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Assessment, diagnosis,
care and support for
people with dementia
and their carers

A national clinical guideline

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Key to evidence statements and recommendations

Levels of evidence

- 1⁺⁺ | High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
- 1⁺ | Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias
- 1⁻ | Meta-analyses, systematic reviews, or RCTs with a high risk of bias
- 2⁺⁺ | High-quality systematic reviews of case-control or cohort studies
High-quality case-control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal
- 2⁺ | Well-conducted case-control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal
- 2⁻ | Case-control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
- 3 | Non-analytic studies, eg case reports, case series
- 4 | Expert opinion

Recommendations

Some recommendations can be made with more certainty than others. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the 'strength' of the recommendation).

The 'strength' of a recommendation takes into account the quality (level) of the evidence. Although higher-quality evidence is more likely to be associated with strong recommendations than lower-quality evidence, a particular level of quality does not automatically lead to a particular strength of recommendation.

Other factors that are taken into account when forming recommendations include: relevance to the NHS in Scotland; applicability of published evidence to the target population; consistency of the body of evidence; and the balance of benefits and harms of the options.

- R** | For '**strong**' recommendations on interventions that '**should**' be used, the guideline development group is confident that, for the vast **majority** of people, the intervention (or interventions) will do more good than harm. For '**strong**' recommendations on interventions that '**should not**' be used, the guideline development group is confident that, for the vast **majority** of people, the intervention (or interventions) will do more harm than good.
- R** | For '**conditional**' recommendations on interventions that should be '**considered**', the guideline development group is confident that the intervention will do more good than harm for **most** patients. The choice of intervention is therefore more likely to vary depending on a person's values and preferences, and so the healthcare professional should spend more time discussing the options with the patient.

Good-practice points

- ✓ | Recommended best practice based on the clinical experience of the guideline development group.



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Every care is taken to ensure that this publication is correct in every detail at the time of publication. However, in the event of errors or omissions corrections will be published in the web version of this document, which is the definitive version at all times. This version can be found on our website www.sign.ac.uk

Scottish Intercollegiate Guidelines Network

Assessment, diagnosis, care and support for people with dementia and their carers

A national clinical guideline

First published November 2023

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1 Introduction

1.1 The need for a guideline

Dementia is a clinical syndrome of cognitive decline that includes a range of cognitive and behavioural symptoms caused by a variety of underlying pathophysiological processes. This includes Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia.^{1,2} There is overlap between the clinical symptoms and pathophysiological processes of these diseases.¹ As well as the cognitive impact, dementia has a physical, psychological, social and economic impact for both people with dementia and their carers and families, and presents challenges for society and healthcare systems.^{1,3}

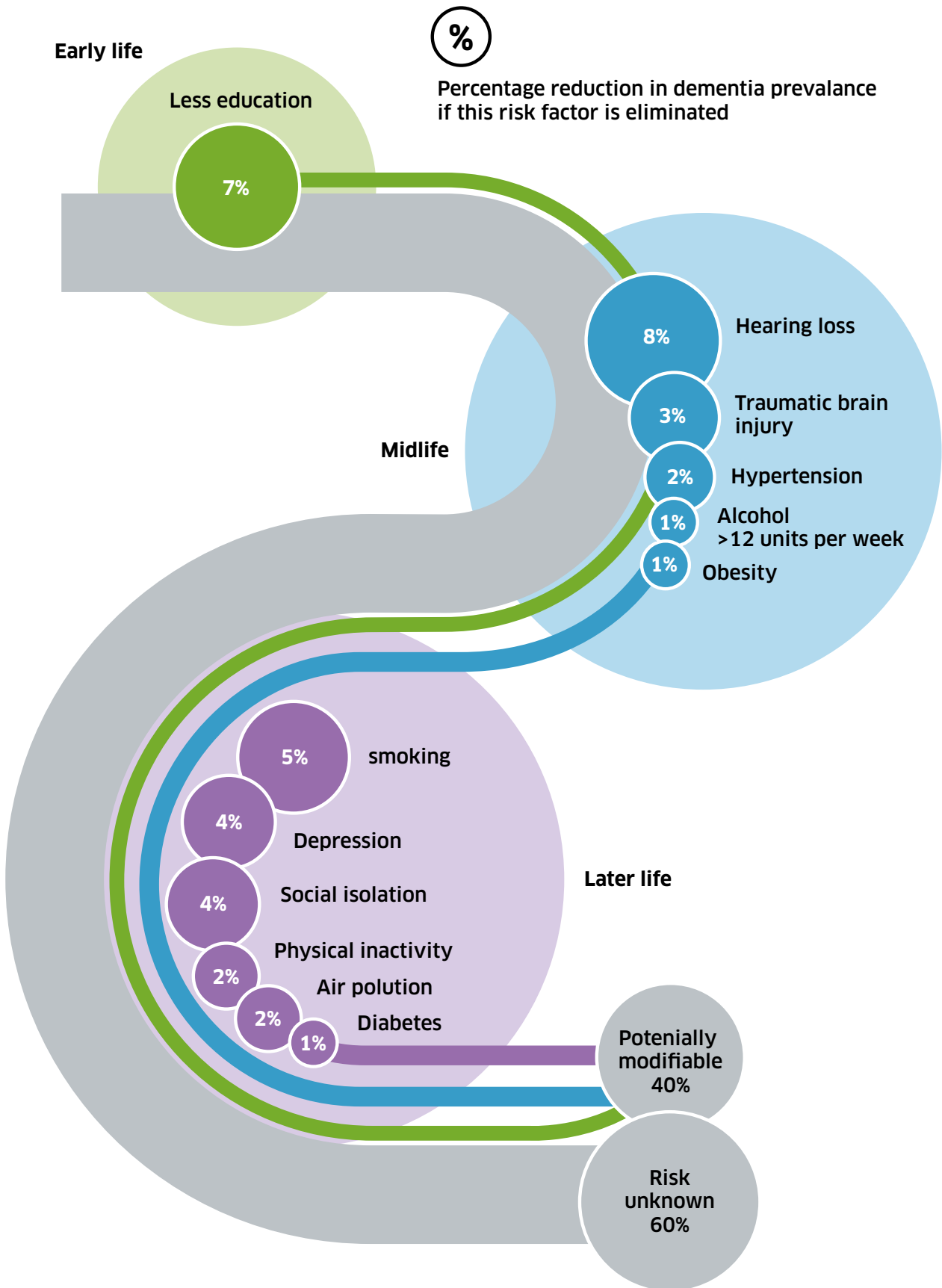
Globally, the number of people living with dementia is anticipated to increase from 57 million in 2019 to 153 million in 2050, an increase of 168%.⁴ In the UK in 2015, around 850,000 people were estimated to be living with dementia,⁵ which is equivalent to 1 in 14 people over 65 years of age or 1 in 79 of the whole population.⁵

An estimated 90,000 people are living with dementia in Scotland, an estimated 3,000 of whom are under the age of 65 (people with young-onset dementia). Around two-thirds are living at home at any one time with the remainder in acute or residential care. The latter accounts for at least 66% of the care home population in Scotland and continues to increase. The estimated annual incidence of diagnosed dementia is 20,000.²

1.1.1 Risk factors for dementia

Non-modifiable risks for dementia are age and family history (which, for the majority of people, is linked to genetic factors).⁶ The 12 most important potentially modifiable risk factors for dementia are: less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury and air pollution (*see Figure 1*).⁷

Figure 1: The life course model of potentially modifiable risk factors for dementia



Source: Lancet commission 2020⁷

1.1.2 Socioeconomic impact

People with dementia are frequently admitted to hospital, often with illnesses that could be managed at home. The current cost of dementia to the UK is £26 billion,⁸ consisting of informal care at £11.6 billion (44.2%), social care £10.3 billion (39.0%) and healthcare £4.3 billion (16.4%).⁵ If the onset of dementia were delayed by 5 years in each individual, it would amount to overall savings of £21.2 billion a year by 2050.⁸

The COVID-19 pandemic had a profound impact not only on health services, but also on wider socioeconomic factors. People with dementia died disproportionately during the pandemic.⁷ [The Dementia and COVID-19: action plan](#) outlined the response to the COVID-19 pandemic and how to extend that response to continue to support people with dementia and their carers.

1.1.3 Policies and strategy

[The Charter of Rights for People with Dementia and their Carers in Scotland](#) takes a human rights-based approach to 'empower people with dementia, those who support them and the community as a whole, to ensure their rights are recognised and respected.' These principles are the foundations of Scottish Government policy and strategy for dementia.⁹

[The dementia strategy for Scotland, Everyone's Story](#) sets out a shared vision for the next 10 years 'where people living with dementia have their strengths recognised, their rights upheld, and where they, their families and care partners/unpaid carers are supported to live an independent life, free from stigma and with person-centred treatment and care, when and where they need it.'¹⁰

The strategy calls for:

- a recognition of the condition in public health as a whole life experience
- an understanding of dementia across policy makers, support and service providers, communities and society
- equity of access to information, advice, treatment, care and support for people with dementia and carers
- upholding people's human rights
- a skilled, knowledgeable and informed workforce

The delivery of the strategy is supported by the [Promoting Excellence Education Framework](#),¹¹ a framework for health and social care staff working with people with dementia, their families and carers, along with the [Standards of Care for Dementia in Scotland](#).¹²

The importance and recognition of the role of carers is supported in legislation.¹³ The Carers (Scotland) Act 2016 (effective from 1 April 2018) 'extends and enhances the rights of carers in Scotland to help improve their health and wellbeing, so that they can continue to care, if they so wish, and have a life alongside caring.' Key to this legislation is a statutory responsibility on local authorities, health boards and health and social care partnerships to provide adult carer support plans and young carer statements and for health boards to involve carers in hospital discharge.

1.1.4 Dementia and health inequalities

Few large-scale studies have investigated social inequalities in dementia. It is recognised that health inequalities persist into old age and that many of the risk factors for dementia are associated with socioeconomic disparities in mortality and morbidity.¹⁴

In relation to personal characteristics, Public Health Scotland reported variations as follows:

- Gender - 67% of people with dementia are women.
- Age - the risk of dementia increases with age. Estimated prevalence rates increase from 0.1% of people under the age of 64 years to 15.9% of people aged over 80 years.

- Learning disability – the rate of dementia is higher amongst people with a learning disability and onset is often earlier. Up to 75% of people with Down's Syndrome who are older than 50 years develop dementia. For those with other causes of learning disability the prevalence of dementia is estimated to be greater than 18% in those aged 65 years or over, approximately three times higher than in the general population.
- Ethnicity – the estimated prevalence rates for dementia in the black and ethnic minority community are similar to the rest of the population, with the exception of young-onset and vascular dementia, which have been found to be more prevalent.¹⁴
- Carers – it is recognised that informal carers of people living with dementia are disproportionately female and often from areas of socioeconomic deprivation.

This list is not exhaustive and other groups may also experience inequality.

The care and support, including diagnostic pathways, for people of protected characteristics under the Equality Act (2010) requires further development.¹⁵ It is known that many of these groups are under-represented in terms of the number of people diagnosed with dementia, and current services do not fit well with their needs.¹⁵ A report and recommendations by The National Advisory Group, [Dementia and equality – meeting the challenge in Scotland](#), highlighted key themes to take forward, including raising awareness, ensuring robust services and support pathways, ensuring appropriate knowledge and skills, and research.

1.1.5 Variation in practice

The National Dementia Strategy recognises the importance of equity of access to services for timely diagnosis. Variations in access to these services, along with variations in the form these services take, are evident throughout Scotland and its care settings.¹⁰

A scoping exercise of neurodegenerative disease clinics in Scotland providing assessment and treatment of cognitive complaints (eg dementia services, older adult mental health services)¹⁶ found that services specialising in assessing primary clinical dementia syndrome showed significant variation across Scotland. Cognitive clinics (also referred to as memory clinics), which provide clinical assessment for individuals with cognitive complaints or suspected neurodegenerative disease were found to have no standardised approach to the assessment of cognitive complaints and variation in the implementation of assessment and care pathways. Information about dementia on health board websites, and the ease of access to relevant information for people with dementia was also variable.¹⁶ Evaluation of responses from approximately 58 clinics or services providing assessment or treatment for cognitive complaints found the majority of respondents did not mention involvement of psychiatry or neurology in their care, home visits, postdiagnostic support, young-onset services or remote appointment options. Psychiatry was referred to most often (36% of respondents).¹⁶

A UK-wide survey of people with young-onset dementia and carers identified the need for specialist services for people with young-onset dementia to be commissioned, and the importance of stability of these services for continuity.¹⁷⁻¹⁹ In Scotland, variation in services for people with young-onset dementia includes a lack of appropriate pathways for diagnosis, prolonged pathways and a lack of, or variation in, age-appropriate services for those with young-onset dementia.

A further area of variation in Scotland is the treatment of cognitive and non-cognitive symptoms of dementia, including comorbid emotional disorders. Stress and distress behaviours are common in people with dementia, particularly as the condition advances. A wide range of pharmacological and psychological interventions are available, reflecting individualised complex needs and the changing pattern of symptoms during the illness. However, there is variation in the availability of psychological approaches, training and ongoing support and supervision.

Quality improvement programmes in Scotland have shown that progress is being made.^{20,21} and there is potential to improve clinical practice and reduce variation in the assessment and non-pharmacological management of the condition for people with dementia. All healthcare professionals working with people with dementia need to assume responsibility for detection and treatment. Those working in long-term care settings should be able to recognise dementia, and support and monitor those in their care.

1.1.6 People with lived and living experience and carers' perspectives

People with lived and living experience and carers may have different perspectives on healthcare processes and outcomes from those of healthcare professionals. The involvement of people with lived and living experience in guideline development is therefore important to ensure that guidelines reflect their needs and concerns and address issues that matter to them. Where the evidence has referred to the term 'lived experience', this has been used in the guideline text.

At the start of the development of this guideline voluntary organisations were asked to identify issues of importance for people with lived and living experience and carers. These included Alzheimer Scotland, Alzheimer Scotland's National Dementia Carers Action Network, Carers Scotland, Carers Trust Scotland, Carer Voices (The Alliance), Together in Dementia Everyday (TIDE), Age Scotland, About Dementia, Life Changes Trust, the Scottish Dementia Working Group, Alzheimer's Society, Young Dementia UK, Minority Ethnic Carers of People Project (MECOPP), LGBT Health and Wellbeing and the Scottish Older People's Assembly.

Common issues raised by people with lived and living experience and carers' groups included:

- Diagnosis
 - Who should communicate a diagnosis of dementia?
 - Information is lacking at diagnosis
- Support, education and training
 - Support and training for carers
 - Education and training for healthcare professionals (particularly GPs and hospital staff)
- Postdiagnostic support for those with dementia and their carers
- Information and communication
 - Communication with people and families
 - Information needs throughout care
 - Communicating with people with advanced dementia
- Follow up
 - The frequency of review appointments and how the person with dementia should be involved
- Coproduction and equality
 - Equal partnerships and involvement of the person with dementia
- Transition between settings and support for transition
- Physical activity
 - Keeping people mobile in care settings
- Age at onset of dementia
 - young-onset dementia
- The impact of the COVID-19 pandemic

1.1.7 Lived and living experience evidence base

Although there is a growing interest in and awareness of the importance of integrating lived and living experience in health research, the development of this guideline has exposed gaps in the evidence base. High-quality studies of the perspectives of family carers of people living with dementia were identified. However, the direct lived and living experience of people with dementia is, with a few small exceptions, noticeably absent from the research.

To overcome this absence, a range of resources highlighting lived and living experiences was identified, including reports and websites from a wide range of organisations: TIDE, Alzheimer Scotland, Age UK, Young Dementia UK, The Alliance, Alzheimer's Society, Age Scotland, About Dementia and Life Changes Trust. These video, audio and written experiences provided rich and diverse information, but few outlined any specific research methodology. Themes, information and quotes from published qualitative syntheses were identified and extracted, and where possible, cross-referenced with online experiences, stories and resources. Many of the key themes identified mirrored those from the consultation.

For people with dementia:

- Living with change and striving for continuity
- Acceptance or avoidance
- Coping, participation, sense of agency and identity
- Relationships, connectedness and hope
- Loss, isolation and loneliness
- Frustration and confusion
- Stigma

For people with young-onset dementia:

- Delays to diagnosis or misattribution of symptoms
- Biographical disruption, finding acceptance
- Uncertainty, adaptation and coping
- Reduced participation and social isolation
- Losses, including loss of self identity
- Shock, anger, sadness, frustration and anxiety
- Stigma and exclusion

For people with dementia living in nursing homes:

- Boredom and monotony
- Loss of identity
- Maintaining freedom and choice
- Meaningful relationships
- Mobility and independence

For carers:

- Role changes
- Financial worries
- Crisis, acceptance, adaptation
- Personal satisfaction and hope
- Stress, loss, guilt, obligation
- Social isolation
- Frustration around formal support

For lesbian, gay, bisexual, trans, queer (or sometimes questioning), and others (LGBTQ+):

- Double stigma, an added challenge
- Anticipated and experienced homophobia/discrimination
- Safety and concealment
- Recognition of same-sex partnerships

For people from ethnic minority groups:

- Deficits in knowledge of professionals and community members
- Lack of awareness of services
- Stigma, denial and concealment
- Lack of trust
- Cultural appropriateness of services

For people with dementia and their carers during the COVID-19 pandemic:

- Separation and loss
- Confusion, despair and abandonment
- Stress and exhaustion

Summaries of the qualitative literature and consultation were considered by the guideline development group at the initiation of the guideline and throughout the guideline development process to consider what matters to people with dementia and their families and carers.

1.1.8 Information points

Information points, to support informed discussion with people with dementia or suspected dementia, their families and carers, are denoted throughout the guideline with the symbol **i**. Further information for people with lived and living experience, their families and carers can be found in section 9.

1.2 Remit of the guideline

1.2.1 Overall objectives and scope of the guideline

This guideline provides recommendations based on current evidence for best practice in the assessment, care and support of adults with dementia. The guideline applies to all settings, including home, long-term care, care homes, hospital, hospice, day-care centres and primary care. Person-centred care should be the focus of the implementation of this guideline.

The focus for this guideline is adults living with dementia. Older people with dementia represent the majority of people living with dementia in Scotland, however young-onset dementia in adults is also included. The guideline covers the adult population, as a true dementia in children (ie an incident, progressive, neurodegenerative disorder) is extremely rare.

