advice and support with assistive technology?

Depending on your specific need, you may want to talk to someone at your memory service or to your GP about a referral to a specialist who can help you with assistive technology.

Mental health professionals such as community psychiatric nurses and occupational therapists can provide information and discuss it with you. There are also leaflets on assistive technology in many memory services and GP surgeries.

There are a range of private and not-for-profit organisations that provide assistive technology.

Ask your Dementia Advisor, social services or memory service for details of local providers.

Where can I find more information on assistive technology for myself?

Alzheimer's Society factsheet 437 Assistive technology - devices to help with everyday living:
www.alzheimers.org.uk/factsheet/437

There is an online tool with information on a wide range of assistive technologies:
<http://asksara.dlf.org.uk/>

Who approves/recommends advice and support for assistive technology?

Assistive Technology with support and advice is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.1.10.2 Environmental design for people with dementia.

1.2.1.1 Integrated health and social care.

1.5.1.1 Promoting and maintaining independence of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.4.2 The service provides access to psychosocial interventions for occupational and functional aspects of dementia.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Behaviour Therapy for anxiety or depression

What is cognitive behaviour therapy?

Cognitive behaviour therapy is a term used to describe a number of talking therapies which are used to overcome emotional and psychological problems. Cognitive behavioural therapy is commonly used to treat stress, anxiety and depression.

The word 'cognitive' refers to thinking, reasoning and memory. Cognitive behaviour therapy is also known as CBT.

There are alternatives to cognitive behaviour therapy. Other similar therapies include behavioural activation, acceptance and commitment therapy, cognitive analytic therapy, and mindfulness-based cognitive behaviour therapy.

Who is cognitive behaviour therapy for?

You may want to try a talking therapy such as cognitive behaviour therapy if you are feeling particularly stressed, worried, anxious, low in mood or depressed.

What does cognitive behaviour therapy do? How does it work?

Cognitive behaviour therapy aims to give you new skills to overcome current life challenges. It aims to change ways of thinking that might be unhelpful. This may make it easier to deal with demanding situations or difficult emotions.

Cognitive behaviour therapy involves meeting regularly with a trained therapist who will help you to learn new skills and techniques which may make you feel better and improve your life. You will talk about your thoughts and feelings with your therapist and they will guide you through different ways of overcoming your problems.

How long does cognitive behaviour therapy take?

The number of therapy sessions you are offered will depend on your needs, for example, how you are experiencing your difficulties. The number of sessions you have will be cooperatively decided by you and your therapist.

What benefits might I see from having cognitive behaviour therapy?

Cognitive behaviour therapy aims to give you a better understanding of your ways of thinking, your emotions and your ways of coping with life situations. Through this understanding you may:

- learn new skills to cope with stress, anxiety and depression, and other related experiences
- feel better, less stressed, less anxious, happier
- be able to carry on with your life and feel more active

What are the possible limitations of cognitive behaviour therapy?

Cognitive behaviour therapy is only one type of talking therapy and you may find that it is not the right one for you. You may wish to consider other types of talking therapies such as counselling or psychotherapy (see page 25), life review therapy (see page 38), or stress and anxiety management (see page 62).

Who can provide cognitive behaviour therapy?

A therapist trained in cognitive behaviour therapy can provide you with cognitive behaviour therapy. This is available through NHS services, or private therapy services which you will have to pay for.

Where can I go to ask for cognitive behaviour therapy?

A referral for cognitive behaviour therapy can be made by your GP or through your memory service if you are feeling stressed, anxious, worried or depressed. You can refer yourself for cognitive behavioural therapy through your local IAPT provider.

Where can I find more information on cognitive behaviour therapy for myself?

There is information on cognitive behaviour therapy is widely available on the internet. The NHS has further information on its website.

NHS Choices – Types of talking therapy

<http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx>

Alzheimer's Society Factsheet 445. Talking therapies (including counselling, psychotherapy and CBT): www.alzheimers.org.uk/factsheet/445

British Association for Behavioral & Cognitive Psychotherapies (BABCP). You can find a registered therapist from this website: <http://www.babcp.com>

What is the evidence for cognitive behaviour therapy for anxiety and depression for people living with dementia?

There is evidence that psychological therapies including cognitive behaviour therapy reduce depression and anxiety for people living with dementia and mild cognitive impairment, as well as for family caregivers.

Orgeta, V., Qazi, A., Spector, A.E. & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment.

Cochrane Database Systematic Reviews, 22(1), CD009125.

Sadek, S., Charlesworth, G., Orrell, M. & Spector, A. (2011). The development of a Cognitive Behavioural Therapy (CBT) manual: A pilot randomised control trial of CBT for anxiety in people with dementia anxiety. *International Psychogeriatrics*, 23, S383–S384.

Selwood, A., Johnston, K., Katona, C., Lyketsos, C. & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101, 75–89.

Sommerlad, A., Manela M., Cooper, C., Rapaport, P. & Livingston, G. (2014).
START (StrAtegies for RelaTive) coping strategy for family carers of adults with
dementia: Qualitative study of participants' views about the intervention.
British Medical Journal Open. Retrieved from:
<http://bmjopen.bmj.com/content/4/6/e005273.full>.

Who approves/recommends cognitive behaviour therapy?

Cognitive behaviour therapy is recommended by the British Psychological Society and
The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.8.1.2 Interventions for co-morbid emotional disorders in people with dementia.

1.11.2.5 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and
social care*. NICE Clinical Guideline 42. Available at www.nice.org.uk/CG42
[NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.3.1 People with dementia have access to interventions to address their emotional
needs.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme*
(4th ed.). London: Royal College of Psychiatrists.

Cognitive Rehabilitation

What is cognitive rehabilitation?

Cognitive rehabilitation is an approach to managing the impact that dementia-related difficulties, such as problems with thinking and memory, can have on everyday life.

Who is cognitive rehabilitation for?

Cognitive rehabilitation is for people who have early-stage dementia. Many cognitive rehabilitation programmes involve families and carers.

What does cognitive rehabilitation do? How does it work?

Cognitive rehabilitation usually starts with identifying things you would like to improve on or manage better. This is done in discussion with a trained professional, leading to agreement about which goals to work on together. The professional will then work with you to devise ways of achieving the goals you have identified. A family member is usually involved as well. Cognitive rehabilitation can involve learning strategies for managing memory problems, or better ways of tackling everyday tasks. Sometimes people choose to learn something new, such as how to use a mobile phone or iPad, to help in everyday situations, or to resume activities they used to enjoy.

Cognitive rehabilitation is not about curing or reducing dementia-related difficulties with thinking and memory; rather it is about learning ways of compensating for these difficulties or managing them better.

How long does cognitive rehabilitation take?

The number of sessions of cognitive rehabilitation will depend on your needs, how much training and support you require, and the specific goals you have set yourself. It will involve practising techniques and skills in between sessions as well.

What benefits might I see from having cognitive rehabilitation?

Cognitive rehabilitation cannot cure memory problems, but it can help you to live well with them. It may improve aspects of your daily life.

What are the possible limitations of cognitive rehabilitation?

Cognitive rehabilitation will require effort from you, both during and outside of sessions. Because the focus is on tackling things that are causing you difficulty, the focus will often be on areas that are challenging for you rather than the things you do well. It often means trying new things or finding different ways of doing things, which may be unsettling initially.

Who can provide me with cognitive rehabilitation?

Cognitive rehabilitation can be undertaken by an occupational therapist, a clinical psychologist or a clinical neuropsychologist.

Where can I ask for cognitive rehabilitation?

If you want cognitive rehabilitation you will need to attend a specialist service for people with dementia, a memory service, a neuropsychology service, a stroke service or a service for people living with ABI (acquired brain injury).

You will need to talk to your GP first about a referral to these services. It may be possible to access cognitive rehabilitation privately.

You may be able to access cognitive rehabilitation through a clinical trial in your area; ask your local memory services if one is currently running.

Where can I find more information on cognitive rehabilitation?

Information can be found through your memory service, your GP, or your dementia advisor.

What is the evidence for cognitive rehabilitation?

Current evidence on the effectiveness of cognitive rehabilitation is promising, showing that cognitive rehabilitation is helpful when it is tailored to individual goals.

Bahar-Fuchs A, Clare L, Woods B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews*, 2013, Issue 6. Art. No. CD003260.

Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M., Kopelman, M., Kudlicka, A., Leroi, I., Oyebode, J., Pool, J., Woods, B. & Whitaker, R. (2013). Goal-oriented cognitive rehabilitation in early-stage dementia: Study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials*, 14, 152.

Clare, L., Evans, S., Parkinson, C., Woods, R.T. & Linden, D. (2011). Goal-setting in cognitive rehabilitation for people with early-stage Alzheimer's disease. *Clinical Gerontologist*, 34, 220–236.

Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H., van Paasschen, J., Nelis, S.M., Hoare, Z., Yuen, K.S. & Rugg, M.D. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry*, 18, 928–939.

van Paasschen, J., Clare, L., Yuen, K., Woods, R.T, Evans, S., Parkinson, C., Rugg, M. & Linden, D. (2013). Cognitive rehabilitation changes memory-related brain activity in people with Alzheimer's disease. *Neurorehabilitation and Neural Repair*, 27, 448–459.

Kurz, A.F., Leucht, S. & Lautenschlager, N.T. (2011). The clinical significance of cognition focused interventions for cognitively impaired older adults: A systematic review of randomised controlled trials. *International Psychogeriatrics*, 1–12.

Who approves/recommends cognitive rehabilitation?

Cognitive Rehabilitation is recommended by the The Royal College of Psychiatrists. Memory Service National Accreditation Programme (MSNAP).

6.2.3 Service provides support for the cognitive aspects of dementia.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Stimulation Therapy and Maintenance Cognitive Stimulation Therapy

What is cognitive stimulation therapy?

Cognitive stimulation therapy (CST) is a group therapy that is used to help strengthen a person's communications skills, thinking and memory. CST groups run for a limited number of sessions. Maintenance cognitive stimulation therapy (MCST) groups continue indefinitely, and aim to maintain the benefits that CST groups provide.

Who is cognitive stimulation therapy for?

CST is for anyone who has a diagnosis of dementia, in mild to moderate stages. It may also be suitable to you if you have a diagnosis of Mild Cognitive Impairment (MCI)

What does cognitive stimulation therapy do? How does it work?

It is used to make the most of your skills and mental functions through exercises and activities. It is a fun social activity, with a different theme and activity each week. There are also elements that help you to focus on the present, for example discussing items in the newspapers, and having a group name and song.

A typical CST session lasts for one hour and may involve games, singing, reminiscence, sharing stories, chatting and discussions, current events, arts and crafts.

MCST, like CST, aims to help slow down cognitive decline. This treatment follows on from a course of CST. This treatment is used to maintain the benefits of CST. It is identical to CST but often runs for much longer.

Practitioners will work from a standardised manual on CST which means most programmes will be similar but not exactly the same.

How long does cognitive stimulation therapy take?

CST usually runs for 14 sessions and you usually attend one or two sessions per week. MCST runs for as long as it is useful to you.

What benefits might I see from having cognitive stimulation therapy?

There are several benefits of attending a CST group, and these are gained through active participation in the activities during the programme. These benefits include:

- improving your confidence, and the way you feel about your self and your memory
- improving your communication skills
- giving you ideas about and an opportunity to practice how to stay physically and mentally active
- giving you the opportunity to socialise and share with people in a similar situation
- improving your quality of life

What are the possible limitations of cognitive stimulation therapy?

CST is a group programme and so it may not suit everyone's taste. The programme usually requires you to be involved in a number of activities designed to be fun and stimulating, such as singing and group games. You will need to continue with doing the exercises you were doing in the programme to maintain the benefits. MCST is designed to do this, however it is not yet widely available.

Who can provide me with cognitive stimulation therapy?

Practitioners trained in CST, often occupational therapists, mental health nurses, care workers and support workers. Often CST is available through your memory services or local mental health services.

Where can I ask for cognitive stimulation therapy?

Your local memory service will advise when and where CST is available. You will need to ask your GP for a referral to a memory service if you are not currently accessing this service.

Where can I find more information on cognitive stimulation therapy?

Information on CST can be found on the internet: www.cstdementia.com

You can also find information on CST at your local memory service.

What is the evidence for cognitive stimulation therapy?

There are large studies evaluating the effectiveness of CST. Findings show a significant positive impact on language skills (naming, word-finding and comprehension).

An interview study suggests improvements in mood, confidence and concentration, and highlights the supportive nature of the group. One study found that longer-term MCST led to continuous benefits in these areas, and maintaining living well with dementia, over a six-month period.

Orrell M., Aguirre E., Spector A., Hoare Z., Streater A., Woods B. et al (2014).

Maintenance Cognitive Stimulation Therapy (MCST) for dementia: A single-blind, multi-centre, randomised controlled trial of Maintenance CST vs. CST for dementia. *British Journal of Psychiatry*, 204(6), 454–461.

Spector, A., Gardner, C. & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Ageing & Mental Health*, 15(8), 945–949.

Spector, A., Orrell, M. & Woods, B. (2010). Cognitive Stimulation Therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry*, 25(12), 1253–1258.

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M. & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *British Journal of Psychiatry*, 183, 248–254.

Who approves/recommends cognitive stimulation therapy?

Cognitive stimulation therapy is recommended by the British Psychological Society and the Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.6.1.1 Interventions for cognitive symptoms and maintenance of function for people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42. Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.2.1 People with dementia have access to a local programme of group cognitive stimulation therapy.

6.2.2 People who have participated in group cognitive stimulation therapy have access to a maintenance CST programme.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Cognitive Training

What is cognitive training?

Cognitive training ('brain training') involves training specific aspects of your memory and other thinking skills. This is usually through an exercise or a game on a computer, but regular pastimes such as crosswords and Sudoku would also count as cognitive training. Cognitive training is not as personally-tailored and has not proved to be as effective as cognitive rehabilitation (see page 18). It is widely available on the internet and gaming consoles as 'brain training'.

Who is cognitive training for?

Cognitive training is for anyone who wants to keep their brain active and enjoys brain training games and puzzles, including people living with dementia.

What does cognitive training involve? How does it work?

Cognitive training assumes that the brain is like a muscle and can benefit from regular exercise to stay healthy ('brain training'). It also assumes that if you have dementia, you can maintain your current level of functioning or slow down decline through training your brain.

Each exercise or game is designed to train specific functions of your brain, such as:

- memory for words
- logic and reasoning
- memory of pictures or images
- problem solving
- mathematics

How long does cognitive training take?

Cognitive training and brain training is meant to be a regular activity done continually, usually at least once a day for a sustained period of time.

What benefits might I see from having cognitive training?

You may see an improvement in the areas that you train. For example, if you are having difficulty remembering a list of numbers, you may see benefits in this area when doing an exercise to train you to remember numbers. In other words, you would not see an improvement in your general memory, but it may help you to be better at remembering a list of numbers.

What are the possible limitations of cognitive training?

- There may be a small financial cost to some forms of cognitive training.
- Cognitive training activities need to be continued to maintain the benefits.
- Cognitive training needs to be personally-tailored to your specific needs in order to have any noticeable effects.
- Any benefits are likely to be restricted to the area being trained in, not more widely transferable.

Who can provide you with cognitive training?

The exercises and games are usually self-administered, using the internet, books and computer programs. Memory service programs are available in some areas.

Where can I get cognitive training (or where can I get advice on cognitive training)?

There is an overlap in how professionals describe cognitive training and cognitive rehabilitation (see page 18). You will need to speak to a specialist professional with knowledge of dementia and cognitive training if you want advice and support in doing cognitive training for yourself. Some memory services may have programs set up to offer a form of cognitive training to you. You may be offered cognitive rehabilitation (see page 18) or cognitive stimulation therapy (see page 20) instead. You can do general 'brain training exercises' by accessing intellectually stimulating materials, such as crosswords and Sudoku which can be found in a variety of newspapers, magazines or booklets, and on electronic media.

Where can I find more information about cognitive training for myself?

You can find many sources claiming to offer brain training on the internet; however many of these will have limited effectiveness in terms of achieving your goals. If you are looking for ways of maintaining your thinking and memory, you may wish to seek advice from a professional at your memory service. You will need a referral from your GP to access your memory service if you are not accessing this already.

What is the evidence for cognitive training?

Yu et al. (2009), in a literature review, concluded that interventions that were more structured and focused were more effective overall.

Yu, F., Rose, K., Burgener, S., Cunningham, C., Buettner, L., Beattie, E., Bossen, A., Buckwalter, K., Fick, D., Fitzsimmons, S., Kolanowski, A., Specht, J., Richeson, N., Testad, I. & McKenzie, S. (2009). Cognitive training for early-stage Alzheimer's disease and dementia. *Journal of Gerontological Nursing*, 35(3), 23–29.

Bahar-Fuchs, A., Clare, L. & Woods, B. (2013). A Cochrane review, found no evidence to show wider improvement, but people get better at the tasks that they practice.

Bahar-Fuchs, A, Clare, L. & Woods, B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews* 2013, Issue 6. Art. No. CD003260. doi: 10.1002/14651858.CD003260.pub2.

Who approves/recommends cognitive training?

Moniz-Cook and Manthorpe (2009) recommend an individualised form of cognitive training which is administered by a trained professional.

Moniz-Cook, E. & Manthorpe, J. (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.

Counselling and Psychotherapy

What is counselling? What is psychotherapy?

Counselling and psychotherapy are two forms of ‘talking therapy’ which you would have if you wanted support with personal issues, such as if you were stressed, worried, anxious or depressed. They involve meeting with and sharing your problems with your therapist on an individual basis in a confidential setting. There are different types of counselling and psychotherapy to choose from. The therapist aims to help you understand your particular problems so that you can work to overcome or manage these differently.

Who is counselling and psychotherapy for?

Counselling and psychotherapy are for people who are struggling on a personal level with problems and feelings arising from a diagnosis and the effect of dementia on their lives and personal relationships.

What does counselling and psychotherapy involve?

How does it work?

Counsellors and psychotherapists are there to listen to you and discuss problems and feelings with empathy. The purpose of these sessions is not usually to give advice, but to provide a safe space to talk and to help you to find insight and understanding into any problems you may be experiencing.

How long does counselling or psychotherapy take?

Depending on your specific needs, one or many sessions may be carried out. How long each client is seen for tends to be a joint decision between client and therapist. Some people may see their therapist for a short period of time, perhaps a few weeks. Other people may want to see their therapist or counsellor for a number of months or years. Longer term therapy is more likely to be available through the private sector.

What benefits might I see from having counselling or psychotherapy?

Counselling and psychotherapy can provide relief from psychological and emotional distress, and can help you to understand your problems more fully.

What are the possible limitations to counselling and psychotherapy?

Talking therapies can involve confronting difficult experiences and memories. Counselling and psychotherapy are not for everyone and there are alternative talking therapies available such as cognitive behaviour therapy (see page 15) or life review therapy (see page 38). Much of the effectiveness of talking therapies depends on your relationship with your therapist, and you may wish to try someone different if you find your therapist is not the right one for you.

Who can provide me with counselling and psychotherapy?

Therapy sessions are carried out by specifically trained counsellors and psychotherapists.

Where can I ask for counselling and psychotherapy?

You should ask your GP or your memory service for a referral for counselling and psychotherapy through the NHS. Counselling and psychotherapy can be provided by both the NHS and private organisations.

Where can I find more information about counselling and psychotherapy for myself?

Your local memory service or a health care professional may be able to provide more information on counselling and psychotherapy.

More information on ‘talking therapies’ can be found on the Alzheimer’s Society website: <http://www.alzheimers.org.uk/factsheet/445>

NHS Choices – Types of talking therapy

<http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx>

You can find out more about counselling and psychotherapy from the following websites. You can also find a list of accredited therapists from these websites if you want to pay for therapy privately.

British Association for Counselling and Psychotherapy (BACP): <http://www.bacp.co.uk>

British Psychoanalytic Council (BPC): <http://www.bpc.org.uk>

United Kingdom Council for Psychotherapy (UKCP): <http://www.ukcp.org.uk>

What is the evidence for counselling and psychotherapy?

There is evidence that psychological therapies including counselling and psychotherapy can help to reduce depression and anxiety.

Junaid, O. & Hegde, S. (2007). Supportive psychotherapy in dementia. *Advances in Psychiatric Treatment*, 13, 17–23. doi: 10.1192/apt.bp.105.002030.

This article explores the use of psychotherapy to help people adjust to changes and difficulties brought about by dementia, improving quality of life.

Lipinska, D. (2009). *Person-centred counselling for people with dementia: Making sense of self*. London: Jessica Kingsley Publishers.

Who approves/recommends counselling and psychotherapy?

Counselling and Psychotherapy are recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.8.1.2 Interventions for comorbid emotional disorders in people with dementia.

1.11.2.5 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.3.1 People with dementia have access to interventions to address their emotional needs.

6.6.1 Carers for people with dementia are offered an assessment, and intervention/s if appropriate, for their emotional, psychological and social needs.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Creative Arts Therapies

What are creative arts therapies?

Creative arts therapies are a type of psychotherapy (see page 25 for counselling and psychotherapy) which use media such as painting, literature, sculpture and music (among others) as a focus for treatment. Creative arts therapies have a therapeutic focus and are different from general arts activities.

You may also be interested in looking at ‘Music Therapy’ on page 43 for more information on how music specifically can be used as part of an intervention.

Who are creative arts therapies for?

