



The British  
Psychological Society

Promoting excellence in psychology

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



British Psychological Society Dementia Advisory Group

# Contents

---

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

© 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](mailto:mail@bps.org.uk) Website [www.bps.org.uk](http://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](mailto: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 carers<sup>1</sup> 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)<sup>2</sup>. 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 2013<sup>2</sup>. 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 diagnosed<sup>13</sup>.

# 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.<sup>3</sup> 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.<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup>

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.<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup>

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.<sup>10</sup> 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.<sup>11,12</sup> 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.<sup>2</sup> 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.<sup>13</sup> 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.<sup>14</sup>

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 Care<sup>15</sup> 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.<sup>16</sup> 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](http://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](mailto:mail@bps.org.uk) Website: [www.bps.org.uk](http://www.bps.org.uk)