There are specific subgroups of the dementia population and types of dementia that have highly specialist needs, and the guideline development group agreed that covering these groups in this guideline would not provide the in-depth information required to support such groups. Two examples are dementia in people with learning disabilities and those with alcohol-related dementia. Sources of further information about dementia in people with learning disabilities are listed in section 9.4.

Prevention of dementia is a rapidly evolving area and would need its own guidance to do justice to the field, and as such was also considered by the guideline development group to be out of scope.

1.2.2 Context

Perspectives were sought from stakeholders across Scotland, including people living with dementia and their carers, on the remit of the guideline. Taking these into account the guideline development group agreed to prioritise areas where specific guidance was needed for Scotland.

The National Institute for Health and Care Excellence (NICE) guideline on dementia: assessment, management and support for people living with dementia and their carers was published in 2018.²² To avoid duplication this guideline refers to the NICE guideline and other professional agencies where relevant. As an example, we do not provide recommendations around the use of cognitive enhancing medication in people with dementia as the guideline development group agreed with the guidance provided in the NICE guideline.²²

1.2.3 Comorbidities to consider when managing the care of people with dementia

People living with dementia who are over 65 years of age have on average four comorbidities, compared with people without dementia, who have two on average.²³ Over 90% of people living with dementia have another health condition, the most common being hypertension (53%), painful conditions (34%) and depression (24%).²⁴ Common comorbidities that have been considered when reviewing the evidence for this guideline are as follows:

- critical illness
- other types of dementia
- delirium
- depression
- frailty
- head injury
- neurological diseases, including Parkinson's disease and cerebrovascular disease
- cardiovascular disease
- vascular disease
- psychological/behavioural issues
- Down's syndrome
- learning disabilities.

1.2.4 Target users of the guideline

This guideline will be of interest to primary and secondary healthcare professionals, social care professionals, community, care home and care at home staff involved in the care of people at risk of, or diagnosed with, dementia, as well as people living with dementia and their families and carers.

1.2.5 A version for people and carers with lived and living experience

A version of this guideline for people with lived and living experience and carers is available from the SIGN website, www.sign.ac.uk.

1.3 Definitions

1.3.1 Mild cognitive impairment

A diagnosis of mild cognitive impairment (MCI) is often given in the early stage of Alzheimer's disease.²⁵ There is a broad range of symptoms associated with MCI, including impact on mental processes (eg attention and memory) and behavioural changes (eg apathy, anxiety or irritability), meaning it is difficult for clinicians to associate them with a single condition in the early stages.²⁵ Studies suggest that each year around 8- 15% of individuals with MCI will go on to develop dementia.

However, symptoms can also be indicative of many other medical conditions and it is estimated that in a quarter of cases individuals with MCI will return to full cognitive functioning.²⁵ There are no guidelines for the diagnosis, treatment or follow up of people with MCI leading to a lack of consistency and standard practice.²⁵ This guideline focuses on dementia and makes reference to MCI only in relation to diagnostic investigations. In the International Classification of Diseases, version 11 (ICD-11) this condition is reclassified as mild neurocognitive disorder, however, as the research consistently uses MCI, this is the terminology used in this guideline.

1.3.2 Dementia

In ICD-11 dementia is characterised by the presence of marked impairment in two or more cognitive domains relative to that expected given the individual's age and general premorbid level of cognitive functioning, which represents a decline from the individual's previous level of functioning. Memory impairment is present in most forms of dementia, but cognitive impairment is not restricted to memory (ie there is impairment in other areas such as executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities). Neurobehavioural changes may also be present and, in some forms of dementia, may be the presenting symptom. Cognitive impairment not attributable to normal aging and severe enough to significantly interfere with independence in an individual's performance of activities of daily living is presumed to be attributable to an underlying acquired disease of the nervous system. This can include trauma, infection or other disease process affecting the brain, or use of specific substances or medications, nutritional deficiency or exposure to toxins, or the aetiology may be undetermined, but not due to current substance intoxication or withdrawal.²⁶

1.3.3 Dementia due to Alzheimer's disease

According to ICD-11 memory impairment is typically the initial presenting complaint of dementia due to Alzheimer's disease. The characteristic course is a slow but steady decline from a previous level of cognitive functioning with impairment in additional cognitive domains (such as executive functions, attention, language, social cognition and judgement, psychomotor speed, visuoperceptual or visuospatial abilities) emerging with disease progression. Dementia due to Alzheimer disease is often accompanied by mental and behavioural symptoms such as depressed mood and apathy in the initial stages of the disease and may be accompanied by psychotic symptoms, irritability, aggression, confusion, abnormalities of gait and mobility, and seizures at later stages. Positive genetic testing, family history and gradual cognitive decline are highly suggestive of dementia due to Alzheimer disease.²⁷ A definitive diagnosis of Alzheimer's disease can be made when both the pattern of illness outlined above is present and a postmortem examination²⁸ demonstrates the typical supporting pathological features of amyloid plaques and neurofibrillary tangles.²⁹

MCI due to Alzheimer's disease is defined as concern reflecting a change in cognition by the individual or an informant, with objective evidence of impairment in one or more cognitive domain, but with the preservation of independent functional abilities.²⁸ People meeting this clinical criterion who also have amyloid-beta (A β) biomarkers on cerebrospinal fluid (CSF) immunoassay and neuronal injury on positron emission tomography (PET) have the highest likelihood of MCI due to Alzheimer's disease.

1.3.4 Vascular dementia

Vascular dementia is a result of significant brain parenchyma injury from cerebrovascular disease (ischaemic or haemorrhagic). The onset of cognitive deficits is temporally related to one or more vascular events. Cognitive decline is typically most prominent in the speed of information processing, complex attention and frontal-executive functioning. There is evidence that the presence of cerebrovascular disease is sufficient to account for neurocognitive deficits in an individual's history, physical examination and neuroimaging.³⁰

1.3.5 Dementia due to Lewy body disease

The precise aetiology is unknown but involves abnormal alpha-synuclein protein folding and aggregation with Lewy body formation primarily in the cortex and brainstem. Onset is insidious with attentional and executive functioning deficits typically reported as the initial presenting complaint, often accompanied by visual hallucinations and symptoms of rapid eye movement sleep behaviour disorder. Hallucinations in other sensory modalities, depressive symptoms, and delusions may also be present. Spontaneous onset of Parkinsonism within approximately 1 year of the onset of cognitive symptoms is characteristic of the disease.³¹ The Dementia with Lewy Bodies (DLB) Consortium consensus criteria provides guidance on optimal methods of establishing and interpreting clinical features and diagnostic biomarkers.³²

1.3.6 Frontotemporal dementia

Frontotemporal dementia is a group of primary neurodegenerative disorders primarily affecting the frontal and temporal lobes. Onset is typically insidious with a gradual and worsening course. Several syndromic variants (some with an identified genetic basis or familiarity) are described that include presentations with predominantly marked personality and behavioural changes (such as executive dysfunction, apathy, deterioration of social cognition, repetitive behaviours, and dietary changes) or with predominantly language deficits (that include semantic, agrammatic/non-fluent, and logopenic forms), or with a combination of these deficits. Memory function, psychomotor speed, as well as visuoperceptual and visuospatial abilities often remain relatively intact, particularly during the early stages of the disorder.³³

1.3.7 Other types of dementia

Other types of dementia include dementia due to psychoactive substances (including medications), or other diseases, behavioural or psychological disturbances. Dementia may also be due to an unknown or unspecified cause.³⁴

According to ICD-11 mixed dementia includes dementia presenting with both Alzheimer's and vascular pathology or other nonvascular aetiologies contributing to the dementia.³³⁻³⁶

1.3.8 Young-onset dementia

The terms 'younger people with dementia,' 'early-onset' of dementia, 'working-age dementia' and 'young-onset dementia' are widely used interchangeably for people with dementia who are younger than 65 years.³⁷ This guideline uses the term 'young-onset dementia'.

Young-onset dementia may have an atypical presentation. The differential diagnosis is broader, and there may be additional psychosocial implications, for example in relation to employment and having a younger family, and potential implications around genetic predisposition to consider.

1.3.9 Stages of dementia: mild, moderate and severe

The experience of dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socioeconomics. However, some general definitions are helpful in assessing the stage of dementia that an individual has reached.

A diagnosis of dementia may occur at any stage. A new diagnosis of dementia does not necessarily mean that the illness is at an early stage. A formal diagnosis informs appropriate management and care, even when dementia is advanced.

This guideline follows ICD-11 diagnostic criteria for staging, with the exception of advanced dementia, for which the definition from the European Palliative Project is used.^{26,38}

Mild dementia: people with mild dementia may be able to live independently, but some supervision or support is often required. However, they can still take part in community or social activities without help and may appear unimpaired to those who do not know them well. Judgment and problem solving are typically impaired, but social judgment may be preserved, depending on dementia etiology. The individual may have difficulty making complex decisions, making plans, and/or handling finances (eg calculating change, paying bills).

Moderate dementia: people with moderate dementia require support to function outside the home and only simple household tasks are maintained. They have difficulties with basic activities of daily living, such as dressing and personal hygiene. Moderate dementia is often characterised by significant memory loss. Judgment and problem solving are typically significantly impaired, and social judgment is often compromised. The individual has increasing difficulty making complex or important decisions and is often easily confused. They may have difficulty communicating with people outside the home without caregiver assistance. Socialising can be increasingly difficult as behaviour may become inappropriate (eg disinhibited or aggressive), with associated behaviour changes (eg calling out, clinging, wandering, disturbed sleep, or hallucinations).

Severe dementia: people with severe dementia typically have severe memory impairment, but this varies according to the etiology. They often have total disorientation for time and place and have difficulty understanding what is happening around them. Individuals are often completely unable to make judgments or solve problems and are fully dependent on others for basic personal care in activities such as for bathing, toileting and feeding. Urinary and fecal incontinence may emerge at this stage.

Advanced dementia: advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of healthcare needs and risks. People with advanced dementia-related health needs require expert health care, nursing and palliative care assessments, together with insights provided by carers and others, particularly when the person has difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness, and the advanced dementia continuum includes the terminal stages of death and dying.^{38,39}

1.3.10 Carers

Unpaid carers are people who provide care and support to family members, other relatives, friends and neighbours.^{13,40} Other terms such as 'informal carers' and 'caregivers' are also used.

It can take time for a family member, or other relation to a person with dementia, to acknowledge their role as a carer for a variety of reasons.⁴⁰ It may only be at a time where the caring role has increased, that this becomes more evident to the carer. It is important to consider that where the recommendations refer to carers they may not have acknowledged that role or title.

Young carers are those who provide unpaid care under the age of 18, or are 18 or over, but still attending school, and are providing (or intend to provide) care for another person.¹³

The term 'carer' is used in this guideline and 'adult carer' or 'young carer' when either are referred to specifically.

Paid carers may also support the carer and the person living with dementia. Where our recommendations, good practice points and information points refer to carers, this means unpaid carers. Otherwise, paid carers are included in the term 'health and social care professionals' (see next section).

1.3.11 Multidisciplinary sector and team approach to care

Because of the international context of the evidence base, the majority of the studies reviewed for this guideline referred to healthcare professionals, so the text and recommendations reflect this terminology. In Scotland, a wider multiprofessional, multisector approach is taken, in line with the integration of health and social care, and this is reflected in good practice points. Where a recommendation directly impacts on other professional domains (eg social work, care home provision), the term health and social care professionals has been used.

The term 'management' has been used through this guideline for brevity and consistency, but the central tenet of dementia care throughout this document is that it is person-centred and responsive to the array of dementia-related symptoms and needs. The guideline development group recognises that language is important and have been guided by various stakeholders around terminology for this guideline, eg the use of 'management of the condition' where appropriate.

1.4 Statement of intent

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results.

The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at through a process of shared decision-making with the individual, covering the diagnostic and treatment choices available. Family/carers should be involved in decision making about diagnosis and treatment if the person with dementia wishes it, or if the person with dementia lacks capacity and the family/carer has Power of Attorney for Welfare, or a guardianship order is in place. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be documented in the person's medical records at the time the relevant decision is taken.

1.4.1 Influence of financial and other interests

It has been recognised that financial or academic interests may have an influence on the interpretation of evidence from clinical studies.

It is not possible to completely eliminate any possible bias from these sources, nor even to quantify the degree of bias with any certainty. SIGN requires that all those involved in the work of guideline development should declare all financial and academic interests, whether direct or indirect, annually for as long as they are actively working with the organisation. By being explicit about the influences to which contributors are subjected, SIGN acknowledges the risk of bias and makes it possible for guideline users or reviewers to assess for themselves how likely it is that the conclusions and guideline recommendations are based on a biased interpretation of the evidence.

Signed copies of declaration of interests forms are retained by the SIGN Executive and are available on request from the SIGN Executive.

2 Key recommendations

The following recommendations were highlighted by the guideline development group as the key clinical recommendations that should be prioritised for implementation.

2.1 Identification and diagnosis of dementia

R | Healthcare professionals should ensure that the discussion of a diagnosis of dementia should include positive and hopeful, yet realistic, messages; information on prognosis and sources of support; information on wellbeing and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia.

2.2 Anticipatory care planning

R | Anticipatory care planning may involve a series of conversations over time, to allow clarification, reflection and updates to the plan to reflect any changing needs. Early discussions are beneficial, as the capacity of the person with dementia diminishes as the disease progresses.

✓ | Anticipatory Care Planning decisions should be reviewed and updated; the frequency of this will be influenced by the pace of disease progression and any changing needs.

2.3 Post diagnostic support

R | Postdiagnostic support should incorporate continuity of care, including a 'one-stop' service or single point of contact, a single professional or case manager. This should be a healthcare or social care professional with appropriate skills, knowledge and expertise in dementia (see the [Promoting Excellence Framework](#))¹¹, working with the GP, to ensure a tailored support package is delivered in a timely manner.

2.4 Grief and dementia

R | Healthcare professionals should be aware that carers of people with dementia may experience pre-death grief from the point of diagnosis and throughout the stages of dementia, and sensitively enquire about these experiences:

- worsening pre-death grief as dementia becomes more severe
- worsening pre-death grief at transition points, such as when the person with dementia is moved to long-term care.

2.5 Non-pharmacological approaches for distressed behaviours

R | For managing distressed behaviour symptoms in people with dementia, tailored activities based on a comprehensive structured assessment may be considered. Activities should be individualised, focus on preserved capabilities and consider previous roles, interests and preferences.

R For carers of people with dementia, provision of tailored psychoeducation and skills training may be considered.

Components may include:

- problem solving
- identifying triggers
- coping strategies for distressed behaviour
- stress reduction
- cognitive restructuring
- communication skills
- crisis management.

2.6 Changing needs of people with dementia

R Healthcare professionals should be aware that existing measures to define end of life in people with dementia based on cognition and ambulatory function may be ineffective and may not recognise the unmet needs at end of life.

Healthcare professionals should focus on the needs of the individual and consider moving away from a focus on defining end of life by disease stage.

3 Identification and diagnosis of dementia

The diagnosis of dementia is a clinical diagnosis, based on information from different sources.

NICE guidance indicates that a diagnosis of dementia should be made following an appropriate clinical assessment by a clinician with knowledge of dementia (including an appropriate neurological examination and cognitive testing).²² Blood tests should be undertaken to exclude reversible causes of cognitive decline if these have not already been addressed. Neuropsychology testing can be considered if it is unclear:

- whether the person has cognitive impairment or
- whether the cognitive impairment is caused by dementia or
- what the correct subtype diagnosis is.

3.1 Identification and assessment of suspected dementia

Assessment of dementia is based on a history and examination which will ideally include information from an informant, usually a family member or carer. A diagnosis should be made in line with ICD-11, most often in the context of a multidisciplinary team assessment, and should demonstrate significant declines in cognition and functioning.

This section covers tests that can be used to assess cognition, however, it is important to note that these are one part of the assessment process, which can often be complex, with a level of uncertainty. Differential diagnosis can be wide when considering both other causes of cognitive impairment such as delirium and depression, and the wide range of causes of dementia. Further in depth cognitive testing, functional assessment, and imaging (eg magnetic resonance imaging (MRI) and computerised tomography (CT)) and other investigations can help with diagnosis but may extend the time to diagnosis.

3.1.1 Brief cognitive tests

Cognitive tests can identify the need for specialist input to help with a diagnosis of dementia.

Many brief cognitive tests are available that can be used in non-specialist settings, including primary care (*see Table 1*).⁴¹ Brief cognitive tests are defined in the context of this guideline as taking less than 30 minutes to complete. These tools are not diagnostic on their own, but can be used to identify people who might benefit from referral for specialist dementia assessment. Most of these tools were developed for use in specialist memory services. Domains assessed include attention, temporal orientation, memory (immediate and delayed recall), visual motor skills, executive function, judgement and language. There is overlap between tests, for example several include questions on temporal orientation and clock drawing.

Factors to be considered in the selection of an appropriate instrument include adequate accuracy for identifying dementia, ease of administration and interpretation, including the time and equipment needed and consideration of cost and training requirements. Many instruments have been translated into a range of languages and some are applicable across language abilities and cultural contexts, making them appropriate for a wide range of people.

Findings from diagnostic accuracy studies are dependent on the setting of use, including the patient population and the expertise of those administering and interpreting the test, and on the test cut-off values or interpretation methods.²² The majority of studies that compare brief cognitive tests with gold standard diagnostic criteria dementia for have been conducted in secondary care settings. Where studies have been conducted outside of secondary care the inclusion of asymptomatic people means that findings may not be transferable to the clinical situation where a person presents with symptoms.