Creative arts therapies are for anyone with a diagnosis of dementia who feels that artistic expression can help with emotional difficulties and maintaining quality of life. This may be something you wish to consider if you do not feel talking therapies are right for you, or if you want an alternative to talking therapies.

What do creative arts therapies do? How do creative arts therapies work?

Creative arts therapies can take place individually or in groups, and usually involve the creation and/or discussion of art in a confidential, therapeutic environment. It allows expression of thoughts and emotions that are difficult to express using words alone. The therapist will help you understand your feelings and emotions through helping you to express them creatively.

How long do creative arts therapies take?

Sessions usually last between one and two hours. The number of sessions can be dependent on individual need and desire.

What benefits might I see from having creative arts therapies?

Creative arts therapies aim to help you overcome emotional problems. They may offer you the following:

- the opportunity to express emotions which are difficult to convey in words alone
- intellectual stimulation
- improving well-being and quality of life

What are the possible limitations to creative arts therapies?

Creative arts therapies require specifically trained therapists and may not be available in your area. They may also involve discussion of difficult emotions or life events.

Who can provide me with creative arts therapies?

Creative arts therapies require therapists specifically trained in a particular form of art therapy. While sessions involving creative arts can be offered by many different types of professional as interesting activities, art therapy specifically addresses deeper and more specific issues, hence requiring a specifically trained therapist.

Where can I ask for creative arts therapies?

Creative arts therapists can be found working within multi-disciplinary teams in hospitals, day centres, hospices, care homes, therapy centres and in private practice across the UK.

Where can I find more information about creative arts therapies for myself?

Your health care professional or memory service may be able to provide you with more information.

Arts 4 Dementia website: <http://www.arts4dementia.org.uk/arts-therapies>

Alzheimer's Society website: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=708&pageNumber=3

What is the evidence for creative arts therapies?

There are many subjective accounts about the benefits of having creative arts therapies, such as improved well-being; however, objective measures of benefits of this type of therapy have yet to be investigated fully.

Beard, R.L. (2012). Art therapies and dementia care: A systematic review. *Dementia*, 11, 633–656.

Urbas, S. (2009). Art therapy: Getting in touch with inner self and outside world. In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.

Who approves/recommends creative art therapies?

Creative arts therapies are recommended by the Royal College of Psychiatrists. Memory Service National Accreditation Programme (MSNAP).

6.7.1 People with dementia and their carers are made aware of other non-pharmacological interventions that they may wish to consider.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Support from Dementia Advisors

What is a dementia advisor?

A dementia advisor is there to provide you with ongoing support to live well with dementia – a single named person you can go to at any stage. This support is sometimes called case management.

Who is a dementia advisor for?

Dementia advisors are for anyone who is affected by dementia. They are primarily for people with dementia, but may also be available for relatives and caregivers of people with dementia.

What does a dementia advisor do?

They provide you with the information you need, when you need it, and will work with you to help you access what you want. They aim to help you live independently, access other services, maintain your well-being and keep control of your life. They can:

- meet with you in person to answer specific questions
- help you find the information that you need
- develop an individual plan for receiving information
- help you to navigate and access other services that you may require (in some areas the dementia advisor role is called a ‘dementia navigator’)

The dementia advisor aims to meet with you regularly, in line with your information plan.

How long do I see a dementia advisor for support?

Dementia advisors will be available to support you after a diagnosis of dementia and will meet you again as your needs change.

What benefits might I see from seeing a dementia advisor for support and advice?

Dementia advisors offer information for free. Research into the benefits of having a single point of contact for information is ongoing. However, the expected benefit of seeing a dementia advisor is the opportunity for support in getting the information you need. You are likely to receive information that is what you need and is current and up to date. The benefits of receiving information on your condition include increased confidence, reduced stress, and reduced uncertainty about the future.

What are the possible limitations of seeing a dementia advisor?

You may not have a dementia advisor in your area. To access a dementia advisor you will need a referral from your GP or another professional, or from your memory service.

Who are dementia advisors?

Dementia advisors are staff or well trained volunteers from organisations such as the Alzheimer’s Society or AgeUK.

Where can I find support from a dementia advisor?

Dementia advisors are community-based and will visit you in your own home. Ask your local GP, memory assessment service, volunteer centre or a local dementia services provider such as Age UK for details on dementia advisors in your area.

Where can I find more information about dementia advisors for myself?

To access a dementia advisor you will need a referral from your GP or another professional, or from your memory service. You can read the Alzheimer's Society Factsheet about dementia advisors on the internet here:

http://alzheimers.org.uk/site/scripts/download_info.php?fileID=532

Who approves/recommends support from dementia advisors?

Support from a dementia advisor is recommended by the Royal College of Psychiatrists and the Department of Health.

Memory Service National Accreditation Programme (MSNAP).

4.2.11 Person is able to access a range of post-diagnostic supports and interventions –
Dementia advisor and support services for patients and carers.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Department of Health, National Dementia Strategy: Objective 4: People will have access to care support and advice after diagnosis – People with dementia will have access to a dementia advisor who will help them throughout their care to find the right information, care support and advice.

Department of Health (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health

Dementia/Memory Cafés

What is a dementia café or memory café?

Dementia cafés are informal meeting groups which are open for anyone affected by dementia to drop in when they like. They are places where people with dementia, families, volunteers and professionals can all meet together to share information and experiences and speak openly about dementia.

Who is a dementia café or memory café for?

Dementia cafés and memory cafés are groups for anyone who is interested in dementia or has been affected by dementia. They are also open to volunteers and professionals.

What goes on in a dementia café or memory café?

How does it work?

Dementia cafés are organised in the community so that you can meet other people affected by dementia and talk informally over a cup of tea or coffee. They are an opportunity to find more information about dementia and meet others who are in a similar situation. Dementia cafés will be organised in a community setting on a regular basis. Sometimes the group will organise a speaker to talk about a subject of interest at these meetings. For example, advance care planning may be discussed at dementia cafés (see page 6 for Advance Care Planning section).

How long do you go to a dementia café or memory café for?

These groups operate on an informal drop-in basis, and you do not need to 'join up' to have membership. You can find out the dates of when each dementia café meeting will take place and choose which ones you would like to attend. You may continue to attend these groups for as long as you want.

What benefits might I see from using a dementia café?

The benefits of attending a dementia café are increased opportunities to meet other people as well as opportunities to gain more information and support. A dementia café aims to prevent you from becoming isolated from other people.

What are the possible limitations to using a dementia café or memory café?

Dementia cafés may not have the expertise to provide information on specific questions you may have.

Who provides dementia cafés or memory cafés?

Groups are often organised by voluntary sector organisations such as Age UK and Alzheimer's Society, among others. They are run by a staff member from these organisations.

Where can I access a dementia café? (How do I join these groups?)

Groups meet in your local community. Your local group meeting may be held in a town/village hall, place of worship, or community centre. Details of meetings may be available in your local paper, GP surgery or the internet (websites below). You may also be able to find details through memory services and Alzheimer's Society.

Where can I find more information about dementia cafés for myself?

NHS Choices (In 'where can I find more information?')

<http://www.nhs.uk/conditions/dementia-guide/pages/dementia-activities.aspx>

You can find a local memory café using this online directory:

<http://www.memorycafes.org.uk/>

These organisations will have information at hand on local opportunities:

Telephone numbers:

Age UK Advice service: 0800 169 6565

Alzheimer's Society: (helpline) 0300 222 11 22

Websites:

Alzheimer's Society: www.alzheimers.org.uk

Age UK: www.ageuk.org.uk

Dementia Web: www.dementiaweb.org.uk

Alzheimer Café: www.alzheimercafe.co.uk

What is the evidence for dementia cafés?

A book has been published summarising how and why the dementia café (here called an Alzheimer café) works. It includes anecdotes, interviews and comments on themes that are discussed at meetings. Qualitative research suggests that dementia cafés are useful as on-going supportive groups.

Jones, G. (2010). *The Alzheimer Café: Why it works*. Berks, UK: The Wide Spectrum Publications.

Thompson, A. (2006). Qualitative evaluation of an Alzheimer Café as an ongoing supportive group intervention. In B.M.L. Miesen & G.M.M. Jones (Eds.), *Care-giving in Dementia Vol 4*. (pp.291–312). London: Routledge.

Who approves/recommends dementia cafés?

Dementia cafés are recommended by the Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

4.2.10 Person is able to access a range of post-diagnostic psychosocial interventions:

Peer support/self-help groups, for example, befriending schemes, dementia cafés.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Family/Systemic Therapy

What is family therapy?

Family therapy and Systemic therapy are forms of psychotherapy which involve helping people who are in a close relationship with each other to understand each other and communicate their feelings and emotions to each other.

Who is family therapy for?

Family therapy is for people with dementia and their families. It is also useful for people who are experiencing difficulties in their relationships with other family members. It is useful when you and people close to you are finding it hard to resolve current issues on your own, and need a safe space to talk openly.

What does family therapy involve? How does it work?

You would attend a family therapy session with your family or anyone who was in a close relationship with you. Family therapy aims to improve understanding between people in close relationships and to help people to communicate their feelings with each other. Family therapy sessions are designed to provide you with a safe place to express yourself with your family and for them to communicate their feelings to you. The therapy will involve you and the people close to you talking openly about the current issues and feelings and listening to each other. The therapist can help you and your family to learn better ways of relating to each other and how you may be able to help each other during times of difficulty.

How long does family therapy take?

Family therapy is conducted over several sessions, depending on your needs. Often you will attend therapy sessions on a regular basis, for example, one to four times per month. If difficulties are more complex, you may need to attend therapy for a longer period of time.

What benefits might I see from having family therapy?

Family therapy may improve your close relationships through helping you and those close to you understand and come to terms with issues affecting you all. It may help to reduce conflict arising from negative ways of relating by helping you and those close to you to learn new ways of dealing with difficult issues together. Family therapy aims to improve your well-being and the well-being of those close to you.

What are the possible limitations of family therapy?

It may be difficult for you and your loved ones to meet together regularly in a therapeutic setting. Although you may want to attend therapy, those close to you may not feel that they are ready to do this or that they need family therapy. In addition, family therapy may lead to you and those close to you having to make difficult choices, which may resolve conflict but may not ultimately lead to a positive outcome for everyone.

Who can provide me with family therapy?

A family therapist or mental health professional with training in family therapy or systemic therapy would be able to offer you family therapy.

Where can I ask for family therapy?

Family therapy is a specialist service which will need a referral from your memory service or your psychiatrist.

Where can I find more information on family therapy for myself?

Association for Family Therapy and Systemic Practice – this website can give you helpful information and advice on family therapy and systemic practice.

<http://www.aft.org.uk>

If you want to access Family Therapy privately, you can also find a list of accredited family therapists and systemic psychotherapists on the AFT website.

NHS Choices – Types of talking therapy – If you are needing more information to help you select the right talking therapy for you, this NHS website can help you:

<http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/types-of-therapy.aspx>

What is the evidence for family therapy?

Studies have found that family therapy and systemic approaches are effective in helping people and their families cope with chronic and life changing illnesses, including dementia.

Carr, A. (2009). The effectiveness of family therapy and systemic interventions for adult focused problems. *Journal of Family Therapy*, 31, 46–74.

Richardson, C. (2005). Family therapy outcomes in a specialist psychological therapy service. *Context, the magazine for family therapy and systemic practice, special edition, grey matters: Ageing in the family*, 77, 46–48.

Who approves/recommends family therapy?

Family interventions are recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.11.2.5 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at: www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.6.1 The service provides access to psychosocial interventions for carers of people with dementia.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Involvement Groups for people with dementia

What is an involvement group?

Involvement groups are an opportunity for people to help their local services and community. These groups meet regularly to discuss how improvements can be made in the community and in professional services in relation to dementia. People who use services are sometimes called service users, and the groups are sometimes therefore called service user involvement groups. Groups are run and organised in a variety of ways.

Who are involvement groups for?

Involvement groups are for people living with dementia who want to be involved in the development of better services and contribute to making their communities more dementia-friendly.

What does an involvement group do? How do involvement groups work?

People with a diagnosis of dementia meet on a regular basis. Some groups are self organised. Some involve family and some do not. Groups usually involve some social time as well as 'business' time.

How long do involvement groups take?

Service-user involvement groups are usually ongoing, and members can continue to attend meetings for as long as they wish.

What benefits might I see from joining an involvement group?

Involvement groups for people with dementia can provide many opportunities such as:

- meeting other people who have similar experiences to you
- involvement in work to improve professional services
- involvement in work to fight stigma and prejudice in local communities

Involvement groups can also improve your confidence and help you to develop new skills.

What are the possible limitations of involvement groups?

Depending on where your group likes to meet, you may need to arrange your own transport. Taking part in regular meetings and events as part of the group's work may mean committing considerable time and energy. There may not yet be a group set up in your area.

Involvement groups for people with dementia encourage people to get involved in improving service provision and community understanding. If you do not feel that this is something you would like to do, this type of group may not be for you.

Who provides involvement groups?

Involvement groups can be organised and led by a health care professional, but can also be run by group members themselves. Voluntary sector organisations, such as Dementia UK and Alzheimer's Society, also organise service user involvement groups.

Where can I join an involvement group?

Health care professionals, voluntary organisations and memory services can direct you towards any groups running in your area.

Where can I find more information about involvement groups for myself?

You can find out more about local involvement groups for people living with dementia by asking professionals in your memory service. The following websites may also have information on involvement groups.

Dementia Engagement and Empowerment Project (DEEP):

<http://dementiavoices.org.uk/>

Alzheimer's Society:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1040

Dementia Action Alliance (DAA):

<http://www.dementiaaction.org.uk/>

What is the evidence on involvement groups?

Current evidence suggests that 'focus groups' of people with dementia create a support network which enables people to voice opinions and discuss needs that they would otherwise be unable to. There is also some preliminary work surrounding involving people with dementia in research and in service provision in general.

Cheston, R., Bender, M. & Byatt, S. (2000). Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health*, 9(5), 471–479.

McKeown, J., Clarke, A., Ingleton, C. & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19, 1935–1943.

Who approves/recommends involvement groups?

There is growing evidence for involvement groups, however, as this is a newly emerging area of research, there is no formal recommendations for involvement groups at present.

Life Review Therapy

What is life review therapy?

Life review therapy is a type of talking therapy that is done one-to-one with a trained therapist, where you look back over your life. It aims to help you to understand your past from different perspectives. It is one of many types of talking therapy (see page 25 for counselling and psychotherapy, see page 15 for cognitive behaviour therapy).

Life review therapy is different from life story work (see page 40 for life Story work).

Who is life review therapy for?

This type of therapy can be useful to people finding it hard to come to terms with their situation in life, and those struggling with depression and feelings of anger or bitterness.

What does life review therapy involve? How does it work?

Sessions of life review therapy involve exploring your life with a trained therapist who assists in examining your own experiences and life events, and helps to find ways of feeling better about your own story. It can help to integrate your life, and bring a sense of continuity and connectedness.

How long does life review therapy take?

It usually takes between 16 and 20 sessions.

What benefits might I see from doing life review therapy?

Feeling better about yourself and your own life, and helping to come to terms with difficult times in life. It can help provide comfort and meaning to you and your family, and can decrease depression and anxiety. It can also allow you to focus on positive memories, and improve your overall emotional well-being, sense and purpose in life.

What are the possible limitations of life review therapy?

It can be emotional, and sometimes upsetting, to think about some past life events. You may want to consider creative arts therapies if you want an alternative to talking therapies (see page 28 for creative arts therapies, or page 43 for music therapy).

Who can provide me with life review therapy?

A trained specialised therapist, usually a clinical psychologist, can offer you life review therapy.

Where can I ask for life review therapy?

Life review therapy is usually provided by a specialist service, or a private therapy service (which you will need to pay for). You will usually talk to your GP about accessing life review therapy. Your GP can then refer you to a specialist mental health or memory service which can provide life review therapy to you.

Where can I find more information on life review therapy?

You can ask at your memory clinic about life review therapy. A referral for life review therapy will need to be made through your memory clinic to access a therapist. If you are looking for a therapist, and don't mind paying for this privately, see the British Psychological Society website for a list of accredited therapists: www.bps.org.uk

What is the evidence for life review therapy?

Life review therapy is currently in the theoretical stages of development, and there is insufficient evidence to draw conclusions at present, but there is some interest in researching this further.

Korte, J., Bohlmeijer, E.T., Cappeliez, P., Smit, F. & Westerhof, G.J. (2012). Life review therapy for older adults with moderate depressive symptomatology: A pragmatic randomised controlled trial. *Psychological Medicine*, 42(6), 1163–1173.

This study found that people having life review therapy reduced depression and anxiety symptoms.

Webster, J. & Haight, . (2002). *Critical advances in reminiscence work*. New York: Springer Publishing. This book looks at how life review therapy and other forms of reminiscence can improve the quality of life for people with dementia.

Who approves/recommends life review therapy?

Life review therapy is an alternative form of talking therapy. It is not currently recommended as a choice of therapy (see page 25 counselling and psychotherapy, page 15 for cognitive behaviour therapy, and page 34 for family/systemic therapy) over other forms based on the current evidence available.

Life Story Work

What is life story work?

Life story work is a continuous process as our stories do not end. Whilst it involves looking back on the past and recording important personal events, it also involves looking forward to future hopes. It is usually done on a one-to-one basis with your partner, a family member or someone who can guide you through the process.

Who is life story work for?

Life story work is for anyone with a diagnosis of dementia to do alone, with their families or with a professional.

What does life story work involve? How does it work?

Life story work is the process of remembering and recording past events and memories so that a biography is created. It is used to help you remember past events and also to communicate and share these memories and future hopes with other people.

A life story book often contains photographs or pictures which can help to illustrate your memories and important moments. If preferred, the end product of life story work can also be in the form of a website, DVD or PowerPoint presentation, a brief timeline, tapestry, soundtrack or scrapbook.

How long does life story work take?

The length of time that this intervention takes varies from person to person, and can continue for as long as you like.

What benefits might I see from doing life story work?

- Creating a life history record can be an enjoyable experience and may involve other members of the family.
- It can help you to maintain good mental health and well-being.
- A life story may be used to help people think about your care in the future when it may be more difficult for you to communicate.
- Your family will also benefit from having a record of your life history so these stories and facts are never lost or forgotten.

Who can support me with life story work?

A trained health care professional, or anyone working closely with a person with a diagnosis of dementia, can provide this. A close friend or family member can also work with a person, on a more informal basis, to produce a life story.

Where can I ask about support with life story work?

Life story work can be provided by health care professionals who work closely with a person with dementia, and who know them well, as well as close friends and family.

Where can I find more information about life story work for myself?

You can find information about starting life story work for yourself through the following websites.

www.lifestorynetwork.org.uk

Alzheimer's Society website: www.alzheimers.org.uk/lifehistorybook

Alzheimer's society have a Factsheet on life history making:

Alzheimer's Society (2011). *Remembering together: Making a life history book*.

http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=855

You can ask for advice on making a life history book from a professional at your memory clinic.

What is the evidence for life story work?

There is a body of evidence suggesting that life story work increases your understanding of your past and present, giving you greater awareness of your preferences for care and allowing care to be more person-centred. Life story work can help by reinforcing your sense of identity. It can also help you communicate and connect with your family and professionals involved in your care.

Life story work can help reduce anxiety and increases well-being through engagement in meaningful activity, maintains sense of self, reduces depression and improves sense of belonging, promotes participatory care and improves relationships between staff and family carers in inpatient settings.

There is evidence that individual reminiscence work, such as the production of a life story, results in benefits to mood, well-being and aspects of cognitive function.

Clarke, A., Hanson, E. & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12(5), 697–706.

Kellett, U., Moyle, W., McAllister, M. et al. (2010). Life stories and biography: A means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*, 19, 11–12, 1707–1715.

McKeown, J., Clarke, A., Ingleton, C. et al. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5(2), 148–158.

McKeown, J., Clarke, A. & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing*, 55(2), 237–247.

Moos, I. & Bjorn, A. (2006). Use of the life story in the institutional care of people with dementia: A review of intervention studies. *Ageing & Society*, 26(3), 431–454.

Sebern, M. & Whitlatch, C. (2007). Dyadic relationship scale: A measure of the impact of the provision and receipt of family care. *The Gerontologist*, 47(6), 741–751.

Thompson, R. (2011). Using life story work to enhance care. *Nursing Older People*, 23(8), 16–21.

Who approves/recommends life story work?

Life Story work is recommended by The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

6.1.1 The Service has access to a range of evidence-based psychosocial interventions.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Music Therapy

What is music therapy?

Music therapy describes interventions which aim to enhance your well-being and quality of life through the use of music and music-based therapeutic activity. This is a type of creative art therapy (see Creative Arts Therapies on page 28 for more information on these).

What does music therapy involve? How does it work?

A qualified music therapist will use a variety of specialist approaches to help you to explore your emotions. Music therapy can also be a part of reminiscence, helping to bring old memories to the surface. Sessions can be in groups or for individuals.

You can take part in music therapy groups which are fun, social activities that involve listening to and sharing music with others.

With your music therapist, you may use a variety of instruments, although one of the most common instruments used is your own voice.

Who is music therapy for?

Music therapy can be for anyone who feels that interaction with music can improve their well-being and quality of life. It is often used when someone finds it difficult to engage with a purely verbal therapy.

How long does music therapy take?

Sessions usually last for one or two hours and music therapy is often ongoing.

What benefits might I see from having music therapy?

By having music therapy, you may benefit from improved cognitive functioning, motor skills and quality of life, as well as an opportunity to express difficult emotions.