3.1.2 In-person testing

High test sensitivity (the ability of the test to correctly identify people with dementia) is desired for testing symptomatic people in primary care. Systematic reviews combining studies of varying quality across specialist and non-specialist settings, where at least one included study had a sensitivity of 80% with an acceptable specificity (the ability of the test to correctly identify people without dementia) of 70% or higher included the Mini Mental State Examination (MMSE),^{22,42} Mini-Cog,^{22,43,44} Addenbrooke's Cognitive Examination 3 (ACE3),^{22,45} Mini-ACE,⁴⁵ Six-item Cognitive Impairment Test (6-CIT),²² six-item screener,^{22,46} Montreal Cognitive Assessment (MoCA),^{22,47} Memory Impairment Screen,²² Clock Drawing Test (CDT),^{22,48} and Rowland Universal Dementia Assessment Scale (RUDAS).^{22,49}

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No systematic reviews of the recently introduced Free-Cog were identified. Two studies in the secondary care setting found acceptable sensitivity and specificity. Neither compared Free-Cog to the gold standard dementia diagnostic criteria.^{50,51}

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The sensitivity and specificity of the General Practitioner Assessment of Cognition (GPCOG) is based on studies in mixed symptomatic and asymptomatic populations.⁵²⁻⁵⁴

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3.1.3 Informant questionnaires

For tests that rely on an informant (someone with sufficient knowledge of the person with suspected cognitive problems, usually a family member or carer) completing a questionnaire, the following were identified as having acceptable sensitivity and specificity: the Eight-item Informant Interview to Differentiate Aging and Dementia (AD8)⁵⁵ and Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE).^{22,56,57}

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3.1.4 Self-completion questionnaires

Test Your Memory (TYM), a tool requiring minimal assessor input, had acceptable sensitivity and specificity.²²

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3.1.5 Remote testing

A Cochrane review found six studies on the accuracy of multidomain tools for remote cognitive testing by telephone.⁵⁸ Tests included those designed for remote use as well as modified forms of in-person tools. Study populations varied widely, with study settings including community, outpatient and inpatient clinics. Most testing was done by clinical psychologists. The primary analysis included multidomain cognitive tests for which there were studies exploring diagnostic accuracy by comparison to a clinical diagnosis of dementia. Case-control test validation studies were excluded, as were studies with fewer than 10 participants.

Telephone-based tools that had high sensitivity and specificity in at least one study included the Adult Lifestyles and Function Interview (ALFI-MMSE), which incorporates the MMSE (sensitivity 94% and specificity 84% at cut-off 15), and the Tele-Free-Cog (sensitivity 90% and specificity 83% at cut-off 20). Cut-off points are not universally agreed, hence the inclusion of those used in these tools.

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No studies were identified on the telephone Montreal Cognitive Assessment (tMoCA) or telephone Addenbrooke's Cognitive Assessment (tACE).

In a secondary analysis, six studies compared the Telephone Interview for Cognitive Status modified (TICS_m) with a range of in-person equivalent tools. In one study the sensitivity was 92% with specificity 74% when compared with the MMSE at cut-off 14.

In the Cochrane review six studies compared the telephone version of the MMSE with various versions of the in-person test.⁵⁸ Correlations between the tests were moderate to strong ($r=0.69$ to 0.85). Mean test scores of video-call and in-person MMSE were comparable in one study, higher in the remote test in three studies and lower in two studies. RUDAS scores were lower in video calls in one study and comparable in another.

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The Cochrane systematic review also identified one study that carried out video-based testing using the RUDAS and reported sensitivity of 80% and specificity of 91% for dementia.⁵⁸

An overlapping systematic review included a wider group of studies, as it encompassed case-control designs.⁵⁹ There is evidence that studies comparing patients with known disease with a control group without the condition tend to exaggerate diagnostic accuracy. In pooled analyses of accuracy for dementia, TICS at cut-off <28 had sensitivity 87% and specificity 77% (five studies) and TICSm at cut-off <28 had sensitivity 91% and specificity 91% (three studies).

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No evidence was identified to recommend one cognitive test over another. Table 1 shows the brief cognitive tests with suitable diagnostic accuracy to identify people who would benefit from referral to secondary care. The table gives information to allow clinicians to pick the most suitable test for their setting and situation.

Table 1: Brief cognitive tests considered suitable for use based on acceptable diagnostic accuracy to identify individuals who might benefit from referral to secondary care

Test	Time to complete (minutes)	Free of charge to NHS? ^a	Formal specific training required?	Person requires written English / literacy skills?
Rapid direct tests				
6-CIT ²²	<5	Yes	No	No
CDT ⁴⁸	<3	Yes	No	No
GPCOG ⁵²⁻⁵⁴ b	2-5	Yes	Minimal	No
Memory Impairment Screen ^b (MIS) ²²	<4	Yes	No	Yes
Mini-ACE ^{22,45}	<5	Yes	Yes	No
Mini-Cog ^{22,44}	<3	Yes	Minimal	No
Six-item Screener (SIS) ^{22,46}	1-2	Yes	No	No
Extended direct tests				
Addenbrooke's Cognitive Examination (ACE) ^{22,45}	10-30	Yes	Yes ^c	Yes
Free-Cog ^{50,51}	5-10	Yes	No	Yes
Mini Mental State Examination (MMSE) ^{22,42,60}	10-15	No	Yes	Yes
Montreal Cognitive Assessment (MoCA) ^{22,29,47}	10-20	Yes (training certification cost)	Training certification required	No
Rowland Universal Dementia Assessment Scale (RUDAS) ^{22,49}	10-15	Yes	Minimal	No

Test	Time to complete (minutes)	Free of charge to NHS? ^a	Formal specific training required?	Person requires written English / literacy skills?
Informant questionnaires				
AD-8 ^{22,55}	<3	No (permission required)	No	No
IQCODE ^{22,56,57}	5-7	Yes	No	No
Self-completion (minimal healthcare practitioner supervision)				
Test Your Memory (TYM) ²²	5-10	Yes	No	Yes
Remote assessment^{22,58,59}				
Tele-Free-Cog	15-20	Yes	No	No
Telephone Interview for Cognitive Status - modified (TICS _m)	15-20	Yes	No	No
Telephone Interview for Cognitive Status (TICS)	10-20	No	Yes	No
Tele-MMSE	10-15	No	Yes	No
<p><i>a 'Yes' indicates that tests are available under creative commons licence or offered free of charge for clinical use by the copyright holders or test developers at November 2023.</i></p> <p><i>b The assessment requires an informant interview for full scoring.</i></p> <p><i>c Training available for NHS staff at www.muls.gla.ac.uk/aceiiiitrainer</i></p>				

3.1.6 Neuropsychological assessment

Neuropsychological assessment carried out in secondary care settings can help when dementia is not clinically obvious. This can include when there is disparity between a person's performance on brief cognitive testing and their presentation, when it is unclear if a person's cognitive impairment is caused by dementia or when it is uncertain what the correct subtype diagnosis is.²²

- R Healthcare professionals should consider using one of the following brief cognitive tests, that have acceptable diagnostic accuracy, to identify people who benefit from referral to secondary care:**
- **Rapid direct tests** (taking ≤5 minutes to complete):
Six-item Screener (SIS), General Practitioner Assessment of Cognition (GPCOG), Clock Drawing Test, Mini-Cog, Memory Impairment Screen (MIS), Six Item Cognitive Impairment Test (6-CIT), and Mini-ACE
 - **Extended direct tests** (ranging from 10 to 30 minutes to complete):
Free-Cog, Montreal Cognitive Assessment (MoCA), Rowland Universal Dementia Assessment Scale (RUDAS), Mini Mental State Examination (MMSE) or Addenbrooke's Cognitive Examination III (ACE-III)
 - **Self-completion questionnaire:**
The Test Your Memory (TYM)
 - **Informant questionnaires** (if a suitable informant is available):
AD8 or IQCODE
 - **Remote cognitive assessment** (where required):
Telephone Interview for Cognitive Status (TICS), TICS modified, Tele-MMSE and Tele-Free-Cog.

- ✓ Factors to be considered by healthcare professionals when selecting a brief cognitive test include:
 - accuracy of the test
 - time taken to complete the test
 - cost to use the test
 - training requirements in use of the test for healthcare professionals
 - ease of use for the person completing the test, considering literacy and language, additional support needs and cultural sensitivity
 - healthcare professional confidence in using the instrument, interpreting findings and feeding back the results to the person who has completed the test.
- ✓ The assessment of dementia should take into account a collateral history (eg from family members or carers) and clinical examination (mental state and focussed physical examination), and not be solely reliant on cognitive assessment.
- ✓ Differential diagnosis should be considered both in terms of the person's cognitive deficit and the other possible causes of dementia.
- ✓ Neuropsychological assessment should be considered, alongside other diagnostic approaches (as determined by a suitably trained specialist), in the diagnosis of dementia, especially for people in whom dementia is not clinically obvious.

3.2 Discussing a diagnosis of dementia

Four high-quality publications were identified addressing the 'when', 'how' and 'who' should be involved in a diagnosis of dementia discussion: three systematic reviews with 52, 54 and 23 included studies, respectively,⁶¹⁻⁶³ and one qualitative phenomenological study.⁶⁴ The question of 'where' the discussion should take place was not investigated.

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The qualitative phenomenological study included interviews conducted with informal carers or people with dementia.⁶⁴ In one systematic review 16 of the 52 included studies focused on healthcare professionals, seven on informal carers, and four on people with dementia.⁶³ The other two systematic reviews included studies on people with dementia and/or carers,⁶² or focused on communication between healthcare professionals and people with dementia and their companions.⁶¹ However, in one of these systematic reviews, only 8 out of 23 included studies focused on communication during assessment of dementia or diagnosis meetings.⁶¹

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There was a relative under-representation of UK participants, with included studies originating from the UK ranging from 9% to 23% in the reviews.⁶¹⁻⁶³ The qualitative study⁶⁴ was conducted in the USA. Participant demographics were not provided in the same detail in each of the publications, so the inclusion or exclusion of black and minority ethnic groups is not known. A range of ages of people with dementia appear to have been included, with the majority aged 65 and over; therefore, they would not include people with young-onset dementia.

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3.2.1 Who should be involved and provide a diagnosis of dementia?

There was consensus from the systematic reviews⁶¹⁻⁶³ and a qualitative study⁶⁴ that carers had an important role to play and should be present and fully engaged in meetings when a dementia diagnosis is communicated.^{61,63,64} One systematic review reported that the carer has a dual role (informant and advocate), and that their presence poses additional challenges for the professional, who needs to balance the communicative needs of the person with dementia and their carer.⁶¹ Another systematic review reported that the carer can provide reassurance to the healthcare professional, helping with communication, and can recall details of the diagnosis following the 'disclosure meeting'.⁶³ The qualitative study also highlighted a need for education on involving carers in such meetings.⁶⁴

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The evidence was equivocal for who should provide the diagnosis. One mixed-studies systematic review could not draw a conclusion from its review of 52 studies, suggesting that specialists, GPs and the wider multidisciplinary team (MDT) may all have a role.⁶³ The single qualitative study found that carers wanted to be told by a ‘caring professional,’ but did not draw conclusions on what type of professional that should be.⁶⁴ Another systematic review found that a person with dementia and the carer have a need for ‘access to health care professionals who know the disease, and respond competently at disclosure of the diagnosis, and communicate test results clearly,’ but also did not draw conclusions on any specific healthcare professional.⁶² Therefore, a variety of healthcare professionals may be involved, and their knowledge and competency may be more important than their professional role. There was, however, a lack of representation of people with dementia in the evidence base, so their preferences are not known.

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R | Healthcare professionals with specialist expertise in dementia, GPs and the wider multidisciplinary team may all be involved in discussing and providing a diagnosis of dementia. All healthcare professionals involved should be competent in discussing a diagnosis of dementia and knowledgeable about dementia.

R | Carers should be encouraged to attend, and be included as active participants in, dementia diagnosis discussions. Their role in supporting person with dementia and the healthcare professional by assisting with communication and recall of the discussion should be acknowledged.

✓ | The diagnosis of dementia should be made by a suitably trained specialist with access to the results of relevant multimodal assessments including collateral history of the person with suspected dementia (eg about symptom progression from family and carers), functional assessment (by occupational therapy, speech and language therapy, psychology, liaison psychiatry, from social work records etc) and any investigations (eg imaging).

3.2.2 When should a diagnosis take place?

There is some evidence to suggest that carers would like to receive a diagnosis at an early stage. One systematic review found that 58% of carers (95% confidence interval (CI) 43% to 72%) expressed a preference for an early diagnosis (evidenced in 13 included studies), as this may be helpful to understand behavioural problems and gain timely access to resources.⁶² The most recent systematic review found three studies reporting that participants perceived that a dementia diagnosis had been delayed.⁶³ However, one study included in this review highlighted the potential for harm to wellbeing if the diagnosis was disclosed before the person with dementia had time to process the changes that were happening to them.

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A qualitative phenomenological study of 12 carers identified the relief that accompanied a diagnosis of dementia, concurring with the view that early diagnosis is welcome:

‘So, in some ways I felt relieved about it. It didn’t come as a surprise. It was hard all those months [before receiving the diagnosis]. It was almost like it would be a relief if he had the diagnosis because it felt like things were really shifting and kind of gray. Whereas once you get the diagnosis, it feels like, okay, this is what we’re dealing with; this is what we can do.’⁶⁴

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Conclusions are unable to be drawn on the perspectives of people with dementia or healthcare professionals regarding the timing of diagnosis. There may be a range of views on what constitutes ‘early’ and ‘delayed’ diagnosis of dementia.

R | Early discussion of a diagnosis of dementia should be considered to help timely access to support and services.

R | **Healthcare professionals should consider discussing a dementia diagnosis in stages, over more than one session or as an ongoing process, allowing time for the information to be absorbed. Timings of discussions should be tailored to the needs of the person with dementia and their carer(s).**

- ✓ | When discussing a dementia diagnosis, take a person-centred approach considering:
 - whether the person with dementia has sufficiently processed the diagnosis and accepted the changes that are happening to them
 - that acceptance of a diagnosis and changes that are happening is individualised
 - the wellbeing of the person and that this discussion could have a detrimental effect on them.
- ✓ | People with undiagnosed dementia may first come into contact with healthcare professionals during an acute hospital admission or with an episode of delirium. A diagnosis should not be delayed when it can be made by an expert with support from multimodal assessments and collateral history, even if there is co-existing delirium.

Further information can be found in the SIGN guideline on risk reduction and management of delirium.⁶⁵

- ✓ | Healthcare professionals should ensure that when a diagnosis is provided, whatever the stage of dementia or the setting, the person with dementia and their carer(s) are informed about postdiagnostic support and services.

3.2.3 How should a diagnosis of dementia be discussed?

In clinical practice, prediagnostic counselling can start at the time of referral from primary care, making it clear to the person that referral is for concerns about dementia.

From the evidence, providing information or prediagnostic counselling (defined as a session that takes place in advance of a meeting to inform a person of a dementia diagnosis)⁶³ may be helpful for people with dementia and their carers. One mixed-studies systematic review recommended that information about memory assessments could be made available more widely (eg at GP surgeries and community locations), so that people knew what to expect when attending a meeting to inform the person of the diagnosis of dementia.⁶³ They reported that the diagnostic process should enable the beliefs, expectations and misconceptions that people with dementia or their carers may have to be expressed and suggested this may take place in a prediagnostic counselling session. This concurred with another mixed-studies systematic review which found a need of the person with dementia and their carer was for guidelines on dementia prior to and after diagnosis.⁶² The review also suggested that providing the dementia diagnosis in stages may assist with absorption of information, however, one included study found that 55% of participants wanted to receive the whole disclosure at once.⁶³

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The evidence highlighted the need for clarity, sensitivity and empathy in the communication of a dementia diagnosis. A systematic review of observational studies raised several ethical dilemmas for healthcare professionals: how to balance the communication needs of people with dementia and carers; how to provide clarity while moderating the emotional impact of a dementia diagnosis, and whether to minimise or expose people with dementia's interactional difficulties and misunderstandings.⁶¹ A mixed studies systematic review reported a number of findings related to the content of the dementia diagnosis discussions, including the provision of positive and hopeful, yet realistic, messages; information on prognosis and sources of support; and information on wellbeing and how the person with dementia can continue with their life, maintain their sense of

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self and accept their identity as someone with dementia.⁶³ This review also reported conflicting findings on whether terms such as ‘dementia’ and ‘Alzheimer’s disease’ should explicitly be used during the disclosure session or whether more ambiguous language may be appropriate.⁶³ } JBI 9/10 9/10

A study found that suicide risk in people with dementia younger than 65 years and within 3 months of diagnosis was 6.69 times that of than of the general population (95% CI 1.49 to 30.12).⁶⁶ } 2+

R | **GPs or professionals referring a person with suspected dementia to secondary care** (eg a memory clinic) **should make it clear to the person that they may have dementia so that they are prepared for a potential diagnosis of dementia.**

R | **Healthcare professionals should consider offering information or prediagnostic counselling** (a session that takes place in advance of a meeting to inform a person of a dementia diagnosis) **for people with dementia and their carers to:**

- **discuss and address the beliefs, expectations and potential misconceptions of people with dementia and their carers**
- **help them better absorb and understand the information provided to them.**

R | **Healthcare professionals should ensure that people with dementia and their carers have access to information before, during and after receiving a diagnosis of dementia. This includes information about memory assessments and the medical, interpersonal and behavioural aspects of dementia. Written information should be provided at the meeting to discuss diagnosis.**

R | **Healthcare professionals providing a diagnosis of dementia should do so in a clear, sensitive and empathetic manner, being aware of the differing communication needs of the person with dementia and their carer(s) and provide the opportunity for questions to be asked.**

R | **Healthcare professionals should ensure that the discussion of a diagnosis of dementia should include positive and hopeful, yet realistic, messages; information on prognosis and sources of support; information on wellbeing and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia.**

✓ | Healthcare professionals should be aware of the increased risk of suicide in people with dementia younger than 65 within 3 months of a diagnosis.

Information points

- i** Encourage the person with dementia and their carer(s) to ask questions about the dementia diagnosis and allow sufficient time for answering. A checklist covering the information people may need can be found in section 9.5.
- i** Encourage the person with dementia and their carer(s) to discuss postdiagnosis support and services.
- i** Provide a positive message about living well with a terminal, life-changing diagnosis of dementia.
- i** Discuss the importance of making plans for the person’s financial and personal welfare as soon as possible (*see section 9.5*).

4 Further investigative procedures

Following a comprehensive assessment, as set out in section 3, further investigations can be considered to help rule out other causes in people presenting with cognitive decline, or to help diagnose dementia subtype in those with a diagnosis of dementia.

The following recommendation is reproduced from the NICE guideline on assessment, management and support for people living with dementia and their carers (NG97).²²

R Offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear.

Only consider further tests if:

- **it would help to diagnose a dementia subtype and**
- **knowing more about the dementia subtype would change management.**

4.1 Diagnosing suspected Alzheimer's disease

In most cases of Alzheimer's disease a diagnosis is made based on clinical symptoms. The gold standard for a diagnosis of Alzheimer's dementia is confirmation of the typical neuropathological findings in people with symptomatic cognitive impairment.⁶⁷

Clinical diagnostic criteria for Alzheimer's disease, established by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA),⁶⁸ show good sensitivity (98%) but low specificity (69%) when compared with neuropathological confirmation.⁶⁹

4.1.1 Positron emission tomography

Positron emission tomography (PET) is a functional imaging technique that uses radioactive substances, known as radiotracers, to visualise changes in metabolic processes and other physiological activities, including blood flow.⁷⁰ A ligand that binds to or is taken up by a specific target is labelled with a radioisotope, enabling its visualisation to produce images.

Fluorodeoxyglucose (FDG)-PET, using a tracer taken up by glucose-using cells, is already established for use in dementia diagnosis.²²

Amyloid PET (aPET) utilises a ligand that binds selectively to amyloid plaques. There are three ¹⁸F-labelled aPET tracers licensed for use; ¹⁸F-Florbetaben (Neuraceq™), ¹⁸F-Florbetapir (Amyvid™), and ¹⁸F-Flutemetamol (Vizamyl™). The Amyloid Imaging Taskforce report (2013) recommends appropriate-use criteria for aPET in selected patients with MCI, atypical Alzheimer's disease, suspected mixed dementia or young onset dementia.⁷¹

There are also tau-specific PET ligands, which enable binding and visualisation of tau proteins in the brain. Tau PET is not considered here.

4.1.2 Interpreting the evidence base

Narrative reviews highlight the difficulties which arise in developing and collating the evidence base on aPET for Alzheimer's disease.^{71,72}

- While aPET positivity may correlate well with amyloid brain pathology, amyloid brain pathology does not necessarily equate to Alzheimer's disease dementia.
- Study populations vary in age and stage of dementia as well as with respect to comorbidities. Confounding of studies by age is a problem given that 20-40% of cognitively healthy people aged over 60 have elevated levels of amyloid.

- A variety of research and commercially available tracers are used.
- Methods of processing and interpreting scan images are not standardised. A range of visual and quantitative methods are encountered across the literature.
- Reference standards and how they are applied varies across studies. Gold standard neuropathological diagnosis is rarely used and since postmortem studies recruit patients at the end of life these will over represent participants with the most advanced disease.
- Many outcomes are explored including diagnostic accuracy, clinical utility and prediction of disease progression.

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4.1.3 Comparison of aPET and FDG-PET

A diagnostic accuracy study (n=101) compared antemortem aPET (using the research ligand ¹¹C-Pittsburgh compound B (PIB)) with antemortem FDG-PET for postmortem neuropathological diagnosis of dementia. Participants were recruited from academic memory research centres and there was an emphasis on early-onset dementia (mean age 67.2 years). The scan to postmortem interval was 4.4 years. At post mortem 32 participants had primary Alzheimer's disease, 56 had non-Alzheimer's disease pathology and 13 showed mixed Alzheimer's disease/frontotemporal lobar degeneration. Both aPET and FDG-PET had high accuracy for predicting intermediate-to-high Alzheimer's disease neuropathological change (ADNC) (sensitivity 96% (95% CI 89% to 100%) vs 80% (95% CI 68% to 92%); specificity 86% (95% CI 76% to 95%) vs 84% (95% CI 74% to 93%)). Amyloid PET had statistically significantly better sensitivity than FDG-PET for detection of intermediate-high ADNC. There was no significant difference in specificity between the modalities. When the two scans were congruent the sensitivity for determining AD pathology was 97% with specificity 98%. Nine out of 24 participants with incongruent scan findings had co-occurring Alzheimer's disease and non-Alzheimer's disease pathology.⁶⁰

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A database modelling study with participants from the Alzheimer Disease Neuroimaging Initiative (ADNI) database (n=319, average age 72–73 years) examined the predictive value of ¹⁸F-florbetapir and ¹⁸F-FDG-PET for conversion to Alzheimer's disease in people with MCI. FDG-PET had a higher predictive value in the model than aPET. The best prediction accuracy was attained by combining both scans with non-imaging variables including high risk apolipoprotein E and the MMSE.⁷³

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4.1.4 Amyloid PET for differentiating between Alzheimer's disease and mild cognitive impairment

A systematic review with meta-analysis reported pooled weighted sensitivities and specificities for aPET in differentiating patients with Alzheimer's disease from healthy control patients. For F-florbetapir these were 89.6% (95% CI 84.2% to 93.6%) and 87.2% (95% CI 81.7% to 91.6%) respectively (seven studies, n= 181). For F-florbetaben pooled weighted sensitivity was 89.3% (95% CI 82.7% to 94.0%) and specificity was 87.6% (95% CI 80.4% to 92.9%)(four studies, n=131). Meta-analysis of flutemetamol studies was not possible. Most studies in the analysis were case-control studies. One study included in the analysis had brain pathology as the reference standard. Participants (n=49, 39 Alzheimer's disease, 10 normal cognitive status) with life expectancy of less than six months were recruited. The sensitivity and specificity for distinguishing participants with Alzheimer's disease from healthy controls was 97.4% and 100% respectively.⁷⁴

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An overlapping systematic review examined and compared the diagnostic accuracy of the three ¹⁸F tracers for Alzheimer's disease where study populations included those with Alzheimer's disease, those with MCI and cognitively normal individuals. Meta-analysis indicated that there was little difference between the accuracy of the tracers and highlighted that specificity was greater for identifying people with Alzheimer's disease when compared with cognitively normal participants than from distinguishing between people with Alzheimer's disease and those with MCI.⁷⁵

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4.1.5 Amyloid PET for differentiating between Alzheimer's disease and other forms of dementia

A systematic review of the use of ¹⁸F-labelled PET tracers identified two studies examining diagnostic accuracy for differentiating between Alzheimer's disease and non-Alzheimer's disease. In the first study (n=107), with clinical judgement as reference standard, sensitivity and specificity for distinguishing between AD and non-AD were low (61.6% and 57.1% respectively). Assessment of external validity of the study was limited as detailed information on the study population was not provided. The second study (n=109) reported high sensitivity for differentiating between Alzheimer's disease (n=30) and frontotemporal lobar degeneration (n=11), dementia with Lewy bodies (n=7), vascular dementia (n=4), and Parkinson disease (n=5). Sensitivity for all groups was 96.7% and specificity ranged from 71.4% to 100%. The small numbers in the studies limit the conclusions which can be drawn.⁷⁴

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4.1.6 Clinical utility of amyloid PET

A systematic review exploring the outcomes measured in clinical utility studies of aPET identified 32 studies (including protocols) published between 2012 and 2020. Twenty five studies (78%) examined impact on diagnosis including change in diagnosis and confidence in diagnosis. Seventeen studies (53%) reported on change in patient management including change of medication, additional investigations, referral for counselling or onto a clinical trial. Few studies looked beyond these clinician-centred outcomes to patient and caregiver-centred outcomes such as anxiety, quality of life and coping.⁷⁶

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A well-conducted systematic review with literature search⁷⁷ identified studies on the clinical utility of aPET where both a pre-aPET working diagnosis and post-aPET final diagnosis were available for study participants with cognitive complaints. Across seven studies (n=1,142) the diagnosis changed due to aPET scan information in 31.3% (n=357) of cases. Where the prescan diagnosis was non-Alzheimer's disease (n=338) there were 135 patients who had a positive aPET scan, of whom 100 (74.1%) had their diagnosis changed to Alzheimer's disease.

In subgroup analysis use of aPET led to a change in patient management for 72.2% of those scanned where findings were available immediately (three studies, n=740) compared with 55.5% of control cases (delayed scan reporting, one study, n=299). In a subgroup of patients meeting the appropriate use criteria (two studies, n=211) there was change in patient management for 41.4%.

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Diagnostic confidence was assessed in a range of ways and as a subjective measure was dependent on clinician expertise. Across six studies (n=725) the systematic review estimated that aPET increased diagnostic confidence/certainty overall by a mean of 12.7% +/- 35% with a decrease in confidence associated with negative aPET cases.⁷⁷

Several additional longitudinal studies published since the systematic review, have each identified changes in diagnosis, diagnostic confidence and/or patient management.⁷⁸⁻⁸² One study was from the UK. This retrospective single-arm study examined the utility of aPET with ¹⁸F-florbetapir for patients attending a tertiary referral clinic. Of 100 patients investigated, most of whom were categorised as having young-onset dementia and/or dementia with atypical clinical features, aPET was positive in 49 patients and led to a change in diagnosis in 30 cases and a change in management in 42 cases, including addition of medication or enrolment into clinical trials.⁸³

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4.1.7 Considerations for the use of amyloid PET

Amyloid PET does not involve a lumbar puncture, a procedure that some people do not find acceptable, which may make it preferable to using CSF biomarkers.

Amyloid PET does involve a scan with radiation exposure. Whilst there is agreement that radiation exposure is detrimental, with repeated or accumulated exposures linked to harmful effects including cancer, there is no agreed cut off. General consensus is that any radiation exposure is potentially

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harmful. All CT and Nuclear Medicine imaging come under Ionising Radiation Medical Exposure Regulations IR(ME)R.⁸⁴ Most health-related exposure works on the principle of ALARA (as low as reasonably achievable). 4

Doses are variable between centres and scanners. Dose from ionising radiation is measured in milli Sieverts (mSv). The Administration of Radioactive Substances Advisory Committee (ARSAC) guidance (January 2022) gave the following effective dose targets for relevant scans: dopamine transporter single-photon emission computed tomography (DaT) SPECT 4.6 mSv, perfusion SPECT 5.8 mSv, FDG-PET 4.8 mSv, aPET 5.8–6.9 mSv, CT of the brain is around 2 mSv. To put this into context, on average people in the UK are exposed to approximately 2.7 mSv of background radiation per year.⁸⁵

In young people with suspected dementia, a brief discussion regarding the benefits and potential effects of the scanning prior to requests should be undertaken. MRI involves no exposure to radiation but has other potential contraindications, for example if the person has a non-MR compatible pacemaker, which should be considered. Local clinical guidance should be followed.

Only one economic analysis of aPET was found, which showed that, in the French healthcare system, aPET was cost effective compared with standard diagnostic assessment and with CSF biomarkers.⁸⁶ Amyloid PET cost more to provide, but accrued a greater number of quality-adjusted life years (QALYs). The patient cohort was followed up for 10 years after diagnosis to capture the longer-term benefits of earlier diagnosis.⁸⁶

4.1.8 Cerebrospinal fluid biomarkers

Cerebrospinal fluid (CSF) biomarkers can help diagnose Alzheimer’s disease. These are amyloid-beta 1–40 and 1–42 (Aβ40, Aβ42), total tau (T-tau) and phosphorylated tau (P-tau). The term ‘established CSF biomarker’ is used to describe a combination of Aβ42 and/or Aβ40 with either T-tau or P-tau. A reduction in CSF amyloid biomarkers (Aβ42, Aβ40) and elevated tau biomarkers (T-tau, P-tau) is indicative of Alzheimer’s disease. There are currently no CSF biomarkers for any other subtypes of dementia.⁸⁷

4.1.9 Interpreting the evidence base

Interpretation of the evidence relating to the diagnostic value of biomarkers (whether CSF, blood or imaging based) in diagnosing Alzheimer’s disease is challenging. Heterogeneous studies and meta-analyses vary in CSF testing methodology and assays, reference ranges used to define abnormal results, age of participants, length and the quality of follow up and whether neuropathology has been assessed, all of which makes comparison difficult.⁷⁵ 2+

When assessing the diagnostic accuracy of CSF biomarkers in clinical studies, neuropathological confirmation of the diagnosis is important to establish the rates of Alzheimer’s dementia pathology in control participants or as co-pathology in people diagnosed clinically with non-Alzheimer’s dementia.^{88,89} 4

Age is also a consideration, as the postmortem examinations of 20–40% of asymptomatic people older than 80 years (depending on clinical criteria used) show neuropathology of Alzheimer’s disease.^{90–92} Similar ratios of abnormal CSF Aβ/tau results are seen in asymptomatic people of this age.^{75,88} 3
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4.1.10 Established CSF biomarkers for differentiating between Alzheimer’s disease and other forms of dementia

A Cochrane meta-analysis examined the accuracy of CSF Aβ42 in differentiating Alzheimer’s disease dementia from other dementia sub-types.⁹³ The pooled sensitivity from 13 studies (n=1,704) was 79% (95% CI 0.73 to 0.85) and the pooled specificity was 60% (95% CI 0.52 to 0.67). For differentiating 2++

Alzheimer's disease from vascular dementia pooled data from 11 studies (n=1,151) gave sensitivity 79% (95% CI 0.75 to 0.83) and specificity 69% (95% CI 0.55 to 0.81). The corresponding data for differentiating Alzheimer's disease from frontotemporal dementia (17 studies, n=1,948) were sensitivity 85% (95% CI 0.79 to 0.89), specificity 72% (95% CI 0.55 to 0.84). And for differentiating Alzheimer's disease from dementia with Lewy bodies (9 studies, n=1,929) were sensitivity 77% (95% CI 0.70 to 0.83) and specificity 66% (95% CI 0.51 to 0.78). The authors concluded that CSF A β 42 on its own should not be used to differentiate between Alzheimer's disease dementia and non-Alzheimer's disease dementias.

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In clinical practice people may present with less defined clinical phenotypes.

A systematic review and meta-analyses of the diagnostic performance of CSF biomarkers found⁹⁴ the pooled ratio between CSF T-tau biomarker concentration in patients with Alzheimer's disease and cognitively healthy control participants was 2.54 (95% CI 2.44 to 2.64, p<0.0001 (15 studies, n=18,427)); for CSF P-tau (89 studies, n=12,624) the pooled ratio was 1.88 (95% CI 1.79 to 1.97, p<0.0001) and for CSF A β 42 (131 studies, n=16,790) the pooled ratio was 0.56 (95% CI 0.55 to 0.58, p<0.0001). There were similar findings for these CSF biomarkers in distinguishing between people with MCI due to Alzheimer's disease and people with stable MCI (at two-year follow up). Interpreting the relevance of these findings to clinical practice is difficult due to the variation in reference ranges used across studies. The study authors concluded that there was sufficient consistency in biomarker ratios for them to be used to inform practice.

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A Cochrane systematic review examined CSF T-tau and tau/A β ratio for diagnosis of Alzheimer's disease dementia in people with MCI in secondary and tertiary care settings.⁵⁸ The NINDS-ADRDA criteria for Alzheimer's disease were used and MCI was defined using either the Petersen,⁹⁵ revised Petersen,⁹⁶ and/or Matthew's⁹⁷ criteria. Sensitivity ranged from 80% to 96% and specificity ranged from 33% to 95%. It was not possible to combine the studies because the small total number of cases (140). The authors concluded that the biomarkers were more effective at ruling out Alzheimer's disease in people with MCI than ruling it in.

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4.1.11 Established CSF biomarkers and amyloid PET findings

A modelling study based on cross-sectional data from 377 participants with mean age 72.1 explored changes in CSF biomarker trajectories as a function of aPET standardised uptake volume ratio (SUVr).⁹⁰ There were 135 participants with mild cognitive impairment and 242 who were cognitively unimpaired. No participants had a diagnosis of Alzheimer's disease. Forty percent of the study population had a positive aPET scan. In the model, changes in CSF markers preceded abnormal amyloid deposition as measured by aPET positivity.

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Another cross-sectional study (n=64, mean age 66.3) explored data for both aPET and CSF biomarkers alongside clinical diagnoses in people undergoing investigations for cognitive complaints.⁸⁸ Forty one of the participants had a clinical diagnosis of AD. A β 42 (cut-off 706.5 pg/mL) had the strongest correlation with ¹⁸F-Flutemetamol PET finding and at this cut-off had sensitivity and specificity of 87% and 88% respectively, for positive aPET test.

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A further study (n=136) examined concordance between CSF biomarker and ¹¹C-Pittsburgh compound B (PIB) PET findings.⁹² Clinical diagnoses that were not informed by biomarker and PET findings were mild cognitive impairment (n=22) non-Alzheimer's dementia (n=34) and Alzheimer's dementia (n=64). There were 16 control participants who had subjective memory complaints but had no abnormalities on cognitive, neurological and psychological investigations. Across all study participants concordance between ¹¹C PIB PET finding and A β 42 at cut off <550ng/L was 84%. At the wider cut off of 640ng/L it was 90% and when combined with tau biomarker data it was 89%. For people with AD the concordance of ¹¹C PIB PET with A β 42 measure at a cut-off of <640 ng/L was 92% whilst for the control group it was 75%.

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4.1.12 Considerations for use of biomarkers

The Alzheimer’s Association expert group⁹⁸ indicated that CSF testing should be arranged by dementia experts following clinical assessment to allow appropriate test counselling, safety screening and consent.

To obtain CSF biomarker samples a lumbar puncture must be undertaken. Although this is an invasive test, the risks are minimal when it is carried out by staff with appropriate training.

A study following up memory clinic attendees undergoing lumbar puncture (n=3,456), included people with a diagnosis of MCI (25.3%) Alzheimer’s disease (28.4 %), and other dementia (12.6%).⁹⁹ Adverse effects reported after successful procedures included back pain (17%) and headache (19%). Another study reported that in cognitively healthy participants, younger people (mean age 28 years) had slightly higher rates of adverse events (14.1 %) than the older control group (12.5 %, mean age 73 years).¹⁰⁰ A broader review of the safety of lumbar puncture agreed with these findings.¹⁰¹

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Consensus guidelines from the European Union (EU) Joint Programme – Neurodegenerative Disease Research (JPND) consortium indicated the need for an examination, review of medications and potentially imaging to be undertaken before safe lumbar puncture.¹⁰²

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There are significant costs, given the time required to undertake the procedures, train staff to an appropriate level and have policies for those individuals where the test is technically challenging. There are modest cost implications for the sample couriering transfer and laboratory analysis.

There are few studies on the cost effectiveness of CSF biomarker testing. One study reported that any modelling of the cost effectiveness of such testing is highly influenced by the pretest prevalence of Alzheimer’s disease.¹⁰³ This study suggested a pretest prevalence of 12.7% after clinical assessment and imaging was required to make the investigation cost effective, requiring a highly clinically selected population from memory clinics. In their model, based on practice, costings and cost-effectiveness modelling from the USA at prices from 2013, the authors concluded that testing established CSF biomarkers was cost effective. It is unclear if these assumptions are generalisable to the Scottish population and healthcare system.