Music therapy can help people of all ages with a range of needs, often related to disability, illness or injury.

What are the limitations of music therapy?

Music therapy requires a specifically trained music therapist, and so may not be provided in your area.

Who can offer me music therapy?

Music therapy can be provided by trained music therapists and trained specialists.

Where can I ask for music therapy?

Music therapists can be found working within multi-disciplinary teams in hospitals, day centres, hospices, care homes, therapy centres and in private practice across the UK.

You usually need a referral to a specialist mental health or memory service from your GP to access music therapy.

Where can I find more information about music therapy for myself?

You can ask a professional at your memory service to provide more information on music therapy.

You can also find out more information from the following websites.

Alzheimer's Society website:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=134

Age UK website:

<http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia-and-music/>

British Association for Music Therapy:

<http://www.bamt.org>

AgeUK:

<http://www.ageuk.org.uk/health-well-being/conditions-illnesses/dementia-and-music/>

What is the evidence for music therapy?

There is some evidence that the use of music therapy in dementia care is beneficial, though most research has been done only in the context of Alzheimer's disease. Individual studies with people with Alzheimer's disease found that recall for new information was improved when the information was presented in the context of song as opposed to spoken information, and MMSE (Mini-Mental State Examination, a measure of cognitive functioning) scores seemed to improve immediately following a music therapy intervention. Another study found that music therapy seemed to improve face-name recognition in short term and in longer term memory.

A 2004 Cochrane review found 10 small studies of music therapy with positive outcomes, but the generally poor quality of the studies meant that no significant conclusions could be drawn. There is also an overview of the use of music therapy in the context of Alzheimer's disease, as well as a book examining the use of music therapy in dementia care.

Aldridge, D. (Ed.) (2000). *Music therapy in dementia care*. London: Jessica Kingsley Publishers.

Carruth, E.L. (1997). The effects of singing and the spaced retrieval technique on improving face-name recognition in nursing home residents with memory loss. *Journal of Music Therapy*, 34, 148–164.

Guetin, S., Charras, K. & Berard, A. (2013). An overview of the use of music therapy in the context of Alzheimer's disease: A report of a French Expert group. *Dementia*, 12(5), 619–634.

Prickett, C.A. & Moore, R.S. (1991). The use of music to aid memory of Alzheimer's patients. *Journal of Music Therapy*, 28(2), 101–110.

Smith, G., (1986). A comparison of the effects of three treatment interventions on cognitive functioning of Alzheimer patients. *Music Therapy*, 6A(1), 41–56.

Vink, A.C., Bruinsma, M.S. & Scholten, R.J.P.M. (2004). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews*, 2004, Issue 3. Art. No. CD003477.

Who approves/recommends music therapy?

Music therapy is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.7.1.2 Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.7.1 The service provides information and signposting on other non-pharmacological interventions that the person with dementia and their carer may wish to consider.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Peer Support Groups

What is a peer support group?

Peer support groups are organised so that small groups of people who have been similarly affected by dementia can meet and support each other through sharing their experiences and thoughts.

Who are peer support groups for?

Peer support groups can be for people who have recently been diagnosed with dementia or are in the early stages of dementia. There are also groups for family members and caregivers which offer peer support. Some groups are designed for you to attend with your family.

What do peer support groups do? How do they work?

Group members can share what they find difficult and challenging and how they have overcome these challenges. Often just sharing a problem, or knowing someone else has felt the same, may make the problem feel more manageable. Group members can share information they have received or talk about the support that they have had.

How long does peer support take?

Groups meet for a set period of time, for example, once a week for six weeks. Depending on your group, you may meet for one or two hours during each session.

What benefits might I see from joining a peer support group?

You may feel differently about your own situation if you share this with people in a similar situation to you. This may lead to you feeling:

- increased confidence
- reduced depression
- increased quality of life

What are the limitations of peer support groups?

It is hoped that by joining a group you will be able to share your experiences with people who understand and have similar experiences. However, you may not feel like sharing your experiences at the moment. You may not feel the people in the group you join are similar to you at all. For instance, individuals under 65 with young onset dementia may not share the same problems with the majority of people attending these groups.

Who can provide peer support groups?

Groups are often led by a professional group facilitator. Professionals from a memory service are often involved in these groups.

Where can I ask to join a peer support group?

Groups are often referral only, which means you will have to be referred through your memory service in order to attend one.

Where can I find more information on peer support groups for myself?

Ask a professional at your memory assessment service about peer support groups available in your area.

You can also find details about peer support groups from the following website.

UK Dementia: <http://www.dementiaweb.org.uk>

What is the evidence for peer support groups?

There is evidence that peer support groups can improve quality of life, reduce depression and improve communication between family members.

Logsdon et al. (2010). Early-Stage Memory Loss Support Groups: Outcomes from a randomised controlled clinical trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65B(6): 691–697.

Who approves/recommends peer support groups?

Peer support groups for people living with dementia are recommended by The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

3.8.6 People with dementia and their carers are able to access post-diagnostic support groups.

4.2.1 The service provides or signposts and refers on to peer support group/self-help groups, for example, befriending schemes, memory café's.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Occupational Therapy

What is occupational therapy?

Occupational therapy is an approach which aims to improve your quality of life and maintain your well-being through doing everyday activities. Part of occupational therapy is enabling you to keep doing the activities that you enjoy. All occupational therapy should be personally tailored to your needs and circumstances and should involve working towards goals you agree with your occupational therapist.

Who is occupational therapy for?

Occupational therapy is aimed at anyone with a diagnosis of dementia and their carers who want support in improving their quality of life and maintaining their well-being.

What does occupational therapy involve? How does it work?

Occupational therapists help people maximise their abilities and overcome their disability through the use of meaningful occupation. They seek to maintain or improve an independent lifestyle and your well-being. They will want to know what is important to you and will work with you to find out ways to achieve your goals, independently and together with your family.

Occupational therapists can help you with the following:

- learn to do things in a different way
- install and use adaptations to live independently in your home
- help you to think about using your strengths

An example of this type of therapy is community occupational therapy for persons with dementia and family carers (CoTID). This involves individualised goal setting with the person with dementia and their carer.

How long does occupational therapy take?

Occupational therapy can take as long as you need to achieve your goals. You may wish to change your goals as your circumstances change, or modify them to overcome new challenges over the course of your treatment. You will plan how long you need with your occupational therapist during the course of your assessment.

What benefits might I see from occupational therapy?

- Increased independence at home.
- Increased engagement in activities that are purposeful and meaningful to you.
- Helping your family or carers to manage better with supporting you.
- Helping you maintain a healthy and meaningful lifestyle.

What are the possible limitations of occupational therapy?

It involves some level of commitment to a programme of intervention in order for it to be effective.

Who can provide me with occupational therapy?

A trained occupational therapist.

Where can I ask for occupational therapy?

You can ask for a referral for occupational therapy through your memory service.

You can also access an occupational therapist privately.

Where can I find more information about occupational therapy for myself?

You can find out more information about occupational therapy from the College of Occupational Therapists (COT): www.cot.co.uk

A COT Occupational Therapy booklet is available to download from the COT website: http://www.cot.co.uk/sites/default/files/marketing_materials/public/Dementia-leaflet.pdf

What is the evidence for occupational therapy?

There is some evidence to suggest that occupational therapy can be beneficial for people with dementia.

Fratiglioni, L., Winblad, B. & Struass, E. (2007). Prevention of Alzheimer's disease and dementia: Major findings from the Kungsholmen project. *Physiology and Behaviour*, 92(1–2), 98–104.

Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A. & Hauck, W.W. (2001). A randomised, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41(1), 4–14.

Graff, M.J., Vernooij-Dassen, M.J.M., Thijssen, M., Dekker, J., Hoefnagels, W.H.L. & Olde Rikkert, M.G. (2006). Community-based occupational therapy for patients with dementia and their caregivers: A randomised controlled trial. *British Medical Journal*, 333(7580), 1196–1201.

Who approves/recommends occupational therapy?

Occupational therapy for dementia is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.5.1.1 Promoting and maintaining independence of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.4.1 People have access to personally tailored occupational therapy to assist them with their occupational and functional needs and to help maintain their health and well-being, independence and community living.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Post-Diagnostic Counselling

What is post-diagnostic counselling?

Post-diagnostic counselling is a process of providing support with coming to terms with your diagnosis of dementia. It also involves thinking about your needs and working out the next steps in your treatment. It can involve individual sessions at your memory service, usually offered after a diagnosis to help discuss the diagnosis, answer questions and give information about further advice and support.

Who is post-diagnostic counselling for?

All people who have received a recent diagnosis of dementia should receive some form of post-diagnostic counselling if they want this, and when they are ready to talk.

What does post-diagnostic counselling involve? How does it work?

When you receive a diagnosis of dementia, health professionals will give you information, advice and support relevant to you. They can also give information, advice and support to your family during this time.

This type of support can include:

- information about your diagnosis of dementia
- time to talk about your diagnosis
- time to discuss further support and planning for the future
- counselling to help with the emotional side of receiving a diagnosis

How long does post-diagnostic counselling take?

Post-diagnostic counselling often involves one to three sessions, but the number of sessions can vary dependent on your need. You will then be told about further options.

What benefits might I see from having post-diagnostic counselling?

- A greater understanding of how your diagnosis may affect you and your family.
- The opportunity to obtain the information you need to know at that time.
- An opportunity to discuss any worries or fears, and to discuss plans for coping and support in future.

What are the possible limitations of post-diagnostic counselling?

The amount of support available for post-diagnostic counselling sessions may vary depending on your local area. When further post-diagnostic support is suggested, you may have to wait until the next group, or until therapy is being run.

Who can provide me with post-diagnostic counselling?

Often this is available from your psychiatrist and sometimes from a clinical psychologist, occupational therapist, mental health nurse or GP.

Where can I ask for post-diagnostic counselling?

Post-diagnostic counselling is an important part of the diagnostic process and should be offered at the time when you are given a diagnosis of dementia.

Where can I find more information on post-diagnostic counselling for myself?

Your GP or memory service staff can give you more information on available support.

What is the evidence for post-diagnostic counselling?

This book gives an overview of the factors that should be offered in post-diagnostic counselling, and explains how individual needs can still be met with limited resources.

Moniz-Cook, E. & Manthorpe, J. (Eds.) (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.

Who approves/recommends post-diagnostic counselling?

Post-diagnostic counselling for dementia is recommended by the British Psychological Society and The Royal College of Psychiatrists
National Institute of Health and Care Excellence (NICE).

1.4.6.1 Addressing needs that arise from the diagnosis of dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

3.8.5 People are given adequate opportunities to talk through the implications of their diagnosis with members of the team, immediately after and/or during the days after they receive a diagnosis.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Post-Diagnostic Groups/Courses

What is a post-diagnostic group or course?

Post-diagnostic groups are for people who have recently been given a diagnosis of dementia, and sometimes their families. The group will run for a set number of sessions with different speakers, or themes to discuss each week. They are sometimes called post-diagnostic support groups, memory groups or memory courses.

Who are post-diagnostic groups for?

Post-diagnostic groups are for anyone who has been diagnosed with dementia recently (and their families). If you have just found out that you have been diagnosed with dementia, you and your family may want to find out more information, and find out what you can do next. You may want to meet other people who are in a similar position.

What does a post-diagnostic group do? How do they work?

During a group or course, you will have the opportunity to learn and talk about many subjects to do with memory, including:

- understanding memory problems and dementia
- learning memory techniques and strategies
- coping with real-life situations
- talking to family, friends and others about memory problems and dementia
- adjusting to a diagnosis
- living well with dementia

Some groups also cover practical issues, providing information on other services available as well as legal issues and any benefits you might be entitled to.

How long do post-diagnostic groups take?

The length of a course or group will vary depending on what is provided in your area. A typical course will be four to twelve sessions, with one session per week for two hours.

What benefits might I see from joining a post-diagnostic group?

Post diagnostic groups can help you to:

- learn about your memory
- think about ways to manage your symptoms of dementia
- increase your confidence and well-being
- give you a sense of belonging and purpose
- feel more able to cope with a diagnosis
- meet other people in similar situations

What are the possible limitations of post-diagnostic groups?

Post-diagnostic groups and courses may not meet your specific needs and information may be of a more general nature. If you have a rarer type of dementia, or have been diagnosed with dementia in the early stages, some of your needs may be met through having specific specialist information (see page 60) or having post-diagnostic counselling (see page 50).

Who provides post-diagnostic groups?

Post-diagnostic groups/courses are usually run by professionals who have an interest and experience in working with people living with dementia. They can be run by dementia advisors, occupational therapists, nurses, psychologists and support workers. They are often run by professionals from your memory service.

Where do I go to join a post-diagnostic group?

Groups/courses are conducted in hospitals, your local memory service, or public venues such as community centres. After you have been given a diagnosis, you may be offered the opportunity to attend a group if a professional feels it may benefit you and your family. Groups provided by the NHS are generally specialist-run, time-limited and focused.

Where can I find more information on post-diagnostic groups?

You can find more information about post-diagnostic groups at your local memory service.

If you are a carer of someone living with dementia, see Alzheimer's Society – Carer Information and Support Programme: www.alzheimers.org.uk/crisp

What is the evidence for post-diagnostic groups?

There are several studies indicating that post-diagnostic groups can provide social, emotional and educational support, a sense of purpose, increased self-esteem and well-being, and a sense of belonging that comes from being part of a group of people in similar situations. One study focussed on the possible benefits that post-diagnostic courses have for carers. It found that people who are part of a group specifically aimed at the problems arising for carers of people with dementia had greater confidence, increased knowledge, and enhanced coping skills, and that they felt better prepared for the future.

Brooker, D. & Duce, L. (2000). Well-being and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Ageing and Mental Health*, 4, 354–358.

Milne, A., Guss, R. & Russ, A. (2013). Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a 'Course for Carers'. *Dementia*.

Moniz-Cook, E. & Manthorpe, J. (Eds.) (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.

Snow, K. (2010). Moving forward: Post-diagnostic groups for people with a mild dementia. *Faculty of the Psychology of Older People Newsletter*, 111, 59–63.

Snyder, L., Quayhagen, M.P., Shephard, S. & Bower, D. (1995). Supportive Seminar Groups: An intervention for early stage dementia patients. *The Gerontologist*, 35, 691–695.

Yale, R. (1995). *Developing support groups for individuals with early stage Alzheimer's disease*. York: The Maple Press Company.

Who approves/recommends post-diagnostic groups?

Post-diagnostic support groups are recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.4.6.2 Addressing needs that arise from the diagnosis of dementia.

1.11.2.2 Support and interventions for the carers of people with dementia.

1.11.2.3 Support and interventions for the carers of people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

3.8.6 People and their carers are able to access post-diagnostic support groups.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Reminiscence

What is reminiscence?

Reminiscence is an activity which involves remembering and retelling past memories and events from your life, often aided by looking at materials from a particular time. It is more general than, and different from, life story work (page 40) and life review therapy (page 38).

Who is reminiscence for?

Reminiscence is for anyone with a diagnosis of dementia.

What does reminiscence do? How does reminiscence work?

Reminiscence is usually done in a group setting with people talking about their memories and listening to each other.

It gives people the chance to revisit familiar times and share common experiences with other people. Reminiscence often includes the use of general prompts such as photos, objects or music from those times.

Reminiscence focuses on using a person's preserved memories, rather than focusing on disability.

You may talk about the following themes during reminiscence sessions:

- childhood, school days, work life
- family and relationships, holidays and journeys
- historic events

Reminiscence aims to maintain good mental health and provide an enjoyable, social activity.

How long does reminiscence take?

Reminiscence can vary in the number of sessions, ranging from one or two to ongoing groups.

What benefits might I see from doing reminiscence?

Attending regular reminiscence sessions may give you the following benefits:

- improved cognitive function
- improved quality of life
- a better understanding of your identity

What are the possible limitations to reminiscence?

Unpleasant memories may be brought up, causing discomfort. A skilled facilitator would be able to work through this with you sensitively.

Who can support me with reminiscence?

Reminiscence can be carried out by a trained professional, usually in a group setting.

Where can I ask for reminiscence?

You may be referred for reminiscence by your memory service.

Where can I find more information about reminiscence for myself?

Information can be provided by health care professionals.

What is the evidence for reminiscence?

A Cochrane review (Woods et al., 2009) found that evidence in support of reminiscence for people with dementia was inconclusive. However, at a meta-analytical level, it was found that improvements were seen in cognition, mood and functional ability, as well as reductions in depressive symptoms in the person with dementia and stress in the carer.

Baines, Saxby and Elhert (1987) found improvement in cognitive and behavioural measures in people with moderate to severe dementia when group reminiscence activity followed reality orientating, compared to a control group which participated in reality orientation only.

Baines, S., Saxby, P., & Ehlert, K. (1987). Reality orientation and reminiscence therapy: A controlled cross-over study of elderly confused people. *The British Journal of Psychiatry*, 151, 222-231.

Goldwasser, Auerbach and Harkins (1987) found improvement in self-reported depression for subjects in a reminiscence group compared to a supportive therapy group, and a third 'control' group which received no treatment. The study found no significant differences in cognitive or behavioural measures.

Goldwasser, A., Auerbach, S.M. & Harkins, S.W. (1987). Cognitive, affective, and behavioural effects of reminiscence group therapy on demented elderly. *The International Journal of Aging & Human Development*, 25(3), 209-222.

Woods, B., Spector, A.E., Jones, C.A., Orrell, M. & Davies, S.P. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 2005, Issue 2. Art. No. CD001120.

Who approves/recommends reminiscence?

Reminiscence is recommended by the British Psychological Society and The Royal College of Psychiatrists.

National Institute of Health and Care Excellence (NICE).

1.8.1.3 Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia.

NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42.

Available at www.nice.org.uk/CG42 [NICE guideline]

Memory Service National Accreditation Programme (MSNAP).

6.2.4 People with dementia and their carers have access to a group reminiscence programme.

6.3.1 People with dementia have access to interventions that address their emotional needs.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Signposting

What is signposting?

‘Signposting’ is when a health professional makes you aware of other services, provides you with information in the form of a leaflet or booklet, or tells you where you can obtain further information or support.

For example, you may wish to know about a specific psychosocial intervention, a professional can signpost the appropriate support and information for you – this means that they will provide you with the relevant information, how to access that treatment and may even refer you to another service or professional offering that treatment.

Who is signposting for?

Signposting, or being given helpful information, is for people who have just received a diagnosis of dementia and want more information on their condition, or information about available support, treatment or networks. Information is also available for families and caregivers.

What does signposting involve? How does signposting work?

Signposting can include information about useful websites, local groups and courses, and other support and services available to you in your area.

Professionals will try to give you the information you want for the questions you have at the time. Information should be available to you throughout your contact with professionals, and therefore signposting is an ongoing process.

Professionals will have information on how you can access other services, and often they can refer you to other services which will be able to provide you with the treatment or support you need.

How long does signposting take?

Most information can be given to you by the professional directly. You may be shown where you can get further information on specific topics. This is an ongoing process and you may find you want different kinds of information at different times.

What benefits might I see from having information signposted to me?

- The information sent to you can answer some of the many questions that you and your family about your condition and the support available to you.
- You and your family can read through leaflets, booklets and internet resources at your own pace. This may mean you can make better-informed decisions.
- Having more information may increase your confidence and decrease your stress, by reducing uncertainty and giving you answers to some of your questions. It may also prepare you to make the most of limited time in appointments with professionals.

What are the possible limitations of signposting?

There may not be any or enough information available in written form relating to your specific questions. Moreover, If you do not use a computer, some online information may be inaccessible to you. It is also crucial that a health professional directs you to the right information at the times that you need this. Being given too much information all at once may feel overwhelming. You may find more specific information as well as signposting through specialist information (see page 60) or post-diagnostic counselling (see page 50).

Who can signpost information to me?

A professional such as your care co-ordinator, dementia advisor, mental health nurse, occupational therapist or psychologist at the memory service can direct you towards useful information. Specialist help-lines, nationally and locally, also offer signposting.

Where can I ask for information to be signposted to me?

At your memory service there will be a range of written information available. Staff at your memory service will be able to direct you to information available on the internet.

Useful information can also be gained from your local dementia café.

An outreach worker from the Alzheimer's Society or from AgeUK, or a dementia advisor, will be able to give or direct you towards the information that you need.

Where can I find more information for myself?

You can get information for this through by talking to a professional at the memory service, or through a dementia advisor. You can also receive information through the voluntary sector, and organisations such as the Alzheimer's Society.

Telephone Numbers:

Alzheimer's Society National Dementia Helpline: 0300 222 1122

Age UK: 0800 169 6565

Internet/Websites:

Alzheimer's Society: <http://www.alzheimers.org.uk>

DementiaUK: <http://www.dementiauk.org/>

NHS Choices: <http://www.nhs.uk/Pages/HomePage.aspx>

What is the evidence for signposting?

There is some research evidence to suggest that services which provide information to people with dementia and or their caregivers in combination with other forms of support such as training or direct help to navigate the health system are helpful in maintaining quality of life and helping to reduce signs of poor mental health. An example of this type of service is the Age UK dementia advisor service.

Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., Brooker, D. & Ballard, C. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *Int J of Geriatric Psychiatry*, 27(6), 628–635.

Who approves/recommends signposting?

Signposting by services is recommended by the Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

6.7.1 The service provides information and signposting to other possible non-pharmacological interventions that the person with dementia and their carer may wish to consider.