4.1.13 Recommended tests

The following recommendation is reproduced from the NICE guideline on assessment, management and support for people living with dementia and their carers (NG97).²²

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- R** | **If the diagnosis is uncertain and Alzheimer’s disease is suspected, consider either:**
- **FDG-PET** (fluorodeoxyglucose-positron emission tomography-CT), **or perfusion SPECT** (single-photon emission CT) **if FDG-PET is unavailable**
- or**
- **examining cerebrospinal fluid for:**
 - **either total tau or total tau and phosphorylated-tau 181 and**
 - **either amyloid beta 1-42 or amyloid beta 1-42 and amyloid beta 1-40.**
- If a diagnosis cannot be made after one of these tests, consider using the other one.**

Functional imaging is well-established technique for use in dementia diagnosis and subtyping. Perfusion SPECT is widely available in Scotland, while access to FDG-PET remains extremely limited. Where available FDG-PET should be considered on a case-by-case basis in discussion with regional PET-CT centres.

The NICE guideline states ‘amyloid imaging techniques have been licensed for use in the UK,’ but makes no recommendation for aPET use.²² Amyloid PET is not currently widely used in Scotland; it is used only for research purposes and is not routinely available.

R | **Routine use of amyloid PET in the diagnosis of dementia or mild cognitive impairment is not recommended.**

- ✓ | Amyloid PET may be considered for improving the diagnosis of Alzheimer's dementia in situations where there is still uncertainty following specialist assessment and structural brain imaging, for example in those with atypical presentations or young-onset dementia.
- ✓ | Any consideration of amyloid PET should follow a full clinical assessment by a dementia specialist, and discussion of the potential risks from radiation.
- ✓ | Testing of established CSF biomarkers should be arranged by dementia specialists following clinical assessment. The risks and benefits of undertaking a lumbar puncture should be discussed with the individual, and any risks managed.

There is insufficient evidence to support the routine clinical use of other blood or CSF biomarkers. Many biomarkers may also be non-specific, reflecting associated comorbidities rather than dementia.

There is a lack of access to biomarker testing as highlighted in a survey of psychiatrists (n=492) working in the UK.²⁵ At present there are no laboratories within Scotland offering established CSF biomarkers testing. } 3

4.2 Diagnosing suspected frontotemporal dementia

NICE guidance indicates that if the dementia subtype is uncertain and frontotemporal dementia is suspected, use either FDG-PET or perfusion SPECT.²²

Do not rule out frontotemporal dementia based solely on the results of structural, perfusion or metabolic imaging tests.

4.3 Diagnosing suspected vascular dementia

NICE guidance indicates that if the dementia subtype is uncertain and vascular dementia is suspected, use MRI. If MRI is unavailable or contraindicated, use CT.²²

Do not diagnose vascular dementia based solely on vascular lesion burden. Be aware that young-onset vascular dementia has a genetic cause in some people.

4.4 Diagnosing suspected dementia with Lewy bodies

NICE guidance indicates that if a diagnosis is uncertain and dementia with Lewy body dementia is suspected, use ¹²³I-FP-CIT SPECT.²²

If ¹²³I-FP-CIT SPECT is unavailable, consider ¹²³I-MIBG cardiac scintigraphy.

Do not however rule out dementia with Lewy bodies based solely on normal results of the above investigations.

4.5 Consideration of genetic testing

It is important to recognise that in some patients dementia can be caused by single gene disorders. This may need to be considered in patients with frontotemporal dementia and early-onset Alzheimer's. This may also need to be considered in patients presenting with clinical features such as chorea or motor neurone disease in addition to dementia.

- ✓ | Refer to current national criteria local guidance and protocols.
- ✓ | Consider offering testing with locally available gene panels in individuals with dementia diagnoses with either:
 - age at onset <55 years
 - family history of dementia of the same type in a first or second degree relative.
- ✓ | It is important to recognise that gene panels currently test for the common monogenic causes of some subtypes of dementia. They do not however test for susceptibility genes, which may also be risk factors within families.

National Services Scotland provides [information on genetic testing](#).

5 Postdiagnostic support

People with dementia benefit from an earlier diagnosis and access to the range of postdiagnostic services.¹⁰⁴

The purpose of postdiagnostic support is to equip people living with dementia, and those who care for them, with the tools, connections, resources and plans they need to live as well as possible and prepare for the future.¹⁰⁵ Standards for service provision are presented in [the Quality Improvement Framework for Dementia Post-Diagnostic Support in Scotland](#). The Scottish Government's local delivery plan states that people newly diagnosed with dementia will be offered a minimum of one year's postdiagnostic support, co-ordinated by a named link worker.¹⁰⁴ Alzheimer Scotland provides a 'five pillar' model of postdiagnostic support and an 'eight pillar' model of care co-ordination that have been adopted in Scotland for the delivery of postdiagnostic support.¹⁰⁶

A total of 23 systematic reviews (qualitative and mixed-methods) of moderate to high quality were identified. Many of the reviews conducted meta-ethnographic analyses of the qualitative studies. Pathways of postdiagnostic support vary across the world. These reviews included studies in the UK, Europe and the USA. Within-country differences also existed, as studies reported the provision of different services, such as memory clinics, counselling, community service referral, specialist referral and mass screening.¹⁰⁷⁻¹⁰⁹ GPs or family physicians (in the USA) are usually the first point of contact.

5.1 Experiences of postdiagnostic support

One systematic review reported people with dementias were dissatisfied with the amount of information provided.¹¹⁰ Another systematic review (n=46 studies) highlighted the need for education about the illness for carers.¹¹¹ The amount of postdiagnostic support varied and the social health of participants was rarely addressed. Treatment mainly focused on medication rather than addressing social health, professional help with memory, speech or communication difficulties or occupational therapy.¹¹⁰ Carers' experiences with seeking or engaging with formal health care and organised support services varied greatly.^{108,110,112}

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Mixed findings could be attributed to variation in practice and service provision across the world or regionally between health boards. However, those who had adverse experiences described existing services as silo based, fragmented, duplicated and inappropriate for their needs.^{108,113} One systematic review reported that difficulties in receiving information and support were primarily thought to be due to poor co-ordination between services and carers' preference for psychosocial support which was not always accessible.¹¹⁴

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5.1.1 Attitudes and beliefs around dementia

A systematic review highlighted that attitudes and beliefs influence health-seeking behaviours, for example, negative views about residential and respite care were associated with non-use of these services. It was therefore recommended that illness perception, cultural beliefs, lack of knowledge, stigma and public acceptance should be addressed in delivery of postdiagnostic support for effective uptake.¹¹⁵ One systematic review suggested a need for public awareness campaigns about dementia, dementia caregiving, and social structures that may have a biased view of caregiving to reduce social stigma and tangibly recognise the carer role, suggesting a societal responsibility that would include healthcare professionals and policy-makers.¹¹⁶

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Experiences of stigma impacted on self identify often resulting in social isolation, avoidance, reduction of activities and social withdrawal, especially in the advanced stages of the disease.^{110,117-119} Emotional wellbeing, consequences and duty of care demonstrated how perceptions of stigma

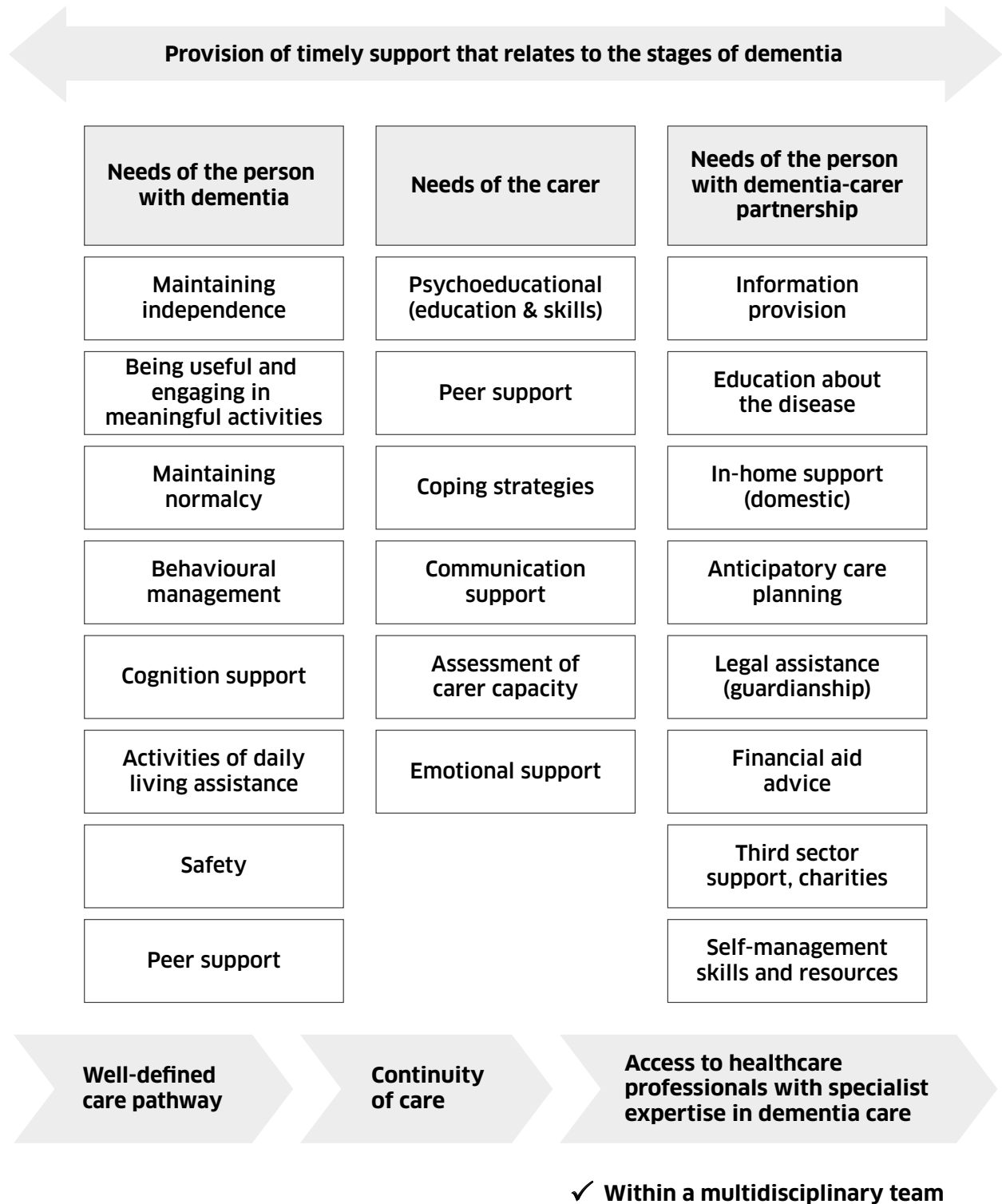
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<p>associated with caregiving may deter help seeking by various means. For example, people were willing to dismiss the label of receiving formal care to avoid public stigma and internalised feelings of embarrassment and shame.¹¹⁵</p>	<p>JBI 6/10 10/10 9/10 10/10</p>
<p>The stigma of dementia is perceived as even greater in people with young-onset dementia; they may be less willing to disclose their diagnosis which may influence their attitude to seeking help.^{117,118,120,121} There was also greater stigma among minority ethnic populations.¹⁰⁷ Carers can also experience stigma.¹²¹</p>	<p>JBI 10/10 7/10 9/10 8/10</p>
<p>Good communication and attitudes (viewed as highly important) were said to facilitate open interactions, as some of the challenges faced by carers and people with dementia included associated stigma.¹¹¹ This was also found in people with young-onset dementia and young carers (see section 5.5).</p>	<p>JBI 9/10</p>
<p>R Service providers should provide postdiagnostic support that is co-ordinated between services, meets the needs of people with dementia and their carers and encourages their engagement with services.</p>	
<p>R Service providers should consider carers’ preferences for psychosocial support and education.</p>	
<p>R Service providers and health and social care providers should consider and address stigma and how the person with dementia and their carer(s) view the illness and options for care, based on their knowledge, experience and cultural beliefs, to encourage health-seeking behaviours and uptake of care and services.</p>	
<p>✓ Postdiagnostic support should be available throughout all stages of the disease, and in all settings, aligned to the needs of the person with dementia or their carers.</p>	
<p>✓ Professionals should be aware of the important relationship and interlinked needs of the person with dementia and their carer(s) and should consider whether relationships are positive, supportive and equitable.</p>	

5.2 Needs and unmet needs from postdiagnostic support

<p>One systematic review categorised needs specifically to those of the person with dementia-carer partnership, the person with dementia or the carer.⁶² It included 54 studies, 46 on the needs of person with dementia and their carers (mean age of person with dementia 77 years) and eight on case management (mean age 79 years). Other reviews focused on the general needs of the carer or the person with dementia from the perspective of the carer.^{107,108,113,114,116}</p>	<p>JBI 10/10 10/10 7/10 8/10 7/10 10/10</p>
<p>Figure 2 provides a summary of what needs should be addressed in post diagnostic support, which is supported by the findings of qualitative studies.</p>	

Figure 2: Overview of post diagnostic support to address the needs of the person with dementia, the carer and the person with dementia-carer partnership.



5.2.1 Needs of the person with dementia

Specific needs of the person with dementia included assistance with activities of daily living (ADL), maintaining their 'normal life' in the community, normalcy (*for facilitating ADL and independence see section 5.2.4*) and meaningful activities, managing mood changes and stress and distress (*see section 6*), behavioural management, cognition management (memory loss and deteriorating cognitive functioning), safety and management of mood.^{62,107,113,116}

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People with dementia expressed safety needs within the social environment, with concerns around stigma or feeling socially isolated, and emphasised the need to maintain normality.^{62,107,110,116-119} Normality included themes on sense of self, or holding onto their identity, responsibility for others, continuing to live in their own home; maintaining relationships and social contacts, staying active and enjoying meaningful activities, health awareness (independent from the diagnosis of dementia), autonomy, usefulness, and religion and spirituality.^{110,118,119} People with young-onset dementia expressed the wish to stay engaged with others, to take part in meaningful activities and to be included in society; in other words, they wanted to be treated as 'normal human beings'.¹¹⁷

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Some needs, such as advanced care planning and management of mood swings, were overlooked.^{62,107,116,117}

5.2.2 Needs of the carer

Carer-specific needs included emotional support, in-home support (domestic), involvement in care planning, and capacity to provide care.^{62,107,108,116,122} One systematic review reported a lack of carer-specific support in the UK.¹¹⁴ There is also a need for psychoeducation for carers (*see section 5.1*).¹¹¹

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In a study of carers of people with frontotemporal dementia attendance at a carer support group with a rolling programme of talks covering medical, legal, financial issues, management of behavioural symptoms, access to support services and a forum to discuss personally relevant issues, participants reported improved skills in all topics, better communication, and improved emotional coping after two years' attendance.

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5.2.3 Needs of both the person with dementia and carer

The following needs of the person within the dementia-carer partnership were identified: education/counselling to deal with behavioural problems, information about relevant services available (including community psychology services, domestic help, support groups and insurance), legal assistance (about guardianship), financial support, advance care planning, a well-defined care pathway, continuity of care, access to family physicians who have adequate knowledge of the disease and specialise in dementia care, and access to healthcare professionals who specialise in older people/ageing and dementia conditions.⁶²

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Short-term treatment programmes based on the concept of self-maintenance therapy have shown an improvement in depression, chronic fatigue and restlessness for both people with frontotemporal dementia and carers.¹²²

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5.2.4 Safety issues

One systematic review discussed the challenges of striking a balance between safety issues and autonomy and independence amongst people with dementia and their carers, for example walking alone or driving.¹⁰⁷ There is a need for professionals and support groups to better understand, and respond to, the carer's dilemma of not wanting to take away the sense of personal agency and dignity from the loved one while still managing the tasks of everyday routine and safety.

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The following safety challenges were identified:¹¹⁶

- Functional safety - doing what it takes to stay at home.

- Emotional safety – the sense of duty despite age (role changes) and losses. The person with dementia also expressed stress and worry regarding the health and wellbeing of their carer(s).
- Physical and social safety – the unacknowledged challenge of taking care into the home. This relates mainly to providers (probably healthcare professionals) giving care in less than ideal situations and the conditions faced by the person with dementia and their carer(s).

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Findings indicate that people with dementia, carers and providers struggle with the home care system. Home care models that are client or person-centred need to be considered to provide seamless, quality, sustainable home care.¹¹⁶ As this is a Canadian study it may not be applicable to the UK setting.

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One systematic review of people with dementia and their carers¹²³ identified mitigating safety concerns (such as the person with dementia getting lost) from studies that included people of minority ethnic, Asian and Chinese populations. The studies expressed safety concerns as a result of symptoms, including memory-related difficulties with instrumental ADL, such as managing money or medication, impaired judgement, such as dressing for the wrong season, and radical behaviour changes, such as extreme apathy or aggression. Extreme behaviours were accompanied by safety concerns, such as getting lost, falling, unsafe driving, causing flooding or fires (kitchen safety) and an inability to recognise rotten food.

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The need for help was identified in managing falls and wander risk, ensuring home safety (eg a safe return programme) and minimising the risk of accidental self harm.⁶²

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The Herbert Protocol for people with dementia at risk of going missing is recommended by Police Scotland. Carers, family or friends of a vulnerable person, or the person themselves, can fill in a Herbert Protocol form in advance, providing information to help the police if the person goes missing.

5.2.5 Communication and communication support needs

Two systematic reviews stated that carers reported the person with dementia had difficulty communicating their symptoms, resulting in uncertainty and distress.^{108,111} When caring for a person with advanced dementia carers reported difficulty in identifying when something was wrong or causing distress, due to the absence of verbal communication from the person with dementia, which was upsetting.¹⁰⁸ This suggests that the person with dementia and their carers may need support to facilitate communication.

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5.2.6 Considerations for professionals/service providers around needs

A systematic review supported the need for open communication and empathy when delivering information and to value the perspectives of people with dementia and their carers.¹¹¹ It proposed several clinical recommendations:

- Improved communication and attitudes around dementia. Primary care providers (GPs) should be made aware of person-centred approaches to care.
- Additional education about dementia and its management to improve healthcare professionals' skills.
- Education and interventions to equip people with dementia and their carers with self-management skills and resources.
- Introduction of services such as dementia care managers (case management) in primary care teams (*see section 5.4*).
- Psychoeducation for carers.