3.8 The memory service is able to offer appropriate support, advice and information to people with memory problems/dementia and their carers at the time of assessment and diagnosis, as needed.

6.5 The service provides or can signpost/refer people and their carers on to interventions for more complex needs, if required.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Specialist Information

(rare and unusual dementia, non-typical problems)

What is meant by specialist information?

This is information given to you by a trained specialist such as a clinical psychologist, neurologist, occupational therapist or psychiatrist for older people which is tailored to your specific condition or symptoms. It is for people with less common forms of dementia.

Who is specialist information for?

People diagnosed with young-onset dementia, fronto-temporal dementia (FTD), posterior cortical atrophy (PCA), Lewy body dementia, Parkinson's disease dementia or any of the many rarer forms of dementia (i.e. other than Alzheimer's disease, vascular dementia or mixed dementia).

What does specialist information involve? How does it work?

This intervention involves an assessment period with a professional as well as discussing your experiences with you and your family. The professional will work with you to discuss ways to overcome specific problems, as well as finding ways to build on your strengths. You may be given information to better understand your specific condition and you may talk about practical ways to manage your symptoms. As well as answering specific questions about your condition, further advice on other services available can be discussed.

How long does specialist information take?

You will agree on how often you meet with a professional. The professional may meet you as and when you need specialist input.

What benefits might I see from having specialist information?

- Receiving specialist information which is tailored to your needs may be more useful than the generic information which has already been given to you.
- You will have the opportunity to talk about your specific experiences and discuss ways of overcoming these issues with the professional.
- Having this information may help you and your family to plan for the future.

What are the possible limitations of specialist information?

Talking about your condition and planning for the future with your family may be a difficult subject to face. This may be an emotionally difficult experience for you and you may wish to seek post-diagnostic counselling before or during this process.

Who can provide me with specialist information?

A professional at your memory service: a clinical psychologist, psychiatrist, neurologist, occupational therapist or mental health nurse. If you have a less common form of dementia, you may also benefit from joining a support group for people with that condition – see, for example, www.ucl.ac.uk/drc/support-groups

Where can I ask for specialist information?

This intervention should be available to you from your memory service following your diagnosis of an unusual type of dementia or specific non-typical problems.

Can I find specialist information for myself?

If you need more specific specialist information, when you have been given a diagnosis of dementia, you can talk to a member of your memory service about this.

Who approves/recommends specialist information?

Specific specialist information for rarer types of dementia is recommended by

The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

3.8.9 The service has access to specialist post-diagnostic counselling provided by an appropriately qualified professional for people with specific needs.

4.2. Professionals working within the memory service ensure that the person (and their carer, where appropriate) is able to access a range of post-diagnostic supports and interventions.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

Stress/Anxiety Management

What is anxiety or stress management?

Anxiety management, sometimes called stress management, is an intervention which aims to help you with worry, stress and anxiety. One type of technique used in anxiety management is relaxation. Relaxation refers to techniques which you can learn to help you with stress, worry and anxiety. Cognitive behaviour therapy (CBT) is also often used to help people to manage overwhelming feelings of stress and anxiety (see page 15 for cognitive behaviour therapy).

Who is stress/anxiety management for?

For people with dementia who are also experiencing anxiety problems or panic, or who want to reduce stress which can cause anxiety.

What does stress/anxiety management involve? How does it work?

Anxiety or stress management includes:

- identifying factors in your life which contribute to stress and anxiety
- learning about lifestyle changes which can reduce stress and anxiety (such as cutting down on caffeine or increasing exercise)
- learning techniques which can help to prevent stress and anxiety (such as relaxation)
- learning techniques which can help you to better cope with stress and anxiety (such as breathing exercises)

Relaxation techniques are often used in anxiety management. These techniques involve doing something which promotes calmness and well-being.

Techniques for relaxation include:

- guided meditation
- yoga
- Tai-Chi
- applied relaxation
- breathing exercises
- exercise
- activities, for example, walking, gardening, music

You can join a relaxation group and learn helpful techniques along with other people.

One type of relaxation programme is called 'Applied Relaxation'. The focus of these techniques is to learn to relax your muscles in situations which you find stressful so that you feel less anxious.

How long does stress/anxiety management take?

Anxiety management groups or individual treatments run for a set number of sessions, usually on a weekly basis. You will need to attend all the sessions in order to have the benefits.

What benefits might I see from having stress/anxiety management?

- Anxiety management should help you to understand the causes of anxiety, and recognise the nature of your anxiety.
- Reduce stress in your life and reduce anxiety in everyday situations.
- By learning relaxation techniques you can reduce your levels of tension.

What are the possible limitations of stress/anxiety management?

Anxiety management is usually a group approach. Whilst you may learn how to cope with anxiety in everyday situations, you may not learn how to apply this to specific situations in which you find it difficult to cope with anxiety. If this is the case individual cognitive behaviour therapy (see page 15) may be more useful to you.

Who can provide me with stress/anxiety management?

Anxiety management groups may be run through your local memory service, primary care counselling service, or through your local Improving Access to Psychological Therapies (IAPT) service. You can also learn about anxiety management through self-help guides.

A psychologist, occupational therapist or mental health nurse can teach you relaxation techniques, and some can be learned through reading books or listening to a CD that guides you through the steps.

Where can I ask for stress/anxiety management?

By speaking to your GP or a professional at the memory service. You will need a referral from a health professional to join these groups.

Where can I find more information on stress/anxiety management for myself?

Any health care professional, including your GP, can point you in the direction of a stress and anxiety management group/course. Books or CDs for self-learning techniques are often available in bookshops or libraries. The Reading Agency 'Reading Well – Books on Prescription' scheme recommends such self-help books, which should be available in your public library – see <http://readingagency.org.uk/adults/quick-guides/reading-well>

What is the evidence for stress/anxiety management?

There is a wide range of different stress management techniques. The evidence varies, and more high quality studies are needed particularly involving people with dementia.

Who approves/recommends stress/anxiety management?

Anxiety management and stress management are recommended by The Royal College of Psychiatrists.

Memory Service National Accreditation Programme (MSNAP).

6.1.1 Support for people and carers.

Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

References

- Aldridge, D. (Ed.) (2000). *Music therapy in dementia care*. London: Jessica Kingsley Publishers.
- Alzheimer's Society (2011). *Remembering together: Making a life history book*. Retrieved 23 September 2014 from: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1434
- Bahar-Fuchs, A., Clare, L. & Woods, B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews* 2013, Issue 6. Art. No. CD003260. doi: 10.1002/14651858.CD003260.pub2.
- Baines, S., Saxby, P. & Ehler, K. (1987). Reality orientation and reminiscence therapy. A controlled cross-over study of elderly confused people. *The British Journal of Psychiatry*, 151, 222–2231. doi: 10.1192/bjp.151.2.222
- Beard, R.L. (2012). Art therapies and dementia care: A systematic review. *Dementia*, 11, 633–656.
- Brodsky, H., Green, A. & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51(5), 657–664.
- Brooker, D. & Duce, L. (2000). Well-being and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Ageing and Mental Health*, 4, 354–358.
- Bruce, E., Hodgson, S. & Schweitzer, P. (1999). *Reminiscing with people with dementia: A handbook for carers*. London: Age Exchange.
- Bruce, E. & Schweitzer, P. (2008). Working with life history. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp.168–186). Maidenhead: Open University Press.
- Carruth, E.L. (1997). The effects of singing and the spaced retrieval technique on improving face-name recognition in nursing home residents with memory loss. *Journal of Music Therapy*, 34, 148–164.
- Cheston, R., Bender, M. & Byatt, S. (2000). Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health*, 9(5), 471–479.
- Clare, L. (2010). Goal-oriented cognitive rehabilitation for people with early stage Alzheimer disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry*, 18, 928–939.
- Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M. et al. (2013). Goal-oriented cognitive rehabilitation in early-stage dementia: Study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials*, 14, 152.
- Clare, L., Evans, S., Parkinson, C., Woods, R.T. & Linden, D. (2011). Goal-setting in cognitive rehabilitation for people with early-stage Alzheimer's disease. *Clinical Gerontologist*, 34, 220–236.
- Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H. et al. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: A single-blind randomised controlled trial of clinical efficacy. *American Journal of Geriatric Psychiatry*, 18, 928–939.

- Clarke, A., Hanson, E. & Ross, H. (2003). Seeing the person behind the patient: Enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12(5), 697–706.
- Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R. et al. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*, 27(6), 628–635.
- EAPC (2013). Recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias. *Palliative Medicine*, published online 4 July 2013, retrieved 10 June 2014 from <http://www.eapcnet.eu/Corporate/AbouttheEAPC/EAPCpublications/EAPCrecommendations/tabid/1616/ctl/Details/ArticleID/612/mid/3090/Default.aspx>
- Filan S.L. & Llewellyn-Jones R.H. (2006). Animal-assisted therapy for dementia: A review of the literature. *International Psychogeriatrics*, 18(4), 597–611.
- Fogle, B. (Ed.) (1981). *Interrelations between people and pets*. Springfield, IL: Charles C. Thomas.
- Fratiglioni, L., Winblad, B. & Struass, E. (2007). Prevention of Alzheimer's disease and dementia: Major findings from the Kungsholmen project. *Physiology and Behaviour*, 92(1–2), 98–104
- Godwin, K.M., Mills, W.L., Anderson, J.A. & Kunik, M.E. (2013). Technology-driven interventions for caregivers of persons with dementia: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias*, 28(3), 216–222.
- Goldwasser, A., Auerbach, S.M. & Harkins, S.W. (1987). Cognitive, affective, and behavioral effects of reminiscence group therapy on demented elderly. *The International Journal of Aging and Human Development*, 25(3), 209–222.
- Graff, M.J.L., Vernooij-Dassen, M.J.M., Thijssen, M., Dekker, J., Hoefnagels, W.H.L. & Olde Rikkert, M.G.M. (2006). Community-based occupational therapy for patients with dementia and their caregivers: A randomised controlled trial. *British Medical Journal*, 333(7580), 1196–1201.
- Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A. & Hauck, W.W. (2001). A randomised, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41(1), 4–14.
- Guetin, S., Charras, K. & Berard, A. (2013). An overview of the use of music therapy in the context of Alzheimer's disease: A report of a French expert group. *Dementia*, 12(5), 619–634.
- Hansebo, G. & Kihlgren, M. (2000). Patient life stories and current situation as told by carers in nursing home wards. *Clinical Nursing Research*, 9(3), 260–279.
- Jones, G.M.M. (2010). *The Alzheimer Café: Why it works*. Berks, UK: The Wide Spectrum Publications.
- Junaid, O. & Hegde, S. (2007). Supportive psychotherapy in dementia. *Advances in Psychiatric Treatment*, 13, 17–23.
- Kellett, U., Moyle, W., McAllister, M., King, C. & Gallagher, F. (2010). Life stories and biography: A means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*, 19(11–12), 1707–1715.

- Korte, J., Bohlmeijer, E.T., Cappeliez, P., Smit, F. & Westerhof, G.J. (2012). Life review therapy for older adults with moderate depressive symptomatology: A pragmatic randomised controlled trial. *Psychological Medicine*, 42(6), 1163–1173.
- Kurz, A.F., Leucht, S. & Lautenschlager, N.T. (2011). The clinical significance of cognition-focused interventions for cognitively impaired older adults: A systematic review of randomised controlled trials. *International Psychogeriatrics*, 23(9), 1364–1375.
- Lipinska, D. (2009). *Person-centred counselling for people with dementia: Making sense of self*. London: Jessica Kingsley Publishers.
- Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L. et al. (2010). Early-stage memory loss support groups: Outcomes from a randomised controlled clinical trial. *Journal of Gerontology: Psychological Sciences*, 65B(6), 691–697.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T. & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5(2), 148–158.
- McKeown, J., Clarke, A., Ingleton, C. & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13–14), 1935–1943.
- McKeown, J., Clarke, A. & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing*, 55(2), 237–247.
- Milne, A., Guss, R. & Russ, A. (2013). Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a ‘Course for Carers’. *Dementia*.
- Moniz-Cook, E. & Manthorpe, J. (2009). *Early psychosocial interventions in dementia: Evidence-based practice*. London: Jessica Kingsley Publishers.
- Moos, I. & Bjorn, A. (2006). Use of the life story in the institutional care of people with dementia: A review of intervention studies. *Ageing and Society*, 26(3), 431–454.
- Murphy, C. (2000). *Crackin’ lives: An evaluation of a life story book project to assist patients from a long-stay psychiatric hospital in their move to community care situations*. Stirling: Dementia Services Development Centre.
- NICE and SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. NICE Clinical Guideline 42. Available at: www.nice.org.uk/CG42 [NICE guideline]
- Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Streater, A., Woods, B., et al. (2014). Maintenance Cognitive Stimulation Therapy for dementia: A single-blind, multi-centre, randomised controlled trial of Maintenance CST vs. CST for dementia. *British Journal of Psychiatry*, 204, 454–461.
- Orgeta, V., Qazi, A., Spector, A.E. & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *Cochrane Database of Systematic Reviews* 2014, Issue 22. Art. No. CD009125
- Prickett, C.A. & Moore, R.S. (1991). The use of music to aid memory of Alzheimer's patients. *Journal of Music Therapy*, 28(2), 101–110.
- Richardson, C. (2005). Family therapy outcomes in a specialist psychological therapy service. *Context: the magazine for family therapy and systemic practice in the UK*, 77, 46–48.
- Royal College of Psychiatrists (2014). *Memory Services National Accreditation Programme* (4th ed.). London: Royal College of Psychiatrists.

- Sadek, S., Charlesworth, G., Orrell, M. & Spector, A. (2011). The development of a Cognitive Behavioural Therapy (CBT) manual: A pilot randomised control trial of CBT for anxiety in people with dementia anxiety. *International Psychogeriatrics*, 23(S1), S383–S384.
- Sebern, M.D. & Whitlatch, C.J. (2007). Dyadic relationship scale: A measure of the impact of the provision and receipt of family care. *The Gerontologist*, 47(6), 741–751.
- Selwood, A., Johnston, K., Katona, C., Lyketsos, C. & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101, 75–89.
- Smith, G. (1986). A comparison of the effects of three treatment interventions on cognitive functioning of Alzheimer patients. *Music Therapy*, 6(1), 41–56.
- Snow, K. (2010). Moving forward: Post-diagnostic groups for people with a mild dementia. *Faculty of the Psychology of Older People Newsletter*, 111, 59–63.
- Snyder, L., Quayhagen, M.P., Shephard, S. & Bower, D. (1995). Supportive seminar groups: An intervention for early stage dementia patients. *The Gerontologist*, 35(5), 691–695.
- Spector, A., Gardner, C. & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Ageing and Mental Health*, 15(8), 945–949.
- Spector, A., Orrell, M. & Woods, B. (2010). Cognitive Stimulation Therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry*, 25(12), 1253–1258.
- Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M. et al. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: A randomised controlled trial. *British Journal of Psychiatry*, 183, 248–254.
- Subramaniam, P. & Woods, B. (2012). The impact of individual reminiscence therapy for people with dementia: Systematic review. *Expert Review of Neurotherapeutics*, 12(5), 545–555.
- Surr, C. (2006). Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science and Medicine*, 62(7), 1720–1730.
- Thompson, A. (2006). Qualitative evaluation of an Alzheimer Café as an ongoing supportive group intervention. In B.M.L. Miesen & G.M.M. Jones (Eds.), *Care-giving in dementia: Research and applications: Volume 4* (pp.291–312). London: Routledge.
- Thompson, R. (2011). Using life story work to enhance care. *Nursing Older People*, 23(8), 16–21.
- Urbas, S. (2009). Art therapy: Getting in touch with inner self and outside world. In E. Moniz-Cook & J. Manthorpe (Eds.), *Early psychosocial interventions in dementia: Evidence-based practice* (pp.146–155). London: Jessica Kingsley Publishers.
- van Paasschen, J., Clare, L., Yuen, K., Woods, R.T, Evans, S., Parkinson, C. et al. (2013). Cognitive rehabilitation changes memory-related brain activity in people with Alzheimer's disease. *Neurorehabilitation and Neural Repair*, 27, 448–459.
- Vernooij-Dassen, M., Draskovi, C.I., McCleery, J. & Downs, M. (2011). Cognitive reframing for carers of people with dementia. *Cochrane Database of Systematic Reviews* 2011, Issue 11. Art. No. CD005318.
- Vink, A.C., Bruinsma, M.S. & Scholten, R.J.P.M. (2004). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews* 2004, Issue 3. Art. No. CD003477.

- Watts, S., Cheston, R. & Moniz-Cook, E. (2013). *Post-diagnostic support for people living with dementia: An interim report prepared for the Faculty of Psychologists working with Older People and the Dementia Action Alliance*. Retrieved 23 September 2014 from: www.dementiaaction.org.uk/assets/0000/3825/Faculty_of_Psychologists.pdf
- Webster, J. & Haight, B. (Eds.). (2002). *Critical advances in reminiscence work: From theory to application*. New York: Springer.
- Williamson, T. (2012). *A stronger collective voice for people with dementia*. York: Joseph Rowntree Foundation.
- Woods, R.T. (2003). Evidence-based practice in psychosocial intervention in early dementia: How can it be achieved? *Aging and Mental Health*, 7(1), 5–6.
- Woods, B., Spector, A.E., Jones, C.A., Orrell, M. & Davies, S.P. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 2005, Issue 2. Art. No. CD001120.
- Yale, R. (1995). *Developing support groups for individuals with early stage Alzheimer's disease*. York: The Maple Press Company.
- Young, L., Howard, J. & Keetch, K. (2013). Once you start writing you remember more. *Journal of Dementia Care*, 21(2), 20–23.
- Yu, F., Rose, K., Burgener, S., Cunningham, C., Buettner, L., Beattie, E. et al. (2009). Cognitive training for early-stage Alzheimer's disease and dementia. *Journal of Gerontological Nursing*, 35(3), 23–29.

Appendix 1: Some terminology used in this guide

Cognitive

Cognitive can mean any of a number of mental processes. Cognitive includes: knowing; thinking; learning; memory.

Carer/Caregiver

Name which is sometimes given to anyone who is involved in giving care or support to someone else. Carers or caregivers can be paid or unpaid. They can be a member of your family or a friend.

Dementia

A set of symptoms associated with an ongoing decline in the brain. Symptoms include memory loss, mental confusion and loss of emotional control. It is progressive, meaning symptoms worsen over time.

Intervention

Any action taken, medical or therapeutic, that has the purpose of lessening the effects of a disease or improving health.

Psychosocial

Relating to the interaction between one's mental state and social environment.

Psychology/Psychological

Relating to the human mind, specifically human thoughts, feelings and behaviour.

Quality of Life

General well-being in regards to health and happiness.

Reminisce/Reminiscence

Remembering and/or talking about previous life events and experiences.

Signpost/Signposting

Being given information on a condition, treatment or other services that can offer you support. It can also mean to be referred to other services.

Therapy/Therapist

Treatment of an illness, or the person administering that treatment.

Well-being

General health, happiness and contentment.

Appendix 2: Who are the professionals? What do they do?

Occupational Therapist

Works with people to help them overcome the effects of a disability caused by physical or psychological illness, ageing or accident. They help people to live as independently as possible, for example, in daily living activities.

Psychiatrist/Consultant Psychiatrist

A doctor who specialises in mental health. They are able to diagnose, treat, and prescribe medication for mental illnesses.

Psychologist/Clinical Psychologist

Someone who studies the mind and behaviour. A clinical psychologist works with people with mental or physical health problems, helping to assess, diagnose and treat them (but does not prescribe medication.).

Psychotherapist

A mental health professional who has had further specialist training in psychotherapy. A psychotherapist works with people who have a psychological illness, emotional and relationship difficulties, or problems such as stress. Psychotherapy can happen on an individual, marital, family or group basis.

Neurologist

A physician who specialises in disorders, injuries and diseases of the brain and the central nervous system. A neurologist can diagnose and, if possible, treat these disorders.

Therapist/CBT Practitioner

Someone trained in the use of psychological methods for helping clients overcome psychological problems. A CBT practitioner is a therapist who has had special training in conducting cognitive behavioural therapy.

Counsellor

Someone who has had training in counselling. They can help with personal, social, or psychological problems, giving the client someone to talk to on a one-to-one basis about their problems.

Support Worker

They provide emotional and practical support to individuals and their families who struggle to live independently because of mental or physical health problems, a learning disability, or emotional and relationship difficulties.

GP/General Practitioner

A doctor who you are registered with at your local practice. They treat general illnesses, and do not normally have a speciality.

Nurse

Someone trained in caring for people with a physical or mental health illness, in hospitals and in the community.

Psychiatric Nurse/Community Psychiatric Nurse

A nurse who specialises in mental health to help care for people with a mental illness.

Radiologist

A physician who specialises in radiology. Radiology involves the use of radiation for the diagnosis and treatment of disease.

Outreach worker

Someone who works in social services, the government or in the community. They provide services to help people and their families get the support they need and improve their quality of life.

Physiotherapist

Someone who is trained to help and treat people with physical problems caused by illness, accident or ageing. They work in hospitals and in the community.