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One qualitative study proposed the following clinical implications for practice: early provision of information about financial aids and entitlements; the opportunity to talk to supportive professionals; and signposting to appropriate statutory and voluntary services (*see section 9.3*). Support needs to be flexible and sensitive, and tailored, to the needs of the individual, taking into account cultural needs.¹⁰⁷ Findings across the reviews overlap, resulting in similar themes in terms of their recommendations for practice.^{62,107,108,111,116}

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A scoping review on receiving a diagnosis of young-onset dementia also highlighted the need for greater sensitivity in communicative style when healthcare professionals discuss the diagnosis process or relay the diagnosis (*see section 3.2*).¹²⁴

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5.2.7 Postdiagnostic information and support needs

Seven studies consistently reported a lack of information materials, professional help (including specialist services), support services (especially for carers), behavioural issues, legal help, and safety issues (the consideration of autonomy versus safety; ‘the need to manage care needs and safety while being aware of the person’s identity and dignity’) (*see section 5.2.4*).^{107,111,112,114-116,122} Support services and voluntary services were also poorly signposted.¹¹²

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Another systematic review further contextualised the perspectives of people with dementia on receiving information, including carers wanting information but not all at once, written information being optimal; help with accessing healthcare, such as contacting healthcare professionals, knowing what services are available and how to access them (which relates to improved signposting to services, and open communication).¹¹¹

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There is a need for information to evolve with the stages of dementia.¹¹⁶ Two systematic reviews emphasised the need for practical strategies, improving knowledge of coping strategies and strategies to preserve normalcy for both carers and the person with dementia.^{107,116} Practical strategies included relying on family support, while emotional strategies included finding meaningful activities.^{107,116}

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5.2.8 Online resources and social media

Use of internet resources and social media (blogs, online forums) were beneficial for obtaining information and making contact with others with similar experiences.^{113,122}

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Carers were positive about the use of computer and online-based technology to provide a videoconferencing support group in a mutual self-help format. It facilitated access while balancing the demands of working full-time, household responsibilities and children. Carers felt they were not alone and found the emotional support they received to be beneficial. Although they continued to feel stressed, they were less burdened.¹²²

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Studies of people with dementia, carers, and service providers identified the need for better signposting to online resources and to third-party organisations, such as charities or voluntary organisations, which were widely considered important in terms of social and emotional support.^{107,112} The qualitative studies reported strong evidence of valuable support from voluntary organisations, although signposting needs to be improved.¹⁰⁷

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R | Postdiagnostic support should address the needs of the person with dementia, carers, and the person with dementia-carer partnership.

R | Postdiagnostic support for people with dementia should include:

- **assistance with activities of daily living to maintain their ‘normal life’ in the community, for example to maintain their identity, relationships, social life, ability to continue living in their own home, staying active and healthy and engaging in meaningful activities**

- **support for managing mood changes and stress and distress** (agitation and aggression) *(see section 6)*
 - **support for memory loss and declining cognitive function** (eg the ability to retain short-term information)
 - **help to balance safety with the need to remain independent, and facilitate normality and daily life**
 - **education about the disease**
 - **anticipatory care planning** *(see section 8.4)*.
- R | **Postdiagnostic support for carers should include:**
- **emotional support**
 - **psychoeducation**
 - **timely information relating to the stages of dementia, access to services and where to find further reliable information**
 - **practical help, such as coping strategies to preserve normality for both themselves and the person with dementia**
 - **family support**
 - **domestic support at home**
 - **involvement in care planning.**
- R | **Postdiagnostic support for the person with dementia-carer partnership should include:**
- **communication support so the person with dementia can express their symptoms and needs and carers to can understand their needs** (eg when something is wrong or causing distress), **particularly in the advanced stages of dementia**
 - **help to manage stress and distress** (eg agitation and aggression)
 - **development of self-management skills and signposting to self-management resources**
 - **help to achieve a balance between safety and retaining autonomy and independence, eg for the person with dementia walking outside, alone continuing to drive, medication management, impaired judgement and memory-related difficulties relating to activities of daily living, kitchen safety, stress and distress** (extreme apathy or aggression)
 - **anticipatory care planning** *(see section 8.4)*
 - **a well-defined care pathway and continuity of care**
 - **access to GPs and healthcare professionals with specialist expertise in dementia care or care of older people.**
- R | **Postdiagnostic support needs to be flexible, sensitive and tailored to the needs of the person with dementia and their carers.**
- R | **Health and social care professionals should signpost people with dementia and their carers to:**
- **non-statutory organisations** (eg charities/voluntary organisations) **that offer social and emotional support**
 - **reliable information sources including websites and social media** (blogs, online forums) *(see section 9)*.
- R | **Health and social care professionals should access education about dementia and its management, including communication skills and person-centred approaches to care** *(see section 9.4)*.

- ✓ Health and social care professionals should consider the postdiagnostic support needs of the person with dementia as part of a holistic assessment that includes any other risk factors and comorbidities that should be considered and appropriately addressed.
- ✓ Health and social care professionals should be aware of potential communication difficulties for people, particularly in the advanced stages of dementia. Health and social care professionals may need enhanced communication skills training to communicate effectively with people with advanced dementia.
- ✓ The format of any information shared should be tailored to the needs and preferences of the person with dementia and their carers. Consider literacy and language, additional support needs and cultural sensitivity.

Information points

- i** Repeat information given at diagnosis about the long-term impact of dementia on the person with dementia and their carers to ensure understanding.
- i** Discuss any safety concerns with the person with dementia, carers and family, and whether the person with dementia is at risk of going missing. If this is a concern, consider discussing completion of Police Scotland's [Herbert Protocol](#) form.

5.3 Access to postdiagnostic support for ethnic minority groups

Only one systematic review of studies of dementia services in the UK explored the disparity in access to postdiagnostic support among ethnic minority groups (carers and people with dementia). They found a lack of available information and the need for language translation and culturally appropriate information that considers the individual's cultural values and the impact on family dynamics.¹¹⁴ These findings suggest that current services are not equipped to deal with cultural differences.

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An international literature review of studies in the experiences of care and service requirements for people with young-onset dementia highlighted the need for culturally appropriate services for minority groups or disadvantaged communities.¹¹⁸

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In a systematic review (n=126 papers) of psychosocial factors relating to people with dementia and their carers' experiences of diagnosis and treatment, 16 studies either focused on the views and experiences of black and minority ethnic groups in the UK and North America or compared the views of different ethnic groups.¹⁰⁷ There was evidence of greater stigma among minority ethnic populations and evidence that they were more likely than white individuals to ascribe the symptoms of dementia to the ageing process rather than recognise them as an illness. Symptoms of dementia were sometimes given cultural or religious explanations. It concluded that support needs to be ongoing, flexible and sensitive to the needs of different groups, take account of what's needed for continuity of care, and to manage care needs and safety while being aware of the person's sense of identity and dignity.¹⁰⁷

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- R** **Service providers of postdiagnostic support should offer culturally sensitive services tailored to the needs of people with dementia and their carers. Information for people with dementia from minority ethnic groups and their carers should be provided in their own language with culturally appropriate information.**
- R** **Healthcare professionals should be aware of the possibility of increased stigma among minority ethnic populations. These groups are less likely to recognise the symptoms of dementia as an illness, and more likely to ascribe these symptoms to the ageing process.**

5.4 Continuity of care needs and models of delivery

Three systematic reviews, which included the needs of people with dementia and their carers of all ages,⁶² carers (majority over 65, age range 26–90 years)¹⁰⁸ and young carers (6 to 35 years)¹¹³ highlighted the need for improved continuity of care. One systematic review reported a consensus of the need for a ‘one-stop’ service or contact to ensure continuity of care and a tailored support package in a timely manner.¹⁰⁸ Difficulties in receiving information and support experiences were primarily thought to be due to poor co-ordination between services.¹¹⁴

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Another systematic review explored the effects of a case-management approach (based on the collaboration of case managers and family physicians) and the needs of the person with dementia-carer partnership.⁶² They demonstrated good evidence that case managers, in collaboration with family physicians, have a pivotal role in addressing the needs of the person with dementia-carer partnership. Nurses specialised in geriatric care often play the role of case managers. Case managers also better addressed the needs of the person with dementia. More people with dementia received non-pharmacological behavioural interventions. Acetylcholinesterase inhibitors were more frequently prescribed by family physicians working with case managers, whereas neuroleptics prescription decreased. As case managers provide support sessions for stress management and coping skills carers’ confidence with care increased. Their decision-making capacity improved, as did satisfaction with social support and in-home help.⁶²

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Another systematic review advocated the introduction of services such as dementia care managers (case management) in primary care teams.¹¹¹ (*see section 5.5*).

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In one systematic review the need for a single point of contact was especially highlighted by young carers of family with dementia (*see section 5.6*). Having one professional who was familiar with their individual circumstances was strongly preferred to support provided by sporadically visiting healthcare professionals, which felt impersonal and restricted communication.¹¹³ There were also specific mentions of experienced or trusted health professionals with the right expertise (knowledge of the disease) acting in the role of case manager, especially for young carers.¹¹³ In addition, the issue arose of training professionals in the art of disclosing diagnosis⁶³ (*see section 3.2*).

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R | **Postdiagnostic support should incorporate continuity of care, including a ‘one-stop’ service or single point of contact, a single professional or case manager. This should be a health or social care professional with appropriate skills, knowledge and expertise in dementia ([see the Promoting Excellence Framework](#))¹¹, working with the GP, to ensure a tailored support package is delivered in a timely manner.**

✓ | Input from multidisciplinary specialists (eg old age psychiatry, geriatrics and specialist care for any existing or identified comorbidities) should be considered as part of postdiagnostic care.

5.5 Postdiagnostic support for people with young-onset dementia

Five studies reported on the experiences and needs of people with young-onset dementia.^{117,118,120,121,124} Three studies reported the process to diagnosis as confusing and distressing.¹²⁰ Few findings described the experience of formal diagnostic support among people with young-onset dementia. There was a consistent theme of lack of age-appropriate support services (appropriate day services), programmes and the impact of financial problems.^{117,118,120,121}

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A review specifically noted that interventions facilitating peer support, which allow people with young-onset dementia to engage in meaningful activities, should be developed.¹¹⁷ Being with others in a similar situation was deemed an important means of support. The study explored the reaction of people with young-onset dementia to diagnosis and acknowledged how these needs can be different from those with late-onset diagnosis.

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<p>Key elements of adjustments made in life because of the diagnosis of young-onset dementia include addressing family and social relationships issues, developing new skills and strategies for remaining at work or transitioning to early retirement, and establishing financial and legal plans for the future.¹¹⁸</p>	<p>JBI 9/10</p>
<p>A scoping review of the lived experiences of people with young-onset dementia reported poor-quality information after diagnosis and a lack of explanation about the next steps.¹²⁴ The accessibility of immediate emotional support was regarded as more beneficial in the short term than information provided from leaflets on dementia and postdiagnostic support. Another review found little information provision related to prognosis, services and coping strategies.¹²¹ Generally, information provision was valued highly. Carers recognised that the support for young-onset dementia is not the same as other conditions and it can be a challenge to access services or support. Of those who received some form of postdiagnostic support, one of the difficulties was that services did not meet user requirements, mainly because they were not perceived as sufficiently age-appropriate. This relates to the need to tailor services to individuals.</p>	<p>JBI 6/10 8/10</p>
<p>People with young-onset dementia and their families experienced problems concerning loss of income associated with the loss of employment and financial concerns, exacerbating an already difficult circumstance.¹¹⁸ Evidence on supported workplaces for people with dementia indicated positive impacts on self esteem and life satisfaction.</p>	<p>JBI 9/10</p>
<p>An Australian review highlighted that effective service provision would only be possible if health services, care of older people services and disability services work collaboratively to provide a holistic approach to supporting people with young-onset dementia and their carers and families.¹¹⁸</p>	<p>JBI 9/10</p>
<p>A major barrier to the access of care among people with young-onset dementia was the denial and refusal to seek help. There are emotions within the diagnosis (not described) that need to be explored, as people with young-onset dementia, their carers or other family members reportedly did not always feel comfortable sharing the diagnosis with others.¹²⁰ It may be related to stigma.¹²⁰ Carers encountered professionals with little awareness of young-onset dementia.¹²¹</p>	<p>JBI 7/10 8/10</p>
<p>One review noted that grief was specific to people with young-onset dementia and their family¹²¹ (see section 7).</p>	<p>JBI 7/10 9/10</p>
<p>The evidence on young-onset dementia also highlighted the need for more empathetic communication, continuity of care, tailored care and better information provision.^{117,118,120,121,124}</p>	<p>8/10 10/10</p>
<p>A scoping review advocated for the role of a specialist key worker immediately after diagnosis of young-onset dementia.¹²⁴ The role should aim to provide continuity of support and enable the person living with young-onset dementia to understand their condition and actively engage in their care plan and journey. They should help to co-ordinate care and support available through local health and social services and voluntary organisations.¹²⁴</p>	<p>6/10 JBI 6/10</p>
<p>A systematic review of carers of people with frontotemporal dementia (which is normally associated with onset at a younger age) highlighted poor overall wellbeing, neglected personal needs and increased social isolation among young carers.¹²² Frontotemporal dementia affecting the younger population resulted in younger carers dealing with loss of a loved person and their support, and the full burden of work, children and life commitments. There was a breadth of emotional, physical and social needs neglected by carers of people with frontotemporal dementia.</p>	<p>JBI 5/10</p>
<p>The Young Dementia Network recommended that the key worker should:¹²⁵</p> <ul style="list-style-type: none"> • have specialist knowledge, skills and experience of the impact of young-onset dementia, including knowledge and awareness of rarer types of dementia, as well as the impact of diagnosis at a younger age for the person diagnosed and their family • provide information, practical and emotional support for family members • provide continuity of support, and facilitate the person living with young-onset dementia to understand their condition and engage in their care plan and journey 	

- act as a co-ordinator of services, organisations and people, helping to link the person living with young-onset dementia to a local group
- be available through a range of organisations depending on local infrastructure such as primary care, voluntary sector or be based within local mental health teams or neurology services.

Providing this initial support through a key worker would provide the necessary emotional support immediately after diagnosis.¹²⁵

- R** | **People with young-onset dementia should be provided with:**
- **immediate emotional support, in the short term, rather than information provision**
 - **age-appropriate support** (eg appropriate day services) **and programmes, tailored to their individual needs, and support with accessing these**
 - **information on prognosis, services and coping strategies**
 - **support to engage in meaningful activities**
 - **peer support**
 - **support with work and employment**
 - **support with financial problems.**
- R** | **All health and social care professionals involved in the care of people with dementia should communicate in an empathetic way.**
- R** | **People with young-onset dementia should be offered a key worker or case manager to provide continuity of support and enable the person living with young-onset dementia to understand their condition and actively engage in their care plan and journey. The key worker should act as a co-ordinator of services, organisations and people and be available through a variety of organisations, depending on local infrastructure, such as primary care or the voluntary sector, or within local mental health teams or neurology services.**
- ✓ | People with young-onset dementia should be offered a key worker/case manager and postdiagnostic support information immediately after diagnosis.
- R** | **Health and social care professionals should be aware of young-onset dementia and the needs (including support with grief) that people with young-onset dementia and their families experience (see section 7).**
- R** | **Health and social care professionals should be aware that a major barrier to accessing care among people with young-onset dementia is denial and refusal to seek help, stigma associated with the disease, and the emotions associated with diagnosis, and sharing this diagnosis with others.**
- ✓ | NHS boards should have distinct diagnostic services and referral pathways for people suspected of having young-onset dementia, and ensure these link to age-appropriate postdiagnostic support services.

5.6 Postdiagnostic support for young carers

One systematic review's findings relate to young-onset dementia (see section 5.5), (UK and international studies, age range of carers 6 to 35 years).¹¹³ Consistent themes were identified on existing services not being appropriate for the needs of the person with young-onset dementia, support needs for young carers and the need for continuity of care in the form of a key person or case manager.¹¹³

Young carers are more vulnerable because of their age and developmental needs. Children of people with young-onset dementia described perceived stigma and associated shame or embarrassment, family conflict, a high care burden, the physical challenge of caring, psychological issues and problems at school. Many children reported undertaking a demanding caring role while facing the developmental challenges of growing up.¹¹⁸ Other concerns include the ‘invisible’ nature of their experience.¹¹³ Communication is more likely to break down in this population, as participants preferred to talk with at least one professional who was familiar with their situation. The condition and their caring role was found to have a detrimental impact on the development and personal lives of young carers in the following ways:

- progress in their studies or career was hindered due to interruptions from assuming care roles
- educational choices were based on the need to stay close to their family or spend time with a parent with dementia
- for young carers at school, the disparity in being acknowledged as young carers due to lack of awareness
- schools did not sensitively match their responses to students’ needs
- stigma and bullying.

All of which lead to the struggle to fulfil their educational potential, enjoy social opportunities and achieve personal goals.

Looking after her was killing me. I was doing so much, was trying to do my uni work as well... I was working part time and trying to look after her... So I’ve given it up now, left uni officially... I hope to go back one day. It’s something that I’ve really enjoyed and I’d hate to waste it. (Hannah, 20)¹¹³

Appropriate support and care services are urgently needed to suit the needs of this population within a ‘whole-family’ approach, based on strong co-operation among adult, child, health and voluntary sectors. This joint work should be facilitated by a case manager who has knowledge of the family’s situation and who is capable of organising specific care to alleviate the burden on the well parent and decrease the burden on the child carer. Family support allows the well parent to retain their role (to parent) and children/young people to assume more age-appropriate roles and successfully engage in school or work.¹¹³

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- R** | **Service providers should offer a whole family approach for people with young-onset dementia and any young carers, with tailored and co-ordinated support and care from all sectors** (including adult and child health services, education services and voluntary sectors). **This should include continuity of care with one case manager or key worker who has knowledge of the family’s situation and who will facilitate support services for the person with dementia to alleviate any care burden and ensure the young carer continues with education or work.**
- R** | **Young carers and families of people with dementia should be offered support from one expert healthcare professional.**
- R** | **If the young carer is still in education, all professionals** (eg healthcare professionals, case managers or key workers, teaching and education staff) **should be aware of their role as a carer so they can offer educational and emotional support as needed. All should work flexibly and cohesively to support the young carer’s needs and facilitate continuity of education** (eg the need to stay close to family or spend time with their parent) **and look for and address any stigma and bullying.**

- ✓ All professionals (eg health visitor, teacher, healthcare professional or case manager) involved in the education and care of very young carers in full time education who are related to, live with or support a person with dementia should consider the support needs of the child independently of the needs of the person with dementia. Professionals should seek to build trusting relationships, so that the young carer can share any needs or concerns they may have, so these can be addressed.

6 Non-pharmacological approaches for distressed behaviours

Distressed behaviours refer to a range of behaviours that indicate that the person with dementia (or others in their environment) is experiencing distress. Within the literature there are several synonyms for distressed behaviour, including non-cognitive symptoms, neuropsychiatric symptoms, behavioural and psychological symptoms of dementia, stress and distress, challenging behaviour and behaviours that challenge.¹²⁶ The use of terminology around this is complex, with further work continuing.¹²⁶

Distressed behaviours can be thought of as an overarching term for a range of behaviours, including, but not limited to, restlessness, pacing, repetitive questioning, agitation, aggression, resisting or not engaging with interventions, apathy, and sleep disturbance. A person with dementia's experience of distress is unique and individualised to them. When distress is present it may indicate that the person with dementia has an underlying biological, psychological, social or environmental need, such as untreated pain, anxiety or unfamiliar surroundings.¹²⁶ Distress can also be present in people with delirium. Distress within the context of delirium is covered in the [SIGN guideline on risk reduction and management of delirium](#).⁶⁵

As distressed behaviours are usually a manifestation of an underlying unmet need in the person with dementia, most guidance recommends non-pharmacological interventions in the first instance.²² Guidance on use of pharmacological approaches is available in the [NICE guideline on dementia: assessment, management and support for people living with dementia and their carers](#).²²

There is variation in how distressed behaviour is measured and addressed. The recommendations in this guideline are based on three specific presentations of distressed behaviour: aggression, agitation and sleep disturbance. These are frequently cited as reasons for a person with dementia to be transferred from their home to a care home or admitted to a specialist dementia unit.¹²⁷⁻¹²⁹

There are many interventions for supporting people with dementia experiencing distressed behaviour. The evidence review focuses on interventions where robust evidence has been identified, in high-quality systematic reviews or primary studies that have superseded the primary analyses.

The Newcastle model is an example of an intervention used in practice. It is a biopsychosocial approach to understanding the potential causes of psychological distress.¹³⁰ The model considers the interpersonal and physical environment and the context in which dementia care is delivered. The Newcastle Model is part of range of approaches explained in the NHS Education for Scotland Psychological Interventions in the response to Stress & Distress in Dementia training programme.¹³¹

Further research is required into such models before a recommendation can be made.

6.1 Assessment of distressed behaviours

A 2019 survey of UK specialists in distressed behaviours in people with dementia, in both community and secondary care setting, found that almost half the respondents used a measure to assess behavioural changes in dementia. The most frequently reported measures of behavioural symptoms were the Challenging Behaviour Scale (CBS) (n=54/241 respondents) and the Neuropsychiatric Inventory (NPI) (n=38/241 respondents). Antecedent, behaviour, consequence (ABC) charts were reported as a functional analysis measure (n=44/241 respondents), with frequency charts recording the number of incidents.(n=26/241 respondents). For agitation and aggression, the Cohen–Mansfield Agitation Inventory (CMAI) was used by 17 respondents.¹³² Other models available include: the Innovative Dementia-oriented Assessment (IdA®), the Progressively Lowered Stress Threshold model, Treatment Routes for Exploring Agitation (TREA), Needs-driven

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dementia-compromised behaviour model (NDB model), Serial Trial Intervention (STI), and the Comprehensive model of behaviour.¹³³

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A systematic review identified 45 measures for assessing distressed symptoms in people with dementia that had explicit psychometric data such as validity and reliability reported.¹³⁴ Most of the measures targeted a specific symptom such as agitation, apathy, sleep problems, wandering or aggression. There were 16 general measures identified, half of which were for administration by a trained interviewer. The review concluded that the NPI-C clinician rating scale was helpful because it can be used in multiple clinical settings, has validation in multiple countries and has a range of versions and subscales. Choice of measures should take account of:

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- Measurement purpose (general screen or to measure a more targeted behaviour)
- The setting in which the behaviour occurs.
- Who will complete the measure and how will it be completed (observation, proxy, interview).
- Time and resources available for the measurement.¹³⁴

6.2 Comparison with pharmacological interventions

A network meta-analysis of studies in care home settings concluded that non-pharmacological interventions, particularly outdoor activities, massage and touch therapy, and exercise, were effective in reducing aggression and agitation, verbal aggression and physical agitation when compared to pharmacological treatments.¹³⁵ When compared with usual care, three non-pharmacological interventions were found to be beneficial for the combined outcome of agitation and aggression: multidisciplinary care, massage and touch therapy, and music combined with massage and touch therapy.

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While there were methodological flaws and heterogeneity amongst the studies, the findings are in keeping with the NICE guideline that recommends non-pharmacological treatments as first line.²²

6.3 Comparisons with usual care or attention control conditions

6.3.1 Personal interventions

A systematic review identified 67 trials that assessed individual resident-level non-pharmacological interventions for agitation or aggression in residents of nursing homes and assisted living facilities.¹³⁶ There was low-quality evidence that, when compared with usual care or attention control music interventions, aromatherapy with lavender and bright-light therapy did not reduce agitation or aggression. One trial on art therapy for people with agitation or aggression in the community was identified but was not sufficiently robust to draw conclusions.^{136,137}

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6.3.2 Multicomponent approaches

A systematic review examined 27 RCTs of care delivery-level interventions for agitation and aggression. Interventions included staff education, training to enhance staff knowledge and skills in managing distressed behaviour in people with dementia, and enhancements to the care environment.¹³⁶ For the majority of interventions and comparisons the evidence was insufficient to draw conclusions. There was low-quality evidence that neither dementia care mapping nor person-centred care was more effective than usual care in reducing agitation or aggression. There was also insufficient evidence to draw conclusions about interventions that aimed to reduce antipsychotic and psychotropic medication use.

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The WHELD (Wellbeing and Health for People with Dementia) study randomised 69 UK nursing homes to receive a non-pharmacological intervention consisting of training for staff in person-centred care and care planning; support for in-home WHELD champions to cascade training; implementation of tailored and structured social activities/pleasant interactions for residents;

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or education about antipsychotic use and review.¹³⁸ WHELD led to a statistically significant improvement in quality of life and agitation (as measured by a 4.27 mean difference between the treatment group on CMAI (secondary outcome) and the treatment as usual group (Cohen's d effect size 0.23)). The authors noted that this small improvement is of a similar scale to that achieved by antipsychotic medications. The WHELD programme also led to a statistically significant improvement in the neuropsychiatric symptoms (Neuropsychiatric Inventory-Nursing Home Version, NPI-NH) of -2.64 compared with a mean worsening of 1.91 in the treatment as usual group. Antipsychotic drug use was at a low stable level across both groups.

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The TIME (Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms) study randomised 33 nursing homes in Norway to a control condition (brief staff education session) or the TIME intervention based on the theoretical framework of cognitive behavioural therapy (CBT) and person-centred care.¹³⁹ The study was conducted over three phases: comprehensive assessment and observation of individuals; systematic reflection with case conferences and development of personalised care plans and implementation and systematic evaluation of treatment measures. Both study groups had a reduction in the NPI-NH item from baseline to 8 weeks. With TIME it was reduced from 8.7 to 6.1 and in the control group it was reduced from 8.4 to 6.8. The between-group difference for change at 8 weeks was 1.1 in favour of intervention (95% CI 0.1 to 2.1, p=0.031).¹³⁹

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The MARQUE (Managing Agitation and Raising Quality of Life) cluster randomised controlled trial (RCT) was conducted across 20 UK care homes (n=492). 140 A six-session manual-based interactive intervention included sessions for staff on managing agitation in dementia by recognising and understanding the unmet needs using a framework (Describe, Investigate, Create, Evaluate); improving communication; care planning; and the importance of incorporating pleasant events in day-to-day caring. No significant differences were noted between study groups in CMAI scores at 8 months (difference -0.4, 95%CI -3.89 to 3.09, p=0.82).¹⁴⁰

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The EPIC (Enhancing Person-centred care In Care homes) cluster RCT conducted across 50 care homes (n=726) in the UK randomised homes to receive staff training in dementia care mapping with expert support to embed person-centred care into practice compared with usual care.¹⁴¹ After 16 months there was no evidence of any difference in reduction of agitation between treatment arms (mean difference -2.11, 95% CI -4.66 to 0.44, p=0.10). Implementation of the intervention was described as poor with full completion of the protocol by only four of the care homes.¹⁴¹

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6.3.3 Carer interventions

A systematic review identified 27 RCTs of carer interventions for managing agitation or aggression in community-dwelling individuals with dementia. Interventions variously focused on addressing carer knowledge, skills and affect.¹³⁶ There was low-quality evidence that interventions targeting carer skills and behaviour were similar to attention control in managing agitation or aggression in the person with dementia. Benefits included increasing carer confidence and reducing carer distress. These interventions included support to develop individualised care plans, stress reduction, education in problem solving, communication, simplifying tasks and engaging the person with dementia in activities, strategies to identify triggers, reducing screen time and coping skills training.

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6.3.4 Understanding distressed behaviour

A Cochrane review examined interventions for people with dementia that incorporated a functional analysis approach to understanding the possible purpose of an individual's distressed behaviour.¹⁴² The analysis is used to develop hypothesis-driven strategies that help carers or paid carers to address the need(s) underlying distressed behaviours. The primary outcome was distressed behaviour as measured by a range of scales and scores and included physical and verbal aggression

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and depression. The review identified 18 trials across community and residential settings. In 14 trials functional analysis comprised part of a wider multicomponent intervention. There was a statistically significant reduction in frequency of challenging behaviours after intervention (13 trials, standardised mean difference, (SMD) -0.12, 95% CI -0.22 to -0.02, $p=0.02$). There was no effect at follow up (five trials, SMD 0.02, 95% CI -0.15 to 0.20, $p=0.79$, $n=520$). There were no statistically significant effects of the intervention on carer burden after the intervention or at follow up. Carer reaction (such as distress, upset and bother) was reduced after the intervention (11 trials, SMD -0.13, 95% CI -0.24 to -0.02, $p=0.02$, $n=1,284$). This benefit was not maintained at follow up.

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6.3.5 Effect of tailoring activities

A Cochrane review compared tailored activities based on past interests and preferences, such as domestic tasks, arts and crafts, singing, gardening and games, with usual care or attention control for people with dementia in their own homes.¹⁴³ When four studies were combined, there was a moderate reduction in distressed behaviour (SMD -0.44, 95% CI -0.77 to -0.10, $p=0.01$). This evidence base was assessed as low certainty. Two studies reported slightly improved quality of life. A similar review with meta-analysis examined the effect of personally-tailored activities on psychosocial outcomes for people with dementia living in long-term care facilities.¹⁴⁴ For the outcome of distressed behaviour, four trials compared with usual care and two compared with active control. There was no statistically significant benefit of tailored activities in this setting (SMD -0.21, 95% CI -0.49 to 0.08, $p=0.15$).¹⁴⁴

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A meta-analysis examined the effect of the degree of personalisation of tailored activities on outcomes relating to reducing distressed behaviour in people with dementia.¹⁴⁵ Studies were rated as highly personalised if structured assessments were used to tailor activities, interventions addressed two or more domains such as preferences and capabilities and there was full flexibility to adjust the intervention. Medium or low levels of tailoring were characterised by semistructured or unstructured assessment or no description of how assessment results informed tailoring. A range of measures for distressed behaviour were used across studies, including the CMAI and the NPI. Across eight studies for which interventions were classified as highly personalised the SMD in distressed behaviour was -0.52 (95% CI -0.74 to -0.29, $p=0.001$). For the six studies characterised as medium level of tailoring, the pooled SMD was -0.38 (95% CI -0.79 to 0.03, $p=0.071$). Similarly, the pooled SMD for the six comparisons at low level of tailoring was not statistically significant (SMD -0.15, 95% CI -0.44 to 0.14, $p=0.076$).¹⁴⁵

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6.3.6 Recommendations

- ✓ When a person with dementia presents with distressed behaviour, a holistic assessment should be undertaken, including consideration of the possible reasons underlying the person's distress. Structured and objective measures can assist in the identification of distressed behaviour. Functional analysis can help identify possible triggers or reasons for the behaviour.
- R **For managing distressed behaviour symptoms in people with dementia, tailored activities based on a comprehensive structured assessment may be considered. Activities should be individualised, focus on preserved capabilities and consider previous roles, interests and preferences.**
- R **For managing agitation and aggression in people with dementia in care homes a multicomponent programme, including staff training and support and interventions tailored to the needs of the person with dementia, may be considered.**

- R** For carers of people with dementia, provision of tailored psychoeducation and skills training may be considered.
- Components may include:
- problem solving
 - identifying triggers
 - coping strategies for distressed behaviour
 - stress reduction
 - cognitive restructuring
 - communication skills
 - crisis management.
- ✓ Staff training in the management of distressed behaviours, to improve the quality of life for people with dementia, should be linked to the Promoting Excellence Framework.¹¹ Training should be part of ongoing multidisciplinary skills development and supported by appropriate leadership, infrastructure and resources to facilitate sustained implementation and staff engagement.

6.4 Sleep problems

6.4.1 Light therapy

A Cochrane review examined the effects of bright-light therapy on sleep outcomes in people with dementia.¹⁴⁶ Based on six studies, there was no statistically significant effect on total sleep after 10 days and up to 10 weeks of treatment. There was no statistically significant effect on sleep efficiency or number of night-time awakenings.

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6.4.2 Multicomponent approaches

Three RCTs of multicomponent interventions for people with dementia who experienced sleep problems, undertaken in community and residential settings were identified in the NICE guideline on assessment, management and support for people living with dementia and their carers.²² Interventions encompassed sleep hygiene, education for carers, additional sunlight exposure, lightbox use and exercise. The multicomponent interventions resulted in improved total night-time sleep, reduced total night-time awake time and improved sleep disorders inventory scores when compared with usual care. There were no improvements in the number of night-time awakenings or total daytime sleep. An additional RCT examined the effect of individualised social activity on people with dementia in nursing homes who had sleep-wake pattern disturbance. The intervention group received 1–2 hours of social activities in 15 to 30-minute sessions over 21 consecutive days. The intervention statistically significantly reduced daytime sleep and the day-night sleep ratio compared with standard care.²²

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- R** For managing sleep disturbance in people with dementia consider a multicomponent approach that includes sleep hygiene education, exposure to daylight, exercise and personalised social activities.

6.5 People living with dementia and their carers' perspectives on using technology to support management of dementia

The rapidly changing and evolving nature of technology means that although included studies are relatively recent, their findings may quickly become outdated. The use and understanding of such technology is also changing with increased familiarity with use in older people.

The evidence identified in systematic reviews was international so differences in healthcare systems may limit the generalisability of the findings.¹⁴⁷⁻¹⁵⁴ The stages and diagnoses of people with dementia ranged from mild to advanced, including mixed, vascular, undifferentiated older-age dementia and Alzheimer’s disease. People with dementia were aged 63 years and over; however, participant demographics varied across the studies. For the studies that included specific interventions (lasting between 8 weeks and 6 months), data collection was conducted shortly after the intervention. No long-term interventions were identified, nor were there any studies that specifically reflected changes or progression over time and the impact of this on remote technology feasibility and acceptability for people with dementia and their carers. All studies focused on remote technology in the home setting.

6.5.1 Mobile health applications

A high-quality systematic review investigated the experiences of people with dementia using mobile health applications (apps) and the facilitators and barriers to implementation.¹⁴⁷ It found technology appeared to improve some aspects of physical, mental and social health, but implementation issues should be considered including design, quality and the information on the device. The digital knowledge and skills required, individual lifestyle, agency and health of people with dementia also need to be considered.

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6.5.2 Perspectives on use of remote technology in supporting management of dementia

One study found that carers had both positive and negative views on the usefulness and ease of use of the Evercare Telecare Medical Support System (TMSS) as an aid in dementia homecare.¹⁴⁸ The system uses a range of technologies to allow the person with dementia to make audio contact with a remote response centre and can include additional motion sensing devices (eg falls alert).

There were mixed views on the use of STAR-C-Telemedicine (STAR-C-TM).¹⁴⁹ The study involved carers using an internet-connected device to engage in training to support them manage behavioural disturbances in family members. It increased carer access to health services and was found to be easy to use, but there was frustration with technical challenges and meetings that did not include the person with dementia.

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Benefits of the eHealth Monitor Dementia Portal (eHM-DP) for carers included time saved, 24-hour access, increased communication with professionals, and an easy-to-use portal, while concerns were data privacy, risk of non-usage, provision of up-to-date information and digital competence.¹⁵¹ Further improvements (improved portal design, personalisation of the portal, further functionalities and integration of the forum/chat area) were identified.

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People with dementia noted challenges of remote assessment. Key themes identified include the skills required by people with dementia to use remote technology, the technology design, the inclusion of health information, and the complexity and flexibility of remote technology systems.^{147,150}

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People with dementia showed low acceptance and compliance when asked to use tablets, activity trackers and sensors/detectors and preferred telephone use to other remote technologies.^{148,150,152} Face-to-face contact with healthcare professionals was preferred. Despite the potential use of remote technology in emergencies, they did not feel safe with machines.^{150,153} People with dementia did not perceive the need for help with activities and felt that technology systems would be useful for those with greater levels of cognitive deficits than themselves.¹⁵⁰

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Positive themes among carers included ease of use and a preference for online consultations.^{149,151,153} Once the remote system was set up, carers reported the system felt comfortable and like a conversation and that it was easy to use, with shorter waiting times and quicker access to healthcare support.^{149,151,153} Some adult children who are carers noted a preference for online consultations.¹⁵³

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Positive themes amongst carers included: reduced stress in help-seeking,¹⁴⁹ increased access to support and healthcare,^{149,151} with reduced travel requirements for carers. Some felt it was easier to have a meeting from home rather than in person,¹⁴⁹ reassurance from monitoring^{150,152,154} the monitoring aspects (eg physiological and sleep data helped reduce carer anxiety),^{150,152,154} improved communication with professionals for carers, reduced communication time and 24-hour access to support and information.¹⁵¹ An overview of caregiving activities resulted in increased carer awareness of personal tasks and support areas,¹⁵¹ and cross-checking of information (self-care information reported by the person with dementia could be cross-checked using technology).¹⁵⁴

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"This was a godsend to me. I live in [a rural area]; it's a ways to get up there. This was fantastic...I can't say enough good things about it, to tell you the truth."