Notes

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Tel: 0116 254 9568 Fax 0116 247 0787 E-mail: mail@bps.org.uk Website: www.bps.org.uk



The British
Psychological Society

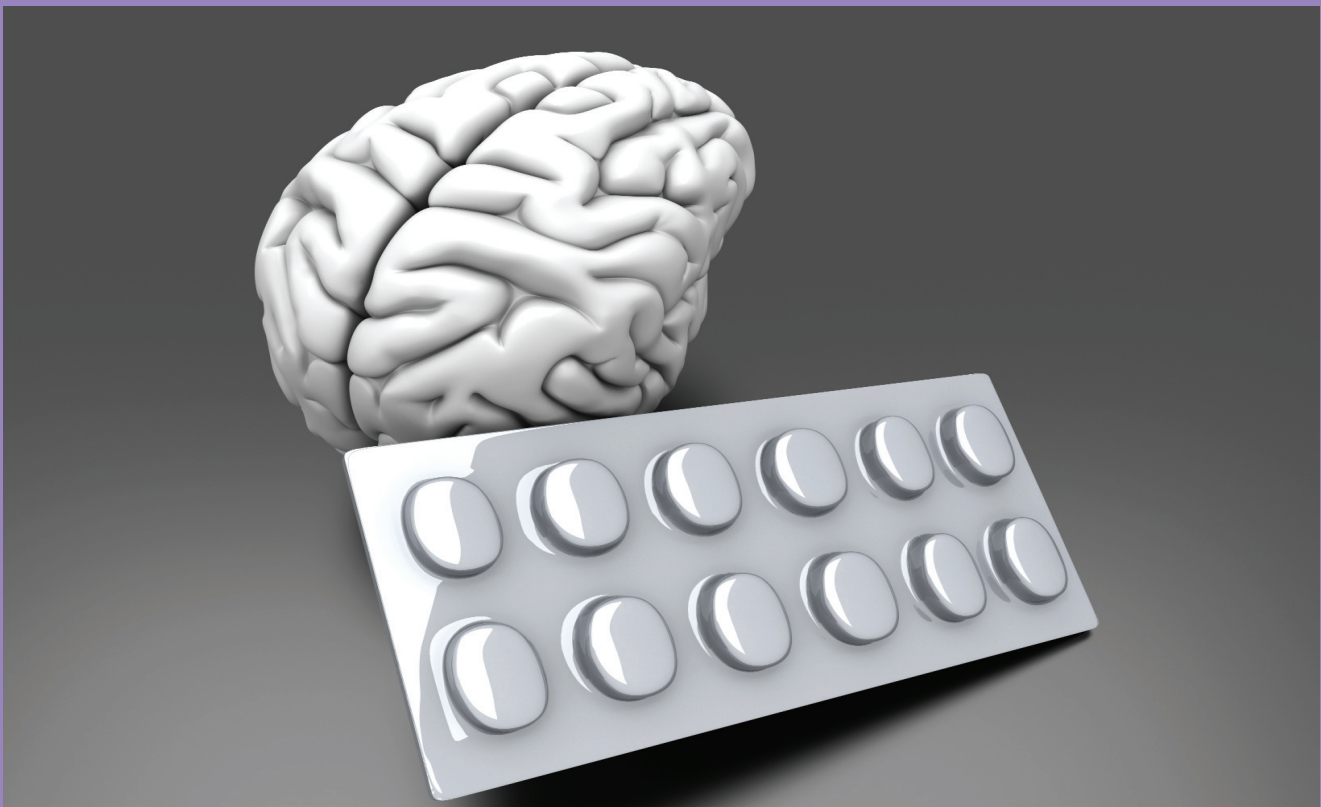


Division of
Clinical Psychology

Faculty of the Psychology
of Older People

Briefing paper

Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia



March 2013

The authors

Dr Donald Brechin

Past Chair, Faculty of the Psychology of Older People.
Leeds & York Partnership NHS Foundation Trust

Dr Gemma Murphy

Clinical Psychologist, MHSOP, Tees, Esk and Wear Valleys NHS Trust

Dr Ian Andrew James

Consultant Psychologist, Northumberland Tyne and Wear NHS Foundation Trust

Jason Codner

University of Teesside

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.

INF 207/2013

Printed and published by the British Psychological Society.

© The British Psychological Society 2013

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Telephone 0116 254 9568 Facsimile 0116 247 0787

E-mail mail@bps.org.uk Website www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

Contents

Executive summary	2
Introduction	3
The policy context	4
What is needed now?	5
Equal access to services for people with dementia	6
A stepped care model of assessment and intervention	6
Step 1: Recognition.....	8
Step 2: Assessment and treatment of contextual issues.....	11
Step 3: High intensity interventions	15
Step 4: Specialist interventions	19
Summary	22
Glossary	24
References	26
Appendix 1: Behaviour monitoring chart.....	31
Appendix 2: Challenging Behaviour Scale (Moniz-Cook, 2001)	33

Executive summary

The Department of Health has stated that the use of antipsychotic medication for people with dementia needs to be reduced in order to limit the risk of harm associated with these medications in this frail and vulnerable group of people. The question is whether there are any alternatives, and whether these can be effective in reducing reliance on antipsychotic medications.

A number of initiatives have developed to support this work, including the Dementia Action Alliance (DAA) 'Call to Action' in June 2011. As one of the partner organisations within DAA, the British Psychological Society committed to reviewing the evidence for evidence-based non-pharmacological alternatives to antipsychotic medication. The present report is the product of this work.

The Faculty of the Psychology of Older People, which is part of the Society's Division of Clinical Psychology, has brought together an expert reference group to review the relevant literature and to lay out the evidence in a clear and accessible manner. The Faculty's work highlights that there are evidence-based alternatives to antipsychotic medication for people with dementia. It also shows that if these are organised in a staged approach (that is, a stepped care approach) then access to these interventions can be increased and the reliance on antipsychotics should be reduced. Therefore, the model is presented to assist commissioners and providers of care when considering how to care for people with dementia, particularly when their well-being is compromised and/or when there are difficulties in managing aspects of the person's behaviour.

This document is intended for use across the UK as a whole. There are, however, areas in which different policy and guidance are relevant for different nations. Nevertheless it is hoped that as this document is addressing assessment and interventions, that it will be transferable across the home nations. Each of the home nations is aware of the rising numbers of people with dementia. They are committed to providing a framework for services to operate within to address this rise by improving the lives and services for people with dementia (Department of Health, 2009; Department of Health, Social Services and Public Safety in Northern Ireland, 2011; Scottish Government, 2010; NHS Wales 2011).

Dr Donald Brechin

Past Chair of the Faculty of the Psychology of Older People

On behalf of the Working Group

Introduction

There are approximately 800,000 people currently living with dementia in the UK with approximately a third of this number residing in a care home (Alzheimer's Society, 2011). It has been predicted that by 2021 there will be over one million people living with dementia. The financial cost is expected to grow from an estimated £20 billion in 2010 to over £27 billion by 2018 (All-Party Parliamentary Group on Dementia, 2011).

The majority of people living with dementia are likely to experience the development of behavioral and psychological difficulties at some point during their illness. It has been suggested that these behaviours may be present in up to 90 per cent of people living with Alzheimer's disease (Robert et al., 2005). Such behaviour includes occurrences of hitting, kicking, nipping, screaming, apathy, pacing, non-compliance, urinating in inappropriate places and disinhibition (James, 2011) as well as confusion, calling out, repetitive questioning, toileting difficulties, misidentifications and sexual challenge (Stokes, 2000).

A variety of terms are used to describe the phenomenology of where the person with dementia engages in behaviour that challenges others and/or reflects a level of apparent distress for the person with dementia. As such, a number of terms may be used to refer to these presentations within this document. The terms 'challenging behaviour', 'behaviours that challenge' (Royal College of Psychiatrists et al., 2007) and 'behavioural and psychological symptoms of dementia' (BPSD; Finkel et al., 1997) are the most commonly used in this field, but all have their limitations and critics and well as their supporters. However, the key point from the psychological perspective assumes these overt (or covert) changes in presentation represent unmet needs rather than an inevitable consequence (symptom) of an illness. As such, they are amenable to change if those needs can be identified and met.

It is important to remember that many of the behaviours identified as challenging are not symptoms of dementia, rather they are symptoms of human distress, disorientation and misperception. As such, it seems counterproductive to frequently treat such behaviours through tranquilisation and sedation without first attempting to deal with the distress and cognitive confusion. Indeed, it is important to recognise that because the behaviours are not the inevitable consequences of a disease, we need to be careful not to treat them as if they are – particularly if this involves using problematic drugs.

Current guidance recommends the use of treatments using a non-pharmacological approach in the initial stages of managing these behaviours (NICE/SCIE, 2006; Banerjee, 2009; National Dementia Strategy, 2009). Consequently, psychosocial and behavioral interventions are recommended as a first line treatment of BPSD (NICE/SCIE 2006; NHS Institute for Innovation and improvement, 2011; Banerjee, 2009).

A number of empirical studies have examined whether non-pharmacological approaches can be used as alternatives to medication (Avorn et al., 1992; Meador et al., 1997; Schmidt et al., 2000). Despite some mixed reviews (Nishtala et al., 2008; Forsetlund et al., 2011), it is evident the best controlled of these studies has shown that regular input from a trained clinician can lead to a significant reduction in the use of antipsychotics (Fossey et al., 2006). The protocol underpinning the work of these clinicians has been published by the Alzheimer's Society (Fossey & James, 2008), and the work itself is being extended with a major non-

pharmacological trial called WHELD (Ballard et al., 2009). This programme has undertaken a major revision of non-pharmacological studies and is currently empirically testing the use of person-centred approaches, exercise regimes, social interaction and the use of systematic medication reviews with respect to the well-being of people with challenges.

In practice, antipsychotic medication is often used as a first-line treatment for behavioural difficulties rather than as a secondary alternative (Alexopoulos et al., 2005; Alzheimer's Society, 2009), despite the evidence that antipsychotic drugs have a limited positive effect and can cause significant harm to people with dementia (Schneider, Dagerman & Insel, 2006; Ballard, Lana, Theodoulou, Jacoby, Kossawakowski, Yu & Juszczak, 2008; Banerjee, 2009). Interventions offered should aim to lessen the distress and harm caused by these difficulties and increase the quality of life of those living with dementia and their carers (Banerjee et al., 2007; Banerjee, 2009).

Implementing behavioural interventions instead of antipsychotic medication could lead to savings of £54.9 million above the cost of the therapy in England alone, resulting in a reduction in side effects such as the occurrence of incidence of stroke and falls (NHS Institute of Innovation and Improvement, 2011), which would result in an increase in the quality of life of people living with dementia.

The policy context

The four UK nations have all published strategies for the care of people with dementia and their carers:

- Living well with dementia: a National Dementia Strategy (England)
- Scotland's National Dementia Strategy
- National Dementia Vision for Wales
- Improving Dementia Services in Northern Ireland.

All these documents emphasise the need to promote a coordinated, evidence-based response to the caring for the increasing numbers of people with dementia.

More recently, the Department of Health in England has stated that the use of antipsychotic medication for people with dementia needs to be reduced. This is based on the work of Banerjee (2009) who reviewed the use of antipsychotic medication in people with dementia on behalf of the Secretary of State for Health. Professor Banerjee noted that of the 750,000 people with dementia in the UK, around 180,000 (i.e. 20 per cent) will be prescribed antipsychotic medication, of whom 36,000 may derive some clinical benefit. However, Professor Banerjee also pointed out that these medications are associated with significant risks. Banerjee estimated that, 'In terms of negative effects that are directly attributable to the use of antipsychotic medication, use at this level equates to **an additional 1,620 cerebrovascular adverse events**, around half of which may be severe, and to **an additional 1,800 deaths per year** on top of those that would be expected in this frail population.'

Since Professor Banerjee's report was published in 2009, there have been a number of initiatives to address antipsychotic use. In June 2011, the Dementia Action Alliance was formed and published a 'Call to Action', advocating that all people with dementia who are prescribed

antipsychotic drugs should have their medication reviewed and that alternatives to their prescription should be considered.

In 2011, the Alzheimer's Society responded to the call by publishing a best practice guide for health and social care professionals. The document aims to assist practitioners by providing practical tools for the assessment and management of behavioural and psychological distress in dementia. This toolkit provides guidance on preventative strategies, alternatives to medication, and safer medication prescribing. In Spring 2012, the Royal College of Nursing (RCN) also published a best practice guide in relation to the use of antipsychotics in dementia, and describes a number case examples of alternative approaches to medication use.

What is needed now?

The response to the Dementia Action Alliance's call to action has been positive and has moved understanding of this area of practice forward. As a partner within the Dementia Action Alliance, the British Psychological Society (BPS) also committed to undertake work to further the aims of the Alliance, and specifically to use the psychological expertise of its members to provide information about working with people with dementia. The BPS committed to summarise the information regarding evidence-based non-pharmacological interventions for people with dementia. This work was taken up by the Faculty of the Psychology of Older People, part of the Division of Clinical Psychology, in 2011.

The literature on psychosocial approaches for people with dementia is extensive, and is featured in a number of individual publications and empirical reviews. Much of this evidence also features in best practice guidance such as the NICE/SCIE Clinical Guideline 42 (NICE, 2006) and the Scottish Intercollegiate Guidelines Network guideline 86 (SIGN, 2006). As such, the Faculty's task is not to reproduce these documents and guidelines. Instead, the Faculty decided to:

- review the existing literature on the use of non-pharmacological interventions for people with dementia;
- produce a high level summary of this literature; and
- present this information in a clear and accessible framework.

The underpinning assumption within the psychosocial literature is that distressed/distressing behaviour represents an unmet need. As such, the therapeutic task is to understand what that need is and to address it, in order to enhance the well-being of the person with dementia. If this is successful, then the behavioral changes will reduce and/or the ability for other people to cope with these behaviours will increase.

By focusing on the non-pharmacological literature, the Faculty is not implying that pharmacological interventions have no role for people with dementia. There are a number of documents and frameworks that describe the use of pharmacological approaches, and the Faculty supports their use where appropriate. Rather, the role of the Faculty (and hence the purpose of this document) is to summarise the psychosocial evidence base and advocate for these approaches as part of a holistic package of care for people with dementia.

Equal access to services for people with dementia

When adopting the interventions outlined below it is important to recognise core principles that should be considered to maintain equal access to services as identified by the NICE guidelines. These recommendations are summarised below;

- The person with dementia should not be excluded from any intervention/services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.
- It is vital that health and social care professionals seek valid consent from the individual living with dementia. This should entail informing the person of the options, and their implications, together with checking that the person understands that they can withdraw from a treatment at any time. In cases where the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 should be followed.
- An assessment of the carer's needs should be completed to inform the intervention plan (Carers and Disabled Children Act 2000; Carers Equal Opportunities Act 2004). Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner (e.g. clinical psychologist, qualified practitioner).

A further priority stipulated by the NICE guidance is the integration and coordination of health and social care services, ensuring that joint planning is maintained and that there is a shared responsibility for the provision and delivery of health and social care for the individual living with the dementia and their carer.

A stepped care model of assessment and intervention

The introduction of the stepped care model in healthcare has provided a framework for organising healthcare delivery in a targeted manner (e.g. from NICE clinical guidelines to the Improving Access to Psychological Therapies programme). Given that there is a large body of literature on psychosocial approaches to dementia, it seems sensible to use a stepped care framework to identify which interventions should be tried and in which order.

The stepped care approach has been used recently in the treatment of care home residents' suffering from anxiety and depression (Dozeman et al., 2012; Alpin et al 2012). In the present context the stepped care model identifies the appropriate interventions that meet the presenting need, reinforcing the message that antipsychotic medication can be implemented as a secondary alternative. The model reinforces the need to ask '**why the behaviour is occurring?**' and has been informed by research such as Moniz Cook, Swift, James et al. (2012), the work of Cohen-Mansfield et al. (2007) on non-pharmacological interventions for BPSD; Guidelines (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007; NICE/SCIE 2006) and Government sponsored reports (Banerjee, 2009; European Union, 2009).

The steps describe the level of assessment and treatment input, identifying the person/professional that can perform the task. The interventions range from the initial

identification and treatment of physical causes (Step 1), understanding the person in more detail and getting the care environment right (Step 2), protocol-driven interventions tailored to specific presentations (Step 3), and intensive individualised psychological formulation-led interventions identified for more complex presentations (Step 4). While specific non-pharmacological interventions are first mentioned at Step 3, they may occur at any step. The model is not intended as a rigid pathway, but it is intended that step 1 is undertaken first. After this, it is pragmatic to undertake the next steps in order, unless otherwise indicated.

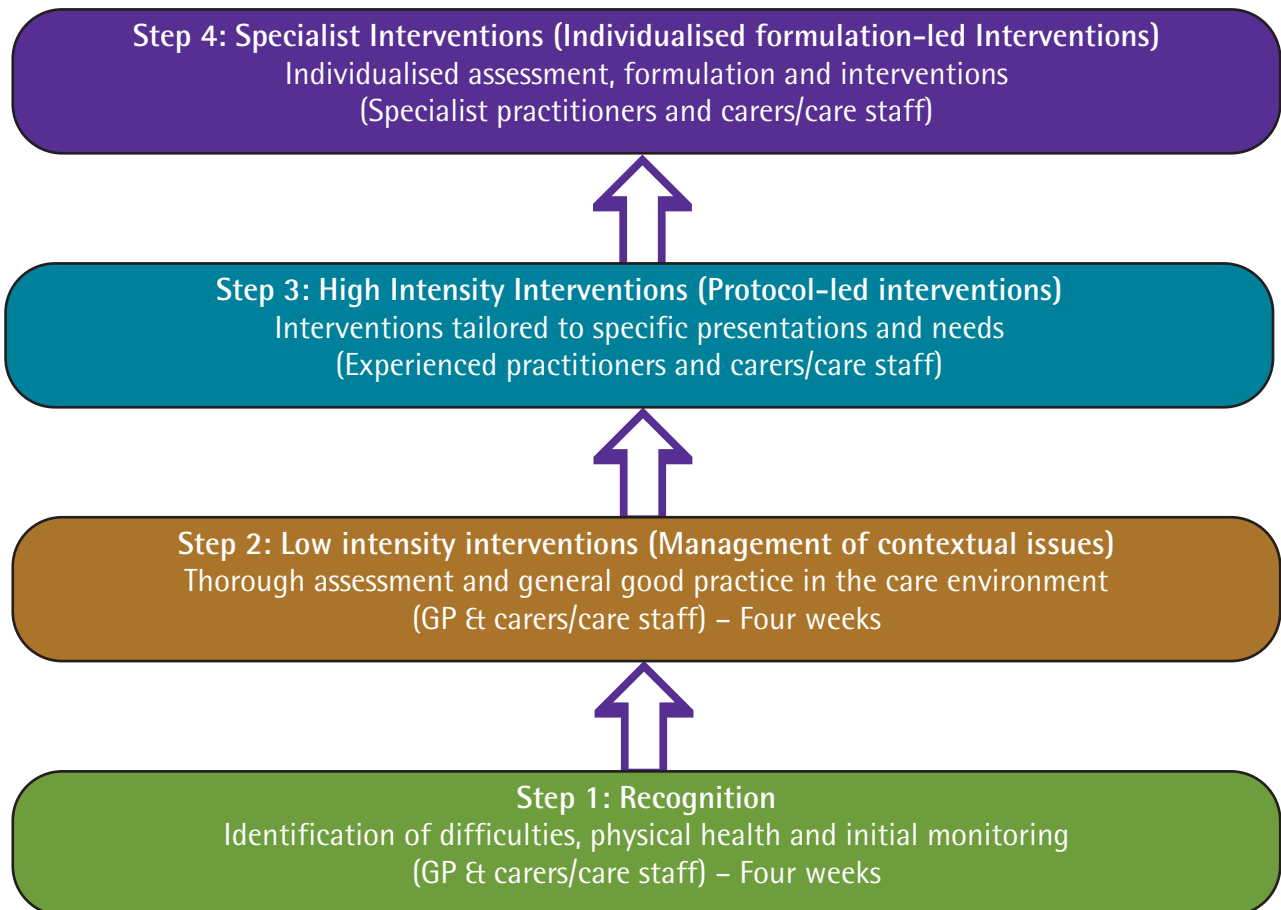


Figure 1: The stepped care model

However, an individual with dementia may present with particular behaviours that require a higher intensity of intervention and as such the person can be stepped up. The model provides sign posts to interventions that meet individual need with the aim of preventing further increase in distress for the individual and the carer. However there is the opportunity for movement from one step to another if the behaviour continues to be unresolved.

Step 1: Recognition

This step is focused on identifying that there is an issue for the person that may relate to the dementia, and recommends taking initial steps to assess and treat commonly occurring causes of distress and behaviour change. As such, all individuals should be initially assessed at this level.

Step 1: Recognition

Identification of difficulties, physical health and initial monitoring
(GP & carers/care staff) – Four weeks

Assessing Causes and Risks

Recognition of physical causes

- Screen for treatable conditions that may be either causing or contributing to confusion and distress, such as: delirium, pain, seizures, vascular events, diabetes, constipation, infections, thyroid disturbance, poor sleep, sensory loss, alcohol misuse, other medical conditions.
- Screen for presence of psychosis, depression, anxiety.
- Screen for negative impact of medication, including interactions/side effects (e.g. some statins causing agitation, Parkinson's medication causing disinhibition).
- If not a physical issue, proceed to step 2

Assess risk issues for client and carer(s).

Actions

- Treat common physical causes and inform family/carers about signs, symptoms, preventative measures for these conditions.
- If a risk identified, step up (low risk = step 2, high risk = step 3 or 4)
- Do not prescribe antipsychotics at this stage, unless psychosis evident in absence of Dementia with Lewy Bodies.
- Adjust medication if required to avoid unwanted interactions/side effects.
- Ask carers to monitor behaviours for four weeks (e.g. try to identify patterns – an example chart is given in appendix 1).
- Provide good practice checklist – an attempt to understand the person/information prescriptions/guided reading for carers.
- Provide information for carers (e.g. Alzheimer's Society website).
- If carer distress is identified, signpost to voluntary organisations/dementia advisors. If distress severe consider referral for carer's assessment, referral to other support (e.g. support group, local IAPT service).

Assessing the causes and risks

Objective 1 of the National Dementia Strategy in England states that an early comprehensive assessment for people with dementia should include:

- the person's physical health;
- depression;
- possible undetected pain or discomfort;
- side effects of medication;
- individual biography, including religious beliefs and spiritual and cultural identity;
- psychosocial factors;
- physical environmental factors; and
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers (NICE 2007).

At this initial stage, the starting point should be an assessment in primary care (for example, by a General Practitioner) to identify and treat any potential physical contributors. This should involve screening for: delirium, pain, diabetes, constipation, infection, sleep disturbance, and other medical conditions. Consideration should also be given to the person's medication regimen and the possibility of drug interactions and side effects. In recent years there has been a particular emphasis on the identification of pain (Woods & Moniz-Cook, 2012), and the realisation that it can play an important role in the distressed behaviour of people with dementia. A useful tool for assessing pain in dementia, which is notoriously difficult to identify, is the Abbey pain questionnaire.

Finally, the GP should assess for mental health issues such as psychosis, depression and anxiety. At this point, the assessment in itself can be an enough to identify and relieve the presenting difficulties.

Actions

The main focus is to treat common physical causes of the behaviours and adjust medication if required to avoid unwanted interactions/side effects. It is not necessary to prescribe antipsychotics at this stage unless there is evidence of psychosis (except for the case of Dementia with Lewy Bodies – DLB) or there is severe distress for the client or immediate harm to the client and/or others (note: relevant prescribing guidelines should be consulted).

The Alzheimer's Society (2011) has produced guidance for health and social care staff that outlines some initial interventions that can be considered at this step. These include:

- Understanding the individual needs of the person with dementia, as it can affect people in different ways. There is not a 'one-size-fits-all' care strategy.
- Recognising triggers and early signs that may precede the behavioural difficulties is crucial as in most cases simple approaches to early signs can prevent the symptoms developing at all.
- Watchful waiting – asking carers to monitor and record behaviours over four weeks (e.g. try to identify patterns). Many difficulties will stop after this period without pharmacological treatment.
- Providing information leaflets, guided reading and good practice checklists (available

from a number of sources, including the Alzheimer's Society website). The use of these types of information in a one-to-one setting to care givers has been found to reduce the BPSD (Livingstone et al., 2005).

- For people with significant language or communication difficulties, consider using the Distress Thermometer and/or asking a family member or carer about symptoms; if significant distress is identified, investigate this further.

If a degree of **risk** to the person or others is identified, consider moving on to step 2. If high levels of risk are identified, move up to step 3 or 4 depending on the circumstances and the judgement of the health/social care professional.

Needs of carers

At this stage, it is also important to identify potential carer needs. The difficulties faced by the person with dementia will also impact on their families, and carer distress is one of the reasons people's relatives are admitted to long-term care (European Union report, 2009). Objective 3 of the National Dementia Strategy identifies the need to provide carers with good quality information regarding the condition. However, the Alzheimer's Society (2010) indicates that, despite good information being available, 'people report that their needs are not met or that information is provided too late or not at all. A key problem is that people have to ask for information, rather than it being provided proactively. Most people do not know what they have to ask for.' As such, carers should be routinely offered sources of information regarding dementia, how it presents and how to manage it (for example, information leaflets from the Alzheimer's Society website), as well as where to seek help and assistance if required.

If carer distress is identified then consideration should be given to signposting to voluntary organisations/dementia advisors. If the level of distress is severe, consideration should be given to a referral for carer's assessment (as required by the Carer's Act), and/or referral to other support (e.g. support group, local IAPT service). Carers who experience anxiety and/or depression are entitled to evidence-based treatments under current NICE guidance for those presentations.

The complex range of services and staff with whom people with dementia and carers are in contact with can be confusing. It is unclear which professional can provide particular pieces of information and no one professional has responsibility for providing the full range of information. This leads to unhelpful gaps. While a more recent report (Health Foundation, 2011) highlights a further difficulty encountered by carer's from services and staff in terms of not sharing information with them about important developments in their relative's life and transition points between services.

When working with staff in wards and care homes it is important to acknowledge and support their existing skills. This is because by virtue of the sheer prevalence of behaviours that challenge, the staff are generally skilled in the treatment of most problematic behaviours they encounter. These skills normally take the form of good communication and interactive styles, verbal and non-verbal approaches. Accepting this existing skill-base, one might then start to explore 'why' in this particular case the staffs' normal approaches are not working effectively; sometimes this may be due to an inconsistent approach between the members of the staff team (James, 2011).

Step 2: Assessment and treatment of contextual issues

At step 1, common physical causes of the behavioural difficulties should have been ruled out. Therefore, step 2 focuses on further understanding of the needs of the individual in their environment and introducing general, good practice interventions within that environment.

By their nature, behavioural difficulties tend to require some form of interaction between the person with dementia and a carer. For example, the carer may need to encourage the person to get out of bed, take medication; or the carer may need to intervene to prevent a problem behaviour becoming risky. As such, good practice requires the use of good interactive and communication skills on the part of the carer. Indeed, audits of interventions carried out by the Newcastle Challenging Behaviour Team (James, 2011) reveal that a key factor in determining the resolution of problematic behaviours is the quality of the interaction of the carers with the person with dementia. Further, those who interact well tend to be good communicators, taking account of the needs and current perceptions of the person with dementia.

Staff and carers require some level of training and support to deliver interventions at this step, but this is at the level of good dementia awareness rather than specialist training. In terms of enhancing communication with the person with dementia, there is a growing literature on improving carers' communication skills (Levy-Storms, 2008; Eggenberger et al., 2013).

Assessing the presentation in context

Objective 1 of the National Dementia Strategy states that an early comprehensive assessment for people with dementia should include:

- the person's physical health;
- depression;
- possible undetected pain or discomfort;

Step 2: Low intensity interventions (Management of contextual issues)
Thorough assessment and general good practice in the care environment
(GP & carers/care staff) – Four weeks

Assessing the presentation in context

Assess and review the following:

- Behaviour records (what, when, who with, etc.).
- Emotional status of the client (e.g. assessing emotions, moods, worries, beliefs).
- Physical environment (e.g. overcrowding, privacy, noise levels).
- Carer communication skills and style of interacting.
- Communication (can the person communicate what they want, and can others communicate with them?).
- Design and layout of environment.
- Social contact (opportunities to spend meaningful time with others).
- Occupation (i.e. how is the person spending their time).

Actions

- Do not prescribe antipsychotics unless psychosis evident (in the absence of DLB).
- Choose intervention on the basis of the assessment: (i.e. general interventions within the care environment).
 - Dementia awareness training for staff.
 - Develop carer communication and interaction skills.
 - Developing life histories.
 - Engagement in meaningful activity/social programme (e.g. reminiscence group)
 - Changes to the physical environment/layout.
 - Frameworks to help understanding the emotional impact the person with dementia can have on the carer and vice versa (eg. emotional triads; James, 2011).
- Carers to monitor behaviours for four weeks – e.g. try to identify patterns (see appendix 1 for an example form). If no change in behaviour, proceed to step 3.

- side effects of medication;
- individual biography, including religious beliefs and spiritual and cultural identity;
- psychosocial factors;
- physical environmental factors; and
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers (NICE 2007).

If assessment has taken place appropriately at step 1, then the first four points on the above list should have been addressed. Practitioners should remain mindful of these areas, but at step 2 more emphasis is given to the next four areas.

Everyday experience tells us that people interpret situations and behaviour differently, and this is just the same with behavioural changes in dementia. Research evidence also shows that there can be low levels of agreement amongst senior staff regarding what constitutes behaviour that challenges (Bird & Moniz-Cook, 2008), adding further complexity to the assessment process. Therefore, it is important to have some objective understanding of exactly what is happening.

As such, the first task is to have clear records of exactly what is taking place, how often, and whether this is causing difficulty and/or distress for those involved. There are specific tools available to help with the recording of such information (e.g. Challenging Behaviour Scale; Moniz-Cook, 2001 – Appendix 2), and the key areas to address include:

- **What** is the individual saying or doing? What are his/her current beliefs about the present situation? (e.g. Does Mrs Smith believe she is in her 30s, caring for young children and an elderly mother? Does Mr Jones believe he's a joiner, single, and currently living in a hotel?). How is the person expressing themselves, are they angry; scared; crying; confused?
- **When** has the behaviour occurred? Consider at what time of day it is, what is going on at the time (e.g. is it meal-time; bed-time; when the person requires assistance; when they are alone/with others?)
- **Where** has it happened?
- **How** often is it happening?
- **Who** is it causing distress for (i.e. the person themselves, others)?

It is also important to understand the context in which these behaviours are occurring, specifically the environment in which the person is living in and what is going on.

- What is the **emotional** status of the individual? Is the person communicating any worries/fears/concerns, are they lower in mood? In situations where the individual is unable to communicate what information do you know from their past to inform your understanding and/or explain their behaviour?
- What are the **physical features** of the environment? Overcrowding, lack of privacy, noise levels, etc., can have a significant impact on an individual's ability to interpret their environment. If an individual is over or under-stimulated this can have a negative impact.
- **Communication**. Can the person easily communicate what they want/need? If not, how do they let people know if they are hungry, thirsty, in pain, lonely, afraid?
- The **design and layout of the environment** can either assist or confuse. Is it easy for someone to find their way around? It is easy to identify where the toilets are/where you can get a drink? Where can the person find other people to speak to?
- **Social contact** (opportunities to spend meaningful time with others) forming relationships, sharing life experiences and their home environment help to allow a shared ownership of the home, and create a positive sense of self.
- **Occupation** (i.e. how is the person spending their time) is vital when we consider an individual's sense of self worth. Lack of meaningful occupation can lead to sensory deprivation, boredom, isolation and low mood. It is important that the person living with dementia continues to experience their identity, have a sense of purpose, and role in their home environment.

A summary of methods used to obtain such information is provided in Fossey and James (2008). The publication outlined non-pharmacological approaches to be used in the place of psychotropic medication.

By assessing what is happening and the context in which it is happening, it is possible to understand the current experiences of the person with dementia. An important feature of this is an appreciation of his/her current beliefs and thoughts regarding his/her current situation, because these cognitions will often drive the behaviours. In the case of Mrs Smith (outlined above), her conviction that she has got children and an elderly mother may result in her forcibly attempting to leave her care home of an evening to try to collect her children from school. Mr Jones, believing himself single, may become sexually dis-inhibited when young female carers try to give him a bath. Hence, by understanding the person's beliefs and other contextual features we will be able to relate and communicate with the person better.

Actions

As identified in step 1, it is not necessary to prescribe antipsychotics at this stage unless there is evidence of psychosis (except for the case of Dementia with Lewy Bodies – DLB where antipsychotics should not be used) or there is severe distress for the client or immediate harm to the client and/or others (note: relevant prescribing guidelines should be consulted).

The findings from the assessment will determine the interventions that can be considered. Outlined below are a number of interventions that can be considered.

- **Improve staff communication with the person with dementia:** Encourage staff to interact with the person, getting to know them as a person and to have appreciation of the person's past. This is because people with dementia can become 'time-shifted' and their current behaviours may be reflection of previous episodes and roles in their lives. Also encourage staff to use good verbal and non-verbal skills, looking for clues to what the person with dementia is thinking and trying to communicate. Support staff in attempting to meet the person with dementia's needs (Cohen-Mansfield, 2000; James, 2011).
- **Dementia awareness training:** The use of staff dementia awareness training on the management of the behaviour that challenges has shown reductions in the occurrence of the behaviour for several months (Livingstone et al., 2005; Lai et al., 2009), and a reduction in use of antipsychotics (Fossey et al., 2006).
- **Life Story:** The development of a life-story booklet provides families and carers an opportunity to deliver person-centred care by placing the individual and their biography at the heart of their own care. A life story book explores the life history of the person with dementia and can support the delivery of new ways of working with people living with dementia (e.g. DoH-funded project with the Life Story network).
It provides people with a practical set of tools to help them engage with the real person and see them beyond their illness, disability or diagnosis.
- **Use of memory/activity boxes:** The use of these boxes promotes better quality communication between the person with dementia and their carer. The box combines life story work, reminiscence and cued retrieval techniques. Typically carers and friends of the person with dementia are asked to populate the box with items that are known to cue positive memories. The contents often include favourite books, possessions, memorabilia ornaments, photographs, etc.
- **Meaningful occupation:** Engagement in meaningful activity such as reminiscence group work, can improve the mood of people with dementia, without any reported harmful side effects (RCN, 2011; Woods et al., 2009). Such activities also increase levels of social interaction (see below)
- **Social interaction:** Increasing social contact is effective in enhancing well-being and reducing distress (Levy-Storm, 2008). Eggenberger et al. (2013) provide a list of useful communication strategies based on their systematic review of interactions with care home settings.
- **Physical environment:** Changes to the physical environment for the person with dementia can trigger the onset of behaviours that challenge. Identifying the trigger can alleviate distress for the person living with dementia (Pointon, 2001). The use of horizontal grid patterns can reduce attempts to open doors (Hussain & Brown, 1987), blinds and cloth barriers placed over doors/door handles (Namazi et al., 1989) have also been evidenced as effective methods for reducing distress. Evidence suggests that making changes to the physical environment to make it 'dementia friendly' is an effective intervention to reduce distress in individuals living with dementia (RCN, 2011).

After **two to four weeks** (or the end of the intervention) some change should have occurred. If there is no reduction in the frequency of the behaviour or the caregiver is experiencing difficulties managing the situation, the assessment and plan should be reviewed and revised as required. If no further change is evident by **four–six weeks**, it would be appropriate to proceed to step 3.

Step 3: High Intensity Interventions

At this stage, more intensive assessment and interventions are focused on specific needs and presentations. These are less focused on the general environment, and more on specific issues/needs that commonly arise in the context of dementia (e.g communication, memory, interpersonal interactions). These assessments and interventions require specific training on the part of those delivering them.

Assessing needs in relation to patterns of presentation

At this step, health and social care staff who are specifically trained and appropriately clinically supervised in the chosen protocol-led intervention are to take the lead, in line with Objective 1 of the National Dementia Strategy. Although the strategy makes reference to ‘behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers’ (NICE, 2007), other suitable assessment and intervention protocols are included here. A review of the clinical frameworks is provided by James (2011), highlighting the work of Kitwood (1997), Kuniks et al. (2003) Volicer and Hurley (2003) and Cohen-Mansfield (2000).

Step 3: High Intensity Interventions (Protocol-led interventions) Interventions tailored to specific presentations and needs (Experienced practitioners and carers/care staff)

Assessments and actions targeted at presentations rather than at the level of the individual assessing needs in relation to patterns of presentation

- Use of structured protocols to assess needs and determine interventions; e.g.
 - TREA model – Treatment Routes for Exploring Agitation (Cohen-Mansfield, 2000);
 - Dementia Care Mapping (Bradford Dementia Group); and
 - Behaviour records (ABC charts) .
- Systematic review of information from earlier steps (medical review, mental well-being, history, physical environment, social and occupational environment) to identify potential determinants of behaviour .

Actions

Tailoring the intervention to the diagnosis and presentation (agitation, boredom, vocalising), and use of decision trees to guide choice of interventions.

- Interventions could include: behaviour management advice, TREA, communication skills training, aromatherapy.
- Some interventions are particularly useful for improving quality of life and mood but are less suitable for the acute treatment of agitated behaviours. However, these interventions may form an important element of a combined treatment package: e.g. dementia care mapping, reminiscence therapy, cognitive stimulation, music, psychomotor & exercise, staff training in high quality interaction
- If there is high risk to self or others, consider medication (in line with appropriate prescribing guidelines).

Specific assessment frameworks will be deployed at this step, some of which link to specific intervention packages. For example, protocol decision trees are used in the TREA model, directing the practitioner to investigate six domains: (1) pain or discomfort, (2) need for social contact, (3) appropriate level of stimulation, (4) hallucinations, (5) depression and control, and (6) poor communication (Cohen-Mansfield et al., 2007). The findings from the assessment are used to determine a specific behaviour management intervention.

Kunik's Model of Behavioural Problems (Kunik et al., 2003) describes a multidimensional model of problematic behaviours. They suggest that there are three aspects that one must examine when accounting for such behaviours, namely features associated with the person, the caregiver, and the environment. Each of these aspects is then divided further into fixed and mutable determinants. Fixed determinants are characteristics that are difficult or impossible to change, while mutable characteristics can be altered via the efforts of therapists, family and staff, etc.

Dementia care mapping (DCM, developed by the Bradford Dementia Group; Kitwood, 1997) provides a structured framework for assessing interactions between caregivers and people with dementia, recording the type and frequency of different classes of interaction. This information is used to enhance the use of positive interactions and increase the well-being of people with dementia.

Behavioural records can also support decision-making at this point, particularly ABC charts (Antecedent, Behaviour, Consequence charts). These can identify patterns in behaviours and likely triggers by recording what happens before, during and after an occurrence of the behaviour, and can be helpful in determining the likely cause of the behaviours. At this stage, it is important that these records are reviewed by someone with training in behavioural assessment and management. Behavioural management programmes can then be derived from this information in order to shape behaviour. Again, these should be designed by someone experienced in the use of behavioural management techniques.

In addition, information ascertained from earlier steps (i.e. medical review, mental well-being, history, physical environment, social and occupational environment) should be reviewed to try and identify potential determinants of behaviours.

Action

Tailoring the intervention to the diagnosis and presentation (agitation, boredom, vocalising), and use of decision trees to guide choice of interventions. This could include:

- Behavioural management: Based on learning theories, behavioural management approaches from a trained practitioner can be of value in helping direct and shape behaviours that are harmful and/or distressing. Moniz-Cook's et al (2012) Cochrane review on functional analytical techniques identified 15 quality studies in this area, showing an encouraging evidence base.
- Staff training in improving communication and quality interaction and reminiscence work has been demonstrated to produce improvement in the BPSD too (see step 2; Woods, Spector, Jones, Orrell & Davies, 2009; Lai et al., 2009; etc.). A good example of a person centred staff training programme was provided by David Sheard, in the BBC documentary series *Can Gerry Robinson Fix Dementia Care Homes?* (BBC, 2009)
- Treatment route to exploring agitation (TREA, Cohen-Mansfield, 2000): this approach uses a decision-tree framework, which uses empirical data to identify the likely cause of a particular behaviour (e.g. verbal agitation – pain, sensory difficulties, lack of social contact, etc), and then suggests relevant interventions.
- Aromatherapy, in particular Melissa essential oil, has been identified as effective in reducing wandering and agitation in severe dementia in double-blind, placebo-controlled trials (Robinson et al., 2007; Ballard et al., 2002). However, recent results have not been as positive.

Other methodologies are useful in dealing with mood and quality of life issues, but do not necessarily target agitated forms of behaviours. However, these methods can often be part of a package of care:

- **Dementia care mapping (DCM):** Randomised controlled trials show that this approach was effective at reducing agitation in people with dementia (Chenoweth et al., 2009, cited in Ballard & Corbett, 2010; Brooker, 2005)
- **Cognitive Stimulation Therapy (CST):** Research trials have shown significant improvements in a range of cognitive functions as well as a reduction in aggressive or problem behaviours (NICE/SCIE 2006; Olazaran et al 2010; Ballard et al., 2011). A comparison of the health economics of cognitive stimulation therapy versus antipsychotic medication by the NHS Institute (NHS Institute, 2011) reported that £70.4 million in health cost savings would be generated by the adoption of behavioural interventions over antipsychotic use (p.9).
- **Psychomotor and exercise interventions** that are performed several times a week for 30-minute periods, that include walking, can produce improvements in mood and the quantity and quality of sleep in people with dementia (Eggermont & Scherder, 2005). The Seattle studies (Teri et al., 2008) have undertaken a major programme of work on the impact of exercise on people with dementia, and demonstrated significant benefits in terms of agitation.
- **Music** as an active (client plays a part in music making) or receptive (client listens to music) intervention in both individual and in group settings has some evidence of a positive effect in reducing the occurrence of agitation, aggressive behaviour and

wandering. (Vink et al., 2011). Cohen-Mansfield (2001) has produced a helpful taxonomy for the non-pharmacological approaches. She used it in her systematic review in which she identified 83 psychological interventions. Her classification is composed of eight types of interventions: sensory, social contact (real or simulated), behaviour therapy, staff training, structured activities, environmental interventions, medical/nursing care interventions, and combination therapies.

- **Medication:** The use of medications as an intervention for problematic behaviours is beyond the scope of this paper, but traditionally attempts to manage these behaviours involve the wide use of antipsychotic drugs (Schneider et al., 2006). Antipsychotic medication in particular should not be used for mild to moderate BPSD because of severe adverse risk reactions and the modest benefits (Ballard, Sharp et al., 2008; Banerjee, 2009). The widespread prescription of antipsychotics as a first line treatment for people with dementia continues, even though both the evidence and recommendations from the Committee on Safety of Medicines (the predecessor to the Commission on Human Medicines) run contrary to this (Ballard, Sharp et al., 2008). The NICE/SCIE guidance recommends that antipsychotic drugs be used for BPSD as a first line response only when there is severe distress or an immediate risk of harm to person with dementia or others. If antipsychotics are prescribed treatment should only be continued beyond 12 weeks in exceptional circumstances. (See Ballard and Corbett, 2010 for a review of the pharmacological interventions for BPSD.)