The STAR-C-TM "...took the stress out of getting help."¹⁴⁹

*"I would find it very helpful if you could find out if they had eaten because they often told us they had when they hadn't. [...] I saw with my parents that I didn't notice anything when I came by, and if we could have followed this we could have intervened more quickly."*¹⁵⁴

Key concerns expressed by carers were the skills required to use technology;^{149-151,153} lack of mental capacity of the person with dementia around remote technology¹⁵²; technical improvements;^{151,154} lack of internet connectivity;¹⁵² challenges of remote consultations (eg difficulties in conveying issues around new or increasing problems over the telephone)¹⁵³ and the requirements for in-home monitoring.¹⁵⁴ Frustration with videoconferencing was expressed by carers (technical challenges, digital literacy and competency) and they also noted potential frustration and anxiety of using remote technology for people with dementia.^{149-151,153} Barriers also included hearing or memory problems.¹⁵³

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Negative experiences and concerns noted by carers produced the following key themes: exclusion of person with dementia,¹⁴⁹ financial cost of technology,^{150,152} denial of the need for help,¹⁵⁰ system inflexibility,¹⁵⁰ data privacy,^{151,154} ethical concerns,¹⁵⁴ non-usage risk,¹⁵¹ lack of response by the person with dementia, preference for face-to-face,¹⁵³ information overload.¹⁵⁴ Concern about meetings without the person with dementia present were expressed.¹⁴⁹

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Some carers were concerned about the flexibility of remote systems when used by the person with dementia,¹⁵⁰ who would have access to the data,^{151,154} the risk of infrequent or non-use of the technology by both carers and health professionals,¹⁵¹ and the person with dementia's reluctance to respond to notifications or alerts. Dehumanising care was noted as a barrier by carers.¹⁵⁴ Carers preferred face-to-face, as they had more confidence to express thoughts, have more in-depth discussion, and this felt clinicians were able to notice changes visually.¹⁵³

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R When using remote technology to monitor or support a person with dementia and their carers in a home setting consider:

- **that the person with dementia may prefer face-to-face contact with healthcare professionals over technology**
- **that the carers may prefer face-to-face contact to allow discussions, and so that healthcare professionals can notice visual changes in the person with dementia**
- **that some carers may prefer online consultation**
- **the skills** (technical, digital literacy, mental capacity and competency), **training and education needs of the person with dementia and their carer(s)**
- **the usability and ease of use of technology for both the person with dementia and their carer(s)**
- **physical changes required in the home environment**
- **the cost, data security, ethical** (eg informed consent) **and privacy issues for the person with dementia and their carer(s).**

- ✓ | While there may be a preference for face-to-face contact, when this may not be possible, remote assessment may be acceptable.
- ✓ |
 - The person with dementia and their family or carers' should have awareness of remote technologies that could potentially support the management of dementia in the home setting.
 - Explain the use of remote technologies to the person with dementia and their family or carer(s) and how they could potentially support the management of dementia in the home setting.

7 Grief and dementia

Dementia can be experienced for more than a decade. During this time, people with dementia and their families and carers may experience forms of grief that have been under-recognised, underdiagnosed and undersupported.¹⁵⁵ In the context of this guideline, grief is defined by the key terms ‘anticipatory grief’ (section 7.1), ‘pre-death grief,’ (section 7.1.1) and ‘complicated/prolonged grief’ (section 7.8).

Grief is a normal process and the majority of people experiencing grief will not need psychological interventions, but may benefit from support from existing networks or peer support groups.¹⁵⁶ A small but significant proportion of the bereaved experience complicated/prolonged grief,¹⁵⁷ and can benefit from psychological interventions.¹⁵⁸ If a person is at risk of, or experiencing, complicated/prolonged grief psychological intervention could be beneficial (see section 7.8).

7.1 Anticipatory grief

The bereavement experience or ‘anticipatory grief’ for informal carers of people with dementia starts long before the physical death of their dependant. From the point of diagnosis of a terminal illness, and throughout the mental and physical deterioration as the illness progresses, carers experience multiple losses.¹⁵⁹ The term ‘anticipatory grief’ describes the threat of separation from the person with dementia and the psychological distress associated with it that occurs before the death of the person with dementia.¹⁶⁰

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Anticipatory grief can be experienced by both carers and people with terminal conditions.¹²¹ People with dementia, as well as their carers, experience multiple losses over the course of dementia.¹⁶¹ Early losses include cognitive decline, such as decline in memory and communication function, followed by losses in personality and self care. The experience of the slow psychological loss of the person with dementia because of their cognitive decline, while they are still physically present, has a profound impact on carers’ wellbeing.^{121,161,162} Occasional and unpredictable periods of lucidity can make accepting and processing the psychological loss of the person with dementia challenging, and these moments may be simultaneously distressing to, and welcomed by carers. Dementia carers may experience a degree of stress preceding the physical death of the care receiver that is equal to or greater than the stress associated with after death grieving.¹⁶³

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“I grieve... things that have become impossible for my husband to do. I sit and wait for the next change to happen. Sometimes the changes happen quickly whereas other times I seriously think that he is starting to come back. My life has become a nightmare. I am always waiting for the bottom to drop. That is why I grieve – I want my life back.”¹⁶³

Anticipatory grief may allow carers to prepare for death and loss through the discussion of dying with the care receiver, giving an opportunity to resolve any difficulties in the relationship.¹⁶⁰ Owing to the changes resulting from dementia, these discussions are generally not possible by the time the condition is recognised as terminal, and dementia carers may endure a ‘tragic variant’ of anticipatory grief.¹⁶⁴

7.1.1 Pre-death grief

The term ‘pre-death grief,’ has been defined to apply specifically to the carers of people with dementia:¹⁶⁵

Pre-death grief in the context of dementia family caregiving is the carer’s emotional and physical response to the perceived losses in a valued care recipient. Family carers experience a variety of emotions (eg sorrow, anger, yearning and acceptance) that can wax and wane over the course of the

disease, from diagnosis to end of life. This pre-death grief is due to care recipients psychological death, which is asynchronous with physical death; a lengthy and uncertain disease trajectory; compromised communication between the person with dementia and the family carer; and changes in relationship quality, family roles and carer freedom.¹⁶⁵

The terms pre-death grief and anticipatory grief are used interchangeably throughout the literature. In this guideline the term ‘anticipatory grief’ is used if both terms are used interchangeably or not clearly stated.

7.2 Pre-death grief in people with dementia

Further research is needed to understand pre-death grief in people with dementia, as no studies were identified that focused solely on the person with dementia. One qualitative synthesis (of 23 papers) focused on the experiences of the onset of dementia in younger people (aged 35–68 years) and their carers (aged 10–78 years).¹²¹ People with dementia experience progressive losses related to their sense of personal identity that can result in experiences that are grief-like, and they may think about their death and the impact of their diagnosis on their future.¹²¹ These findings¹²¹ were based on three primary qualitative interview studies^{166–168} in younger people (age range 35–68 years) with dementia, who discussed their experiences of grief and loss, although this was not the main focus of the studies. Two of the studies were based in the UK^{166,167} and one in the USA;¹⁶⁸ all three were of high quality. In total they interviewed 36 people. The USA-based study¹⁶⁸ recommends that ‘there is a need for counselling, especially grief counselling, for both the person [with dementia] and family members.’

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One high-quality qualitative study of 30 people and their carers attending a Geriatric Day Hospital Program in Canada explored the reaction of people with dementia to their initial diagnosis of Alzheimer’s disease or vascular dementia.¹⁶⁹ Their carers provided further insight into the person with dementia’s reaction, but no data was collected on the reactions of the carers themselves. The majority (67%) of people with dementia were aged between 65 and 84 years, with 33 % aged over 85; 67% were women. Most were high-school educated or above (64%). Eighty-three per cent had very mild to mild cognitive impairment as assessed by the MMSE and no participants had severe cognitive impairment. Most carers were adult children of the person with dementia (67%) or their spouse (23%). This study showed that the person with dementia experienced a grief reaction following their diagnosis triggered by actual and/or anticipated losses associated with dementia. The losses included relationships, social roles, competencies, self-esteem, sense of autonomy and control, but the most feared loss appeared to be that of a sense of personal identity.¹⁶⁹ The authors recommend ongoing education, support and psychotherapeutic interventions beginning from the diagnostic phase for people with dementia.

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R | **Health and social care professionals should be aware that people with dementia may have experiences that are grief-like. These can relate to:**

- **progressive losses in personal identity that can result in mourning for the old self**
- **thinking about their death**
- **loss of their plans for the future**
- **loss of social roles, relationships and competencies.**

7.3 Pre-death grief in the carers of people with dementia

A number of qualitative systematic reviews,^{121,162,170} mixed-methods systematic reviews and other reviews, examined the experiences of carers with pre-death grief.^{161,163} Reviews only included studies of younger people with dementia and their carers,¹²¹ and one focused only on the carers of people with young-onset dementia.¹⁷⁰ The majority of the studies were based in the USA.

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There was consensus across the reviews that the experience of pre-death grief in carers can start at diagnosis.^{121,159,161-163,170} While it can fluctuate across the course of dementia, it usually worsens as the dementia becomes more severe and the losses associated with the dementia mount.^{44,161-163} Carers are most likely to experience pre-death grief and need support with grief at transition points, such as at diagnosis or during a move to residential care or into or out of hospice care, and as the dementia worsens.^{161,162,170-172}

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Adult children and spouses may experience grief in different ways throughout the course of dementia. The nature of pre-death grief may be more difficult for spouses because of the loss of the intimacy and companionship they had with their partner before they developed cognitive problems.^{159,161,163} One mixed-methods review suggested that in the early stages of dementia spouses were more likely to accept the diagnosis and discuss the future openly, whereas adult children carers of people with mild dementia tended to deny the seriousness of the condition.¹⁶¹ For spouse carers of people with young-onset dementia, grief for the loss of a shared future was emphasised, such as the loss of retirement plans.¹⁷⁰ The children of a person with young-onset dementia may grieve the loss of normality and for some, a parent they never fully had.¹⁷⁰

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*"I was grieving for the whole time because it's for something that I never had, I was grieving for that person that I never had . . . and that I was never going to have."*¹⁷⁰

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R Healthcare professionals should be aware that carers of people with dementia may experience pre-death grief from the point of diagnosis and throughout the stages of dementia, and sensitively enquire about these experiences:

- **worsening pre-death grief as dementia becomes more severe**
- **worsening pre-death grief at transition points, such as when the person with dementia is moved to long-term care.**

7.4 Assessment and measurement of anticipatory and pre-death grief in carers

Pre-death grief in dementia has many facets that can be measured using self-scoring questionnaires.¹⁷³ For measurement of pre-death grief in carers, a number of tools have been developed, with support for the use of different measures of anticipatory grief.¹⁷³ Further research is needed for the evaluation of anticipatory and pre-death grief in carers and the responsiveness and interpretability of instruments to measure pre-death grief.¹⁷³

Pre-death grief in carers is varied and influenced by individual circumstances and the losses carers experience during the course of dementia; three reviews and one high-quality primary study emphasised the need for a full and holistic assessment before any form of intervention or support aimed at ameliorating grief is offered.^{159,162,163,171} It is difficult for carers of people with dementia to 'recognise' and talk about their experiences of pre-death grief.¹⁷⁴ Careful consideration of appropriate interventional strategies is important because coping strategies, such as avoidance of grief and distancing from the care receiver, can be protective of the carer in enabling them to cope with caring and their daily tasks.^{162,174}

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R Healthcare professionals should offer a holistic assessment of carers that includes pre-death grief, with consideration of appropriate management and interventional strategies. Interventional strategies should be carefully considered because coping strategies for carers such as, avoidance of grief and distancing from the person with dementia, can be protective for the carer enabling them to cope with caring responsibilities and their daily tasks.

7.5 Pre-death grief and depression in carers

Carer depression increases as anticipatory grief increases.¹⁶¹ A cohort study of spouses (20%) and adult child carers (80%) of people with dementia in Singapore found an association between carer grief and depressive symptoms, with a 5.76 point increase in the depression scale score for each standard deviation increment in the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) (95% CI 4.20 to 7.32) $p < 0.001$ ¹⁷⁵ Pre-death grief may have a worse impact on wellbeing and be associated with worse outcomes than depression for carers.¹⁷⁵

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While the experience of pre-death grief may be associated with depression, they are not equivalent.^{161,165} Two USA-based, cross-sectional surveys suggest that what appears to be clinical depression in this group may sometimes be pre-death grief.¹⁶¹ The cohort study from Singapore suggested that pre-death grief is likely to act on wellbeing through a different mechanism to carer burden, and current treatments for carer burden may not take account of the impact of grief and may even worsen it.¹⁷⁵

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R | **Health and social care professionals should be aware that pre-death grief experienced by carers of people with dementia:**

- **is associated with depression, and care should be taken to avoid misdiagnosis of depression; treatment for carer burden and depression, may not directly address pre-death grief**
- **can be distressing and disabling, and has an impact on wellbeing.**

✓ | Grief and depression can co-occur and grief should not preclude the carer from receiving treatment for depression.

7.6 Support and management approaches for carers with pre-death grief

There is evidence that care professionals should offer support to carers and the family unit, as well as the person with dementia, including interventions aimed at developing skills for coping with loss and grief.^{159,161-163,165,170,171} Nursing staff were the professionals most often described as active providers of support aimed at helping carers to cope with psychosocial aspects of dementia and grief.^{162,165,170,171}

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There is a lack of guidance and training for professionals on the assessment and support of carers experiencing pre- (and post-) death grief.^{159,161,162,165,170,171} With no clear knowledge and skills framework or evidence-based guidance, grief-focused support of carers often depends on descriptions of practice and professionals' experience instead.¹⁷¹ A qualitative synthesis suggested that: 'Training for professionals may help them to identify carers experiencing grief and provide an appropriate forum for carers to discuss their grief therefore reducing the isolation and stigma.'¹⁶²

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A non-randomised controlled trial examined the effect of a grief management coaching intervention delivered in a range of ways (face-to-face, individual, group, telephone or online) by counsellors with extensive knowledge and experience in dementia care. The findings suggest that the abilities of clinicians skilled and knowledgeable in dementia care and grief was central to tailoring the coaching intervention specifically to the needs of each participant.¹⁷⁶

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Areas where professional support for pre-death grief could focus, include:

- psychoeducation on illness trajectory, caregiving skills and self-help strategies^{159,165,172,174}
- investing in other relationships and activities^{158,162,170}
- accessing consistent social support before and after death of the care receiver^{158,159,161,162}
- cognitive behavioural support strategies.^{172,174,177,178}

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An RCT of a 12-session telephone-based CBT programme did not lead to improvement in pre-death grief at the end of the 6-month programme, but moderate benefit was reported after a further 6 months' follow-up ($p=0.003$).¹⁷⁸ The programme included a module on changes, loss and grief, with a focus on recognising and accepting negative emotions, redefining relationships and psychoeducation around preparing for the death of the person with dementia. Techniques were adapted to each carer's needs, creating highly individualised treatment. Sessions were conducted by clinical psychologists. In the module, grief was understood as 'a normal and appropriate reaction to the carer's experience over the disease trajectory.' Carers who were still caring at home had a stronger decline in pre-death grief than those whose care recipient had moved into a nursing home placement. The authors suggest that carers in the intervention group were more able to come to terms with their grief over time than the control group.¹⁷⁸

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Another small RCT found benefit from a grief intervention programme.¹⁷⁷ There were improvements in the symptoms of grief-related emotions (emotional pain $p=0.011$) and a decrease in the feelings of loss of meaning and desperation regarding the future loss (absolute loss scale $p=0.029$), which increased in the control group. The intervention was based on an established grief intervention programme for complicated grief. Adaptations were made for use in the grieving process for carers. Participants were not eligible if they were currently receiving psychological or psychiatric treatment. It was based on the CBT model and also included interpersonal therapy techniques and motivational intervention. The sessions were facilitated by an expert in providing care to individuals with dementia. Face-to-face groups of five or six participants undertook 10 weekly 90-minute sessions. However, the investigators also facilitated the group sessions and randomisation of participants was unclear.¹⁷⁷

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A qualitative study of nine male carers in Norway described the grief and loss experienced by men as dementia progressed.¹⁷⁹ All the men interviewed would have welcomed the availability of male-only support groups, so that they could share their experiences with others whom they felt were similar to themselves and able to understand their experiences and to lessen the loneliness and isolation they were experiencing. One man said:

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*"It was good to talk to someone who has been through the same things I have. It's not easy to talk to these lasses...I'm 86, these are just twentysomething youngens. And they talk as if I'm hard of hearing. Sometimes they think I'm stupid too."*¹⁷⁹

Grief management coaching for carers of people with Alzheimer's disease or dementia significantly reduced grief ($p=0.003$), as measured by the MM-CGI.¹⁷⁶ The intervention group received on average six 1-hour coaching sessions; the number of sessions needed was determined by assessment by the coaches. Session content included transitions, dimensions of grief, living with grief, honouring grief, maintaining self and enhancing resilience. The programme was run by registered clinical counsellors with extensive knowledge and experience in coaching. The authors distinguished coaching as different from therapy. Two follow-up sessions were offered. The control group ($n=77$) was encouraged to participate in all existing education and support programmes.¹⁷⁶

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A non-randomised controlled feasibility study showed short but not long-term benefits from a group-based multicomponent chronic grief management intervention.¹⁸⁰ Immediately after the 3-month intervention period there was an improvement compared with the control group in heartfelt sadness and longing, but no difference between study groups in the feelings of personal sacrifice, burden, worry or isolation. At 6 months from baseline there were no significant differences between study groups. The intervention included a 12-session group-based multicomponent chronic grief management intervention on grief in primary carers of people with dementia who had moved to live in a care facility in the last year. The programme, delivered by a specialist nurse, focused on improving knowledge of late-stage dementia, communication and grief processing, including recognising and processing losses and separation, relinquishing old attachments and readjusting and investing in new attachments. It also covered conflict resolution and chronic grief

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and depression.¹⁸⁰ The mean baseline measure for the intervention group did not suggest they were experiencing complicated grief, but most were in the range considered 'common grief reaction' by the measure. } 1-

It is important to consider whether interventions and approaches are targeting grief experienced as a normal process within the context of caring for a person with dementia or whether the individual is experiencing complicated grief (*see section 7.8*) that would meet ICD-11 diagnostic criteria of prolonged