Step 4: Specialised Interventions

At Step 4, highly individualised assessments and interventions are undertaken that focus specifically on the individual and use specific psychological frameworks to understand their individual experience and needs. At this level, specialist training is required in specific theoretical approaches, assessment techniques and tailored interventions. In many circumstances when working at Step 4, the agents of change are the carers, and as such many of the interventions involve getting the carers to adopt new approaches and a different style of interaction with the person with dementia. To do this effectively, therapists with specialist training are required because skills in family therapy, group therapy, CBT, psychodynamic approaches are often useful when working with the carers.

Although primarily psychological in nature, these interventions will often occur in a multidisciplinary setting and a range of specialist perspectives will be integrated into a biopsychosocial formulation of the individual.

Step 4: Specialist Interventions (Individualised formulation-led Interventions)
Individualised assessment, formulation and interventions
(Specialist practitioners and carers/care staff)

The development of an individually-tailored intervention based around an individualised biopsychosocial formulation

Assessing Needs

Specialist Practitioners

- Full functional analysis
- Biopsychosocial formulation

Actions

Management plan (routinely monitored) which may include:

- Psychological interventions
- Social and occupational interventions
- Medication (can include antipsychotics if indicated)
- Regular specialist reviews

Assessing needs

At this step only staff specifically trained and appropriately clinically supervised to deliver idiographic formulations should take the lead at developing individually tailored interventions. Specialist practitioners may do this from a range of models or perspectives, for example full functional analysis or idiographic biopsychosocial formulation (such as Cohen-Mansfield's unmet need approach, 2000; Comprehensive model of psychiatric symptoms of progressive degenerative dementia, Volicer & Hurley, 2003; the Roseberry Park model, Dexter-Smith, 2010; Newcastle Columbo model, James, 2011). The end result, however, would be an individually tailored intervention that is specific to the person with dementia, the carers and environment. It is important to highlight that the above formulations are structural frameworks and it is the skill with which they are employed with the carers (i.e. the process features associated with the

models) that determine the success of the interventions. All of the models described above contain descriptions of how they should be used and employed and it is important that these protocols are used (see James, 2011).

Often, but not exclusively, clinical psychologists can take a lead with these formulation-led approaches. This is because while other professional groups produce formulations, (for example, formulation features in the curriculum for psychiatrists' training, Royal College of Psychiatrists, 2010), psychologists receive the most in-depth training in psychological theory and formulation. Thus, they are often well-placed to promote its use through practice, teaching, supervision, consultancy and research. From an organisational perspective the grounding, training and experience of a psychologist can provide mental health teams with a unique coherent alternative to the medical model (Onyett, 2007) which can help teams take the conceptual leap away from the use of antipsychotics.

Action

The interventions employed at this step may bear some similarities to those used at Step 3, but they will be derived from the idiosyncratic formulation rather than a manual-based treatment protocol from a single theoretical perspective. Although the list of actions appears shorter than in previous steps, the reality will be that more professionals are involved in the care of the person, deploying more specialist knowledge and expertise.

The formulation will have identified the clients' needs and their current (hypothesised) thinking patterns, and the interventions will be specifically tailored to meet a person's needs (i.e. to facilitate communication, reduce anxiety, promote independence, and relieve boredom or pain). In those circumstances where the person's needs cannot be met directly, the therapist may attempt to substitute the need via the introduction of some alternative feature (for example, if the person is asking for his deceased wife, a simulation presence DVD of his family may be used). On occasions, the therapist also might try to shift the person's perspective to create a more achievable goal (e.g. to ask the person if he would like to see his sister). In some circumstances, the therapist may have to concur with the client's erroneous view of reality and work from this perspective in order to reduce agitation or distress (for example, go along with the person's belief that his wife is still alive).

It is also essential at this stage that all aspects of a person's care are reviewed. As such, the management plan will need to be routinely monitored by the specialist team involved. The reviews should include:

- psychological interventions;
- social and occupational interventions;
- medication (can include antipsychotics if indicated) and
- regular specialist reviews.

Carers

The needs of carers will again come to the fore at Step 4. As described in detail in Step 1, carer needs should be assessed and signposting, support and treatment should be made available (see page 8). However, it should also be borne in mind that the carer will probably be intimately involved in delivery of the interventions at Step 4, and the professional team will be engaging with the carer on a regular basis to this end. As such, the professionals involved will

need to be mindful of the carer's state of well-being and their ability to cope with the situation, so that support can be offered as required. In Moniz-Cook et al.'s (2012) Cochrane review there are a number of examples of studies that have employed carer interventions to good effect. Examples of successful programmes includes the STARs framework (Teri et al., 2005). The use of CBT and acceptance and commitment therapy also show promise (Marriott et al., 2000; Márquez-Gonzalez et al., 2010).

Prescribers

Wood-Mitchell et al. (2008) demonstrated that there are numerous factors that maintain psychiatrists' prescribing practices and, in some cases, their preferences for using medication. On the positive side the psychiatrists seemed to be aware of best practice biopsychosocial methods, yet were sceptical of their efficacy and the staff's ability to carry them out effectively.

Such findings suggest that psychiatrists, GPs, and other medical professionals need to be educated in the use of non-pharmacological methods, and also be part of the broad training programmes required to teach care staff to use the methods effectively.

Summary

1. The majority, if not all, of people living with dementia are likely to experience behavioural and psychological difficulties at some point during their illness. This is because the behaviours reflect people's attempts to fulfill their needs and thus they are a natural consequence of being alive.
2. In the past the problematic behaviours were treated as if they were symptoms of dementia, which suggested that they had a clear discernable aetiology. This view led to the prescribing of specific types of medication for different behaviours (i.e. use of the medical model). However, most clinicians now accept that the behaviours are products of a range of biopsychosocial features (e.g. distress, disorientation, misinterpretation, psychosis, pain, delirium, etc.), and are not unique to dementia. As such, it is evident that there is no 'magic bullet' with respect to the treatment of the behaviours rather clinicians are required to obtain a understanding of the biopsychosocial causes.
3. Current guidance recommends the use of non-pharmacological approaches in the initial stages of managing these difficulties, but in reality antipsychotic medication is often used as a first line treatment. Implementing behavioural interventions could lead to savings of £54.9 million above the cost of the therapy, resulting in a reduction in side effects such as the occurrence of incidence of stroke and falls in people with dementia.
4. The stepped care model discussed in this document reinforces the need to ask 'why the behaviour is occurring?' and 'who is it distressing for?' (i.e. doing a good assessment). This places the behaviour in the context of the person's life history and the social and physical environment in which they live, and shapes the intervention required. In the future greater care will need to be exercised in the prescribing of such medication outside of accepted guidelines, because their limited effectiveness and numerous side effects may lead families to question whether these drugs are being used in their relative's 'best interests'.
5. The model is intended to guide the delivery of care, and it is generally intended that individuals would work their way through individual steps (i.e. choosing the least invasive/intensive interventions first). However, the person's individual situation and needs may require that they 'miss out' some steps and proceed to a higher step, and this is entirely appropriate.
6. Do not prescribe antipsychotics unless (i) psychosis is evident (except in the case of Dementia with Lewy Bodies), (ii) there is severe distress for the client; or (iii) immediate harm to the client and/or others. If antipsychotics are prescribed they should follow good practice using target, titration, and time, and should be reviewed with a view to discontinuation at the earliest opportunity.
7. There is not a 'one-size-fits-all' care strategy: people are individuals and so the reasons for their behaviour do vary. Therefore, watchful waiting, asking carers to monitor and record behaviours over a period of weeks (e.g. to try to identify patterns) to test out strategies and the success of individualised approaches is essential. Most behavioural difficulties will stop after four weeks without pharmacological treatment (Alzheimer's Society, 2011).

8. Clinical psychologists receive the most in-depth training in using psychological theory and evidence, and have a great deal of experience in applying this knowledge in clinical situations. As such, this staff group possess knowledge, skills and experience that complements the medical model (Onyett, 2007), and can be instrumental in helping teams take the conceptual leap away from the use of antipsychotics.
9. The stepped care model is applicable to acute and general hospital settings by helping to provide a framework and guidance around improving the quality of care for people with dementia and thus reducing the length of stay in hospital settings.
Up to 60 per cent of acute hospital beds are occupied by older people, approximately 40 per cent of whom have dementia. However, patients who have dementia experience many more complications and stay longer in hospital than those without dementia.
10. When adopting the interventions outlined it is important to recognise core principles that should be considered to maintain equal access to services. Namely that the person living with dementia should not be excluded from any intervention/ services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.
11. The integration and coordination of health and social care services should be promoted to ensure that joint planning is maintained and that there is a shared responsibility for the provision and delivery of health and social care for the individual living with the dementia and their carer.

Glossary

Alzheimer's Society: The leading support and research charity for people with dementia, their families and carers. It is a membership organisation, which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland through a range of activities, by providing a network of local services, research, publications and factsheets.

Antipsychotic medications/drug: The name given to a group of medications that is usually used to treat people with psychosis. It is also frequently prescribed to people with dementia to manage the BPSD.

Aromatherapy: A form of alternative and complementary medicine based on the use of very concentrated 'essential' oils from the flowers, leaves, bark, branches, rind or roots of plants with purported healing properties. In aromatherapy these potent oils are mixed with a carrier (usually soyabean or almond oil) or the oils are diluted with alcohol or water and rubbed on the skin, sprayed in the air, inhaled or applied as a compress.

Behavioural and psychological symptoms of dementia (BPSD): The term given to people living with dementia who experience development of behavioural and psychological difficulties at some point during their illness. Also known as 'behaviour that challenges' and 'neuropsychiatric symptoms of dementia'.

Cognitive stimulation therapy (CST): A brief treatment for people with mild to moderate dementia. Treatment involves sessions of themed activities running a few times a week over a period of several weeks. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. CST can be provided irrespective of drug treatments received.

Dementia care mapping (DCM): An observational tool designed to assess the quality of life of people with dementia with the aim of promoting patient focused holistic practices.

Dementia with Lewy bodies (DLB): Dementia is a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities. DLB is one type of dementia where abnormal protein deposits develop in nerve cells in the brain. These deposits or structures are known as Lewy bodies.

Formulation: A formulation aims to explain, on the basis of psychological theory, the development and maintenance of the service user's difficulties, at this time and in these situations; summarise the service user's core problems; suggest how the service user's difficulties may relate to one another, by drawing on psychological theories and principles; indicate a plan of intervention which is based in the psychological processes and principles already identified; and is open to revision and re-formulation (Johnstone & Dallos, 2006).

Improving Access to Psychological Therapies: An NHS programme rolling out frontline psychological services, combined where appropriate with medication which traditionally had been the only treatment available, across England offering interventions approved by the National Institute of Health and Clinical Excellence (NICE) for treating people with depression and anxiety disorders.

National Institute of Health and Clinical Excellence: Develops evidence-based guidelines on the most effective ways to diagnose, treat and prevent disease and ill health. They produce

guidelines for professionals to inform practise as well patient-friendly versions of their guidelines to help educate and empower patients, carers and the public to take an active role in managing health conditions.

Reminiscence therapy: Involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of tangible prompts such as photographs, household and other familiar items from the past, music and archive sound recordings.

Treatment routes for exploring agitation (TREA): An objective, systematic method for developing individualised non-pharmacological treatment plans based on an analysis of the agitated person's unmet needs, past and current preferences, past role-identity, cognitive, mobility, and sensory abilities/limitations, and possible causes for particular agitated behaviours. The methodology calls for ascertaining the type of agitated behaviour and the most likely aetiology, and then matching the intervention to the aetiology and to the participant's characteristics.

Randomised controlled trial: Where people are allocated at random (by chance alone) to receive one of several clinical interventions. One of these interventions is the standard of comparison or control. The control may be a standard practice, a placebo, or no intervention at all.

Social Care Institute for Excellence: Improves the lives of people who use care services by sharing knowledge about what works. It is an independent charity working with adults, families and children's social care and social work services across the UK. It also works closely with related services such as health care and housing. It gathers and analyses knowledge about what works and translates that knowledge into practical resources, learning materials and services for use by those working in care services. This includes managers, frontline staff, commissioners and trainers. People and their families who use these services can also use these resources.

Watchful waiting: An active process that over a defined period of time involves an ongoing assessment of contributing factors and simple non-drug treatments. It is the safest and most effective therapeutic approach unless there is sever risk or severe distress (Alzheimer's Society, 2011).

References

- All-Party Parliamentary Group on Dementia (2010). *A misspent opportunity: Challenging the dementia skills gap*. London: Alzheimer's Society.
- Alexopoulos, G.S., Jeste, D.V., Chung, H., Carpenter, D., Ross, R., & Docherty, J.P. (2005). The expert consensus guideline series. Treatment of dementia and its behavioral disturbances. Introduction: methods, commentary, and summary. *Postgraduate Medicine*, 6–22.
- Alzheimer's Society (2009). *Counting the cost. Caring for people with dementia on hospital wards*. London: Alzheimer's Society.
- Alzheimer's Society (2010). *Information needs of people with dementia and their carers*. London: Alzheimer's Society.
- Alzheimer's Society (2011). *Optimising treatment and care for people with behavioural and psychological symptoms of dementia – A best practice guide for health and social care professionals*. London: Alzheimer's Society. Available from http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=609.
- Ballard, C., O'Brien, J., James, I. & Swann, A. (2001). *Dementia: management of behavioural and psychological symptoms*. Oxford: Oxford University Press.
- Ballard, C.G., O'Brien, J.T., Reichelt, K. & Perry, E.K. (2002). Aromatherapy as a safe and effective treatment for the management of agitation in severe dementia: the results of a double-blind, placebo-controlled trial with Melissa. *Journal of Clinical Psychiatry*, 63(7), 553–558.
- Ballard, C.C. & Cobett, A. (2010). Management of neuropsychiatric symptoms in people with dementia. *CNS Drugs*, 24(9), 729–739.
- Ballard, C., Lana, M.M, Theodoulou, M., Douglas, S., McShane, R., Jacoby, R., Kossakowski, K., Yu, L.M., Juszczak, E. on behalf of Investigators DART AD (2008). A randomised, blinded, placebo-controlled trial in dementia patients continuing or stopping neuroleptics (the DART-AD trial). *Public Library of Science Medicine*, 5(4):e76. doi:10.1371/journal.pmed.0050076
- Ballard, C., Day, S., Sharp, S., Wing, G. & Sorensen, S. (2008). Neuropsychiatric symptoms in dementia: importance and treatment considerations. *International Review of Psychiatry*, 20, 396–404.
- Ballard, C., Khan, Z., Clack, H. & Corbett, A. (2011). Nonpharmacological treatment of Alzheimer disease. *Canadian Journal of Psychiatry*, 56(10), 589–595.
- Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London: Institute of Psychiatry, King's College London.
- Banerjee, S., Willis R., Matthews, D., Matthews, D., Contell, F., Chan, J. & Murray, J. (2007). Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry*, 22(8), 782–88. doi: 10.1002/gps.1741.
- Bird, M. & Moniz-Cook, E. (2008). Challenging behaviour in dementia; a psychosocial approach to intervention. In B. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing*, p.571–594. Chichester: Wiley.

- British Psychology Society (2011). *Good Practice guidelines on the use of psychological formulation*. Leicester: Author.
- Brooker, D. (2005). Dementia care mapping: a review of the research literature. *The Gerontologist*, 45 (Special Issue 1), pp.11–18.
- Chenoweth, L., King, M.T., Jeon, Y.H., Brodaty, H., Stein-Parbur, J., Norman, R.M., Haas, M. & Luscombe, G. (2009). Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*, 8, 317–25.
- Cohen-Mansfield, J. (2000). Nonpharmacological management of behavioural problems in persons with dementia: The TREA model. *Alzheimer Care Quarterly* 1, 22–34.
- Cohen-Mansfield, J., Libin, A. & Marx, M.S. (2007). Nonpharmacological treatment of agitation: A controlled trial of systematic individualized intervention. *Journals of Gerontology. Series A Biological Sciences and Medical Sciences*, 62, 908–16.
- Committee on the Safety of Medicines (2004). *Atypical antipsychotic drugs and stroke: Message from Gordon Duff, Chairman, Committee on Safety of Medicines (CEM/CMO/ 2004/1)*. Medicines and Healthcare Products Regulatory Agency.
- Department of Health (2009). *Living well with dementia – the national dementia strategy*. Department of Health: London.
- Department of Health, Social Services and Public Safety in Northern Ireland (2011). *Improving services in Northern Ireland. A regional strategy*. DHSSPSNI: Belfast.
http://www.dhsspsni.gov.uk/show_publications?txtid=53089.
- Dexter-Smith, S. (2010). Integrating psychological formulations into older people’s services – three years on (Part 1). *PSIGE Newsletter*, 112, 8-11.
- Division of Clinical Psychology (2007). *Marketing strategy for clinical psychologists*. Retrieved from [dcp.bps.org.uk/document-download-area/document-download\\$.cfm?file_uuid=AC0686B5-1143-DFD0-7E06-1EA51AB27AEA&ext=pdf](http://dcp.bps.org.uk/document-download-area/document-download$.cfm?file_uuid=AC0686B5-1143-DFD0-7E06-1EA51AB27AEA&ext=pdf).
- Douglas, S., James, I. & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10, 171-179. doi: 10.1192/apt.10.3.171.
- Eggermont, L.H.P. & Scherder, E.J.A. (2005). Physical activity and behaviour in dementia: A review of the literature and implications for psychosocial intervention in primary care. *Dementia*, 5(3), 411–428. doi:10.1177/1471301206067115.
- Eggenberger, E., Heimerl, K. & Bennett, M., (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345–58.
- European Union Social Protection and Social Inclusion Unit (2009). *Discussion paper: Coping with Alzheimer’s and other related diseases – improving patient care at home: How to cope (non-pharmacologically) with crisis situations (behavioural disorders) occurring in patients’ home*. Retrieved from <http://www.peer-review-social-inclusion.eu/peer-reviews/2009/alzheimers-and-related-diseases/pr-fr-2009-discussion-paper/download>.
- Finkel, S., Silva, J.C., Cohen, G., Miller, S. & Sartorius, N. (1997). Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *International Psychogeriatrics*, 8, 497–500.

- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *British Medical Journal*, *332*(7544), 756–61. doi:10.1136/bmj.38782.575868.7C.
- Fossey, J. & James, I.A., (2008). *Evidence-based approaches for improving dementia care in care homes*. London: Alzheimer's Society.
- Health Foundation (2011). *Learning report: Making care safer*. London: The Health Foundation.
- Hussain, R.A. & Brown, D.C. (1987). Use of two-dimensional grid patterns to limit hazardous ambulation in demented patients. *Journal of Gerontology*, *42*, 558–560.
- James, I.A. (2011). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment*. London: Jessica Kingsley.
- James, I.A., Mackenzie, L., Pakrasi, S. & Fossey, J. (2008). Non-pharmacological treatments of challenging behaviour. *Nursing and Residential Care*, *10*(5), 228–232.
- Johnstone, L. & Dallos, R. (2006). Introduction to formulation. In L. Johnstone & R. Dallos (Eds.), *Formulation in psychology and psychotherapy: Making sense of people's problems* (pp.1–16). London, New York: Routledge.
- Kitwood, T. (1997). *Dementia reconsidered*. Buckingham: Open University Press.
- Kunik, M., Martinez, M., Snow, A. et al. (2003). Determinants of behavioural symptoms in dementia patients. *Clinical Gerontology* *26*(3), 83–89.
- Lai, C.K.Y., Yeung, J.H.M., Mok, V. & Chi, I. (2009). Special care units for dementia individuals with behavioural problems. *Cochrane Database of Systematic Reviews*, *4*. doi: 10.1002/14651858.CD006470.pub2.
- Levy-Storms, L. (2008). Therapeutic communication training in long-term care institutions: Recommendations for future research. *Patient Education and Counseling* *73*, 8–21.
- Livingstone, G., Johnston, K., Katona, C., Paton, J. & Lyketsos, C. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry* *162*(11), 1996–2021.
- Márquez-González, M., Romero-Moreno, R. & Losada, A. (2010). Caregiving issues in a therapeutic context: New insights from the acceptance and commitment therapy approach. In N. Pachana, K. Laidlaw & R. Knight (Eds.), *Casebook of clinical geropsychology: International perspectives on practice*, pp.33–53). New York: Oxford. University Press.
- Marriott, A., Donaldson, C., Tarrrier, N. & Burns, A. (2000). The effectiveness of cognitive behavioural family intervention in reducing the burden of care in carers of patients of Alzheimer's disease. *British Journal of Psychiatry*, *176*, 557–562.
- Moniz Cook, E.D., De Vugt, M., Verhey, F., James, I. (2008). Functional analysis-based interventions for challenging behaviour in dementia. (Protocol). *Cochrane Database of Systematic Reviews*, *1*. doi: 10.1002/14651858.CD006929.
- Moniz-Cook, E., Swift K., James, I., Malouf, R., De Vugt, M. & Verhey, F. (2012). Function analysis-based interventions for challenging behaviour in dementia. *Cochrane Library*, *2*. Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006929.pub2/abstract;jsessionid=C8458739_A4EC3A21257500EE5D388DED.d04t01

- Moniz-Cook, E., Woods, R. & Richards, K. (2001a). Functional analysis of challenging behaviour in dementia: The role of superstition. *International Journal of Geriatric Psychiatry*, *16*, 45–56.
- Moniz-Cook, E., Woods, R., Gardiner, E., Silver, M. & Agar, S. (2001b). The Challenging Behaviour Scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. *British Journal of Clinical Psychology*, *40*(3), 309–322.
- Namazi, K.H., Rosner, T.T. & Calkins, M.P. (1989). Visual barriers to prevent ambulatory Alzheimer's patients from exiting through an emergency door. *The Gerontologist*, *29*, 699–702.
- NHS Institute for Innovation and Improvement. (2011). *An economic evaluation of alternative to anti psychotic drugs for individuals living with dementia*. Matrix Evidence. Coventry: NHS Institute for Innovation and Improvement.
- NHS Wales. (2011). *National dementia vision for Wales. Dementia supportive communities*. Retrieved from <http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf>.
- NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care. Clinical Guideline 42*. National Institute for Health and Clinical Excellence & the Social Care Institute for Excellence.
- NICE (March 2011). *Dementia Supporting people with dementia and their carers in health and social care*. Retrieved from www.nice.org.uk/nicemedia/live/10998/30317/30317.pdf.
- Olazaran J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., del Ser T., Woods, B., Beck, C., Auer, S., Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J.M., Collins, H., Teri, L., Mittelman, M., Orrell, M., Feldman, H.H. & Muniz, R., (2010). Non-pharmacological therapies in Alzheimer's Disease: A systematic review of efficacy, *Dementia and Geriatric Cognitive Disorders*, *30*, 161–178.
- Onyett, S. (2007). *Working psychologically in teams*. Leicester: The British Psychological Society.
- Opie, J., Rosewarne, R. & O'Connor, D.W. (1999). The efficacy of psychosocial approaches to behaviour disorders in dementia: a systematic literature review. *Australian and New Zealand Journal of Psychiatry*, *33*, 789–799.
- Pointon, B. (2001). Whose service is it? A pressing need for change. *Journal of Dementia Care*, *9*(5), p.23-25.
- Robert, P.H., Verhey, F.R., Byrne, E.J. et al. (2005) Grouping for behavioral and psychological symptoms in dementia: clinical and biological aspects. Consensus paper of the European Alzheimer disease consortium. *European Psychiatry*, *20*, 490–496.
- Robinson, L., Hutchings, D., Dickinson, H.O., Corner, L., Beyer, F., Finch, T., Hughes, J., Vanoli, A., Ballard, C. & Bond, J. (2007). Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: A systematic review. *International Journal of Geriatric Psychiatry*. *22*(1), 9–22. DOI: 10.1002/gps.1643.
- Royal College of Nursing (2011). *Dignity in dementia: transforming general hospital care: findings from survey of professional*. Royal college of Nursing.
- Royal College of Psychiatrists (2010). *A competency-based curriculum for specialist core training in psychiatry*. Retrieved from: www.rcpsych.ac.uk/training/curriculum2010.aspx.

- Royal College of Psychiatrists (2011). *Report of the National Audit of Dementia Care in General Hospitals*. Editors: J. Young, C. Hood, R. Woolley, A. Gandesha & R. Souza. London: Healthcare Quality Improvement Partnership.
- Royal College of Psychiatrists (2005). *Atypical antipsychotics and behavioural and psychiatric symptoms of dementia*. royal college of psychiatrists. Retrieved from <http://www.rcpsych.ac.uk/PDF/BPSD.pdf>.
- Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007). *Challenging behaviour: a unified approach Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices college report CR 144*. Retrieved from <http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf>.
- Schneider, L.S., Tariot, P.N., Dagerman, K.S., Davies, S.M., Hsiao, J.K., Ismail, M.S., Lebowitz, B.D., Lyketsos, C.G., Ryan, J.M., Stroup, T.S., Sultae, D.L., Weintraub, D. & Lieberman, J.A. (2006). Effectiveness of atypical antipsychotic drugs in patients with Alzheimer's disease. *New England Journal of Medicine*, 355, 1525–1538.
- Schneider, L., Dagerman, K. & Insel, P. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomised placebo-controlled trials. *Journal of American Medical Association*, 294, 1934–1943.
- Stokes G. (2000). *Challenging behaviour in dementia: A person centred approach*. Bicester: Winslow Press.
- Scottish Government (2010). *Scotland's national dementia strategy*. Retrieved from www.scotland.gov.uk/Publications/2010/09/10151751/0. Edinburgh: Scottish Government.
- Teri, L., Logsdon, R.G., McCurry, S.M. (2008). Exercise interventions for dementia and cognitive impairment: The Seattle Protocols. *Journal of Nutrition, Health and Aging*, 12, 391–394.
- Vink, A.C., Bruinsma, M.S. & Scholten, R.J.P.M. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews*, 4. doi: 10.1002/14651858.CD003477.pub2.
- Volicer, L. & Hurley, A. (2003). Management of behavioural symptoms in progressive degenerative dementias. *Journal of Gerontology*, 58A (9), 837–845.
- Welsh Assembly Government (2011). *National dementia vision for Wales*. <http://wales.gov.uk/topics/health/publications/health/guidance/dementia/?lang=en>
- Wood-Mitchell, A., James, I.A., Waterworth, A., Swann, A. & Ballard, C. (2008). Factors influencing the prescribing of medications by old age psychiatrists for behavioural and psychological symptoms of dementia: a qualitative study. *Age and Ageing*, 37(5), 547–52.
- Woods, B. & Moniz-Cook, E. (2012). Pain relief – a first-line response to agitation in dementia? *Nature Review Neurology*, 8, 7–8.
- Woods, B., Spector, A.E., Jones, C.A., Orrell, M., Davies, S.P. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews*, 2. doi:10.1002/14651858.CD001120.pub2.
- Woods, B., Spector, A., Prendergast, L. & Orrell, M. (2005a). Cognitive stimulation to improve cognitive functioning in people with dementia'. *Cochrane Database of Systematic Reviews*, Issue 4. Chichester: John Wiley.
- Woods, B., Spector, A., Jones, C., Orrell, M. & Davies, S. (2005b). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews*, Issue 2. Chichester: John Wiley.

Appendix 1: Behaviour monitoring chart

Behaviour Chart for

Behaviour displayed

Please record any episodes of the above behaviour (day/night)
 Aim – to record the frequency and the circumstances of the incident

Date & Time	What was the person doing just before the incident?
Where did the incident occur?	What did you see happen? (actual behaviour)
Which staff were involved (initials)	What did the person say at the time of the incident?
Possible reason for the behaviour?	
How did the person appear at the time of the incident? (tick all that apply)	
Angry <input type="checkbox"/> Anxious <input type="checkbox"/> Bored <input type="checkbox"/> Content <input type="checkbox"/> Depressed <input type="checkbox"/> Despairing <input type="checkbox"/> Frightened <input type="checkbox"/> Frustrated <input type="checkbox"/>	Happy <input type="checkbox"/> Irritable <input type="checkbox"/> Physically unwell <input type="checkbox"/> Restless <input type="checkbox"/> Sad <input type="checkbox"/> Worried <input type="checkbox"/> Other (please state): <input type="checkbox"/>
How was the situation resolved?	

What is a behaviour chart?

A behaviour chart is a chart to recognise challenging behaviours. An example of a chart already filled out is shown to the right of this page.

What information does a behaviour chart give you?

A behaviour chart gives us a really detailed picture of challenging behaviours. It shows us how often the behaviour is happening and what is happening at the time of the behaviour.

Who should fill out the behaviour charts?

The behaviour charts need to be filled out by the staff member who witnesses the behaviour following discussion with senior staff on duty.

Do I fill out a chart for every time the behaviour occurs?

Yes please. We need to know how much of a problem it is (e.g. how often it happens). If you do not record it each time we can miss important information. In addition if we don't get completed charts it will lead us to think that there is no problem.

How long will we have to complete the behaviour charts for?

It will usually be between 3-8 days, or approximately 20 completed charts.

Behaviour Chart for.....Harry.....

Behaviour displayedHitting out.....
Please record any episodes of the above behaviour (day/night)
Aim – to record the frequency and the circumstances of the incident

Date & Time 28/01/2007 1pm	What was the person doing just before the incident? In their room being assisted to change after being incontinent.
Where did the incident occur? bedroom	What did you see happen? (actual behaviour) Harry started shouting and was hitting out at staff with a closed fist. He hit staff on the arm 3 times causing a red mark.
Which staff were involved (initials) SW, AN	What did the person say at the time of the incident? “get off me”, “I don’t want your help”
Possible reason for the behaviour? Didn’t want staff to help with getting him changed. Embarrassed by people undressing him.	
How did the person appear at the time of the incident? (tick all that apply)	
Angry	<input type="checkbox"/>
Anxious	<input checked="" type="checkbox"/>
Bored	<input type="checkbox"/>
Content	<input type="checkbox"/>
Depressed	<input type="checkbox"/>
Despairing	<input type="checkbox"/>
Frightened	<input type="checkbox"/>
Frustrated	<input checked="" type="checkbox"/>
	Happy <input type="checkbox"/>
	Irritable <input type="checkbox"/>
	Physically unwell <input type="checkbox"/>
	Restless <input type="checkbox"/>
	Sad <input type="checkbox"/>
	Worried <input type="checkbox"/>
	Other (please state): <input type="checkbox"/>
How was the situation resolved? Staff kept trying to reassure Harry and carried on with the care intervention. As soon as staff had finished he stopped being aggressive.	

THE CHALLENGING BEHAVIOUR SCALE (CBS) FOR OLDER PEOPLE LIVING IN CARE HOMES

Name

Age Sex ... M / F Diagnosis of Dementia ... Y / N / Don't know

Residence Date

Checklist Completed By

<p><u>PHYSICAL ABILITY</u> (delete as applicable)</p> <ol style="list-style-type: none"> 1. Able to walk unaided / Able to walk with aid of walking frame / In a wheelchair 2. Continent / Incontinent of urine / Incontinent of faeces / Incontinent of urine + faeces 3. Able to get in or out of bed/chair unaided / needs help to get in or out of bed/chair 4. Able to wash and dress unaided / needs help to wash and dress 5. Able to eat and drink unaided / needs help to eat and drink

Over the page is a list of challenging behaviours that can be shown by older adults in residential or nursing settings. For each behaviour listed consider the person over past 8 weeks and mark:

INCIDENCE: Yes / Never. If Yes move to Frequency

FREQUENCY:

- 4: This person displays this behaviour daily or more
- 3: This person displays this behaviour several times a week
- 2: This person displays this behaviour several times a month
- 1: This person displays this behaviour occasionally

DIFFICULTY:

Then for each behaviour shown mark down how difficult that behaviour is to cope with, when that person shows it, according to the following scale:

- 4: This causes a lot of problems
- 3: This causes quite a lot of problems
- 2: This is a bit of a problem
- 1: This is not a problem

N.B. If a person does not show a behaviour no frequency or difficulty score is needed. If the person causes a range of difficulty with anyone behaviour, mark down the score for the worst it has been over the last few (eight) weeks.

©E.Moniz-Cook2001

CHALLENGING BEHAVIOUR		INCIDENCE	FREQUENCY	DIFFICULTY	CHALLENGE
		Yes Never	1-occasionally 2-regularly 3-regularly/often 4-often or daily	1=0 problem 2=1st or 2nd 3=3rd or 4th 4=lots of problem	1=not 2=slightly 3=moderately 4=severely
1	Physical Aggression (hits, kicks, scratches, grabbing, etc.)				
2	Verbal Aggression (insults, swearing, threats, etc.)				
3	Self Harm (cuts/hits self, refuses food/starves self, etc.)				
4	Shouting				
5	Screaming/Crying out				
6	Perseveration (constantly repeating speech or actions, repetitive questioning or singing)				
7	Wandering (walks aimlessly around home)				
8	Restlessness (fidgets, unable to settled down, pacing, 'on the go', etc.)				
9	Lack of motivation (difficult to engage, shows no interest in activities, apathy, etc.)				
10	Clinging (follows/holds on to other residents/staff, etc.)				
11	Interfering with other people				
12	Pilfering or Hoarding (possessions, rubbish, paper, food, etc.)				
13	Suspiciousness (accusing others, etc.)				
14	Manipulative (takes advantage of others, staff, etc.)				
15	Lack of Self Care (hygiene problems, dishevelled, etc.)				
16	Spitting				
17	Faecal Smearing				
18	Inappropriate Urinating (in public, not in toilet, etc.)				
19	Stripping (removes clothes inappropriately, flashes, etc.)				
20	Inappropriate Sexual Behaviour (masturbates in public, makes inappropriate 'advances' to others, etc.)				
21	Sleep Problems (waking in night, insomnia, etc.)				
22	Non-compliance (deliberately ignores staff requests, refuses food, resists self care help, etc.)				
23	Dangerous Behaviour (causes fires or floods, etc.)				
24	Demands Attention				
25	Lack of Occupation (sits around doing nothing, etc.)				
TOTALS		25	100	100	400
Add scores (1 – 25) for each column					

STAFF PROMPT SHEET

HOW OFTEN DOES THE PROBLEM / BEHAVIOUR OCCUR?

- 4:** This person displays this behaviour **daily or more**
- 3:** This person displays this behaviour **several times a week**
- 2:** This person displays this behaviour **several times a month**
- 1:** This person displays this behaviour **occasionally**
- 0:** This behaviour is **never** displayed by this person

HOW MUCH OF A PROBLEM IS THIS BEHAVIOUR?

- 4:** This causes **a lot** of problems
- 3:** This causes **quite a lot** of problems
- 2:** This causes **a bit** of a problem
- 1:** This is **not** a problem

WE ARE INTERESTED IN THE WORST THE RESIDENT HAS BEEN OVER THE LAST TWO MONTHS.

If a person does not show a behaviour no difficulty (or problem) score is needed.

If the person causes a range of difficulty with any one behaviour, mark down the score for the worst it has been over the last few weeks.

Instructions for use of the Challenging Behaviour Scale

Background

1. This scale was initially derived as the Problem Behaviour Checklist (Inventory) and used in a staff training study. Reference: Moniz-Cook, E.D., Agar, S., Silver, M., Woods, R.T., Wang, M., Eiston, C. and Win, T. (1998) 'Can Staff Training Reduce Behavioural Problems in Residential Care for the Elderly Mentally Ill?' *International Journal of Geriatric Psychiatry*, 13, p.149-158.
2. On the basis of initial reliability and validity studies it was changed and re-labelled – The Challenging Behaviour Scale (CBS).
3. Reliability and validity studies were carried out in Continuing Care Hospitals and residential and nursing homes. Although you can use the scale for non-demented institutional populations its global properties will be of little use. For example people with a depressive illness may present with self harm whereas this is not often seen in dementia.
4. This scale was developed on the basis of staff report : hence eating problems do not feature strongly and were included under the 'non-compliant' category. You may wish to add some items of eating problems for your own use but the norms will have to be adjusted.
5. This is a global scale and although it has been subject to factor analysis, other scales for aggression, agitation and eating problems are more useful for specific behaviours. This scale does have a category for 'apathy' / depression / doing nothing which may be of use in monitoring.
6. The Incidence and Frequency ratings are useful in measuring 'actual behaviour' if guidelines are followed (see later). The Difficulty and Challenging scores are more measures of staff coping / management / perception. The Difficulty domain is only required to calculate Challenge scores whilst the Challenge score is a measure of management difficulty or coping.

Contract

1. I would be grateful if you would supply me with information of use of this scale, (i.e. if you decide to use it and how). I wish to develop it further and keep a database of it's use.
2. Please do not circulate the Scale and Staff Prompt Sheet without my permission, as I am currently negotiating detail publication with a test agency.
3. Please refer to Moniz-Cook, E.D., Woods, R.T., Gardiner, E., Silver, M. & Agar, S. (2001) 'The Challenging Behaviour Scale (CBS): Development of a Scale for Staff Caring for Older People in Residential and Nursing Homes'. *British Journal of Clinical Psychology*. 40 (3): 309-322 for detail of development, reliability and validity. Please turn over for specific instructions.

Esme Moniz-Cook
Professor of Clinical Psychology & Ageing /Consultant Clinical Psychologist
University of Hull/Humber NHS FT
The Hull Memory Center
39-41 Coltman Street
Hull HU3 2SG
© E. Moniz-Cook 2001

CHALLENGING BEHAVIOUR SCALE INSTRUCTIONS

1. Use as a structured interview with at least 2 members of staff (one qualified and one unqualified), for individual clinical work or for `research` work / monitoring.
2. If you hand these out then make sure that one person who knows the person well (key worker), a qualified member of staff and one other do the checklist in a group.
3. If a staff member is stressed out this may influence the results (especially on some items and the Difficulty and Challenge rating).
4. Repeat testing is best done with the same staff group, but reliability is not bad if group is different as long as it is a group and not one person.
5. You need to wait approximately 8 weeks before you repeat testing because of wording of frequency items.

Scoring

1. Multiply each Frequency x Difficulty item to get a Challenge item score.
2. Add Challenge score to make total Challenge (do not add Frequency, add Difficulty and then multiply for Challenge).
3. By this method the maximum Challenge score is 400.
3. If you want to measure the (more reliable) actual behaviour use total Incidence and total Frequency on their own.

Notes

1. The Incidence and Frequency domain are fairly stable measures of actual behaviour. The Difficulty domain is not often used on its own but is used to calculate the Challenge domain, which is a measure of staff coping / management. This latter domain (Challenge) is very sensitive and is only reliable if you follow the rules.
2. It is useful in assessing behaviour in whole environments, e.g. a ward – ask the person in charge to complete with at least the key worker and one other.
3. Measurement of individual cases – use as a structured interview with the same pair of staff pre and post / at least one staff member of the baseline pair.

References for CBS

- Moniz-Cook, E.D., Agar, S., Silver, M., Woods, R.T., Wang, M., Elston, C & Win, T. (1998) `Can Staff Training Reduce Behavioural Problems in Residential Care for the Elderly Mentally III?`, *International Journal of Geriatric Psychiatry*, **13**, 149-158.
- Moniz-Cook, E.D. (1998) `Psychosocial Approaches To Challenging Behaviour In Care Settings – A Review`. *Journal of f Dementia Care*, **6** (5), .33-38.
- Silver, M., Moniz-Cook, E.D & Wang, M. (1998) `Stress And Coping With Challenging Behaviour In Residential Settings For Older People` *Mental Health Care*, **2** (4), 128-131.
- Moniz-Cook, E.D., Gardiner, E. & Woods, R.T. (2000) `Staff Factors Associated with the Perception of Behaviour as `Challenging` in Residential and Nursing Homes`. *Aging and Mental Health*, **4**(1), 48-55.
- Cole R.P., Scott, S. & Skelton-Robinson, M. (2000) `The effect of Challenging Behaviour and Staff Support on the Psychological Wellbeing of Staff Working with Older Adults. *Aging and Mental Health*, **4** (4) .359-365.
- Moniz-Cook, E.D Woods, R.T. & Richards, K. (2001) `Functional Analysis of Challenging Behaviour in Dementia: The Role of Superstition`. *International Journal of Geriatric Psychiatry*, **16**, p.45-56.
- Moniz-Cook, E.D., Woods, R.T., Gardiner, E., Silver, M. & Agar, S (2001) `The Challenging Behaviour Scale (CBS): Development of a Scale for Staff Caring for Older People in Residential and Nursing Homes`. *British Journal of Clinical Psychology*. **40** (3).309-322.
- Moniz-Cook, E.D Stokes, G. & Agar, S. (2003) `Difficult Behaviour and Dementia in Nursing Homes: Five Cases of Psychosocial Intervention`. *International Journal Clinical Psychology and Psychotherapy*, **10**, 3, 197-208
- Freeman - Asthill, L. (2004) `Staff training and challenging behaviour in a day hospital.` *Dementia* **3** (3), 384-392
- Lam, C.L. Chan, W.C. Cycbie, C.M. Mok, S.W. Li. & Linda C.W. Lam. (2006) `Validation of the Chinese Challenging Behaviour Scale: clinical correlates of challenging behaviours in nursing home residents with dementia`. *International Journal of Geriatric Psychiatry* **21** 792-799
- Hoe, J. Hancock, G. Livingston, G. & Orrell, M. (2006) Quality of Life of people with dementia in residential care homes *British Journal of Psychiatry* **188**, 460-464
- Orrell, M., Hancock, G.,Hoe, J., Woods B., Livingston, G. & Challis, D. (2007) A cluster randomised controlled trail to reduce the unmet needs of people with dementia living in residential care *International Journal of Geriatric Psychiatry* **22** 1127- 1134
- Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, de Vugt M, Mountain G, O'Connell M, Harrison J, Vasse E, Dröes RM, & Orrell M For the INTERDEM group. (2008) A European consensus on outcome measures for psychosocial intervention research in dementia care *Aging & Mental Health* **12** ,1, 14- 25
- Moniz-Cook E D (2010) National Institute of Health Research (NIHR) Research : Living well with dementia in care homes Alzheimers Society Newsletter **97** (April), 6-7
- Moniz-Cook (2010) Psychosocial Interventions for 'living well' in care homes *Alzheimers Society Research eJournal* Issue **11**, pp 12 – 15

Updated January 2012

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Tel: 0116 254 9568 Fax 0116 247 0787 E-mail: mail@bps.org.uk Website: www.bps.org.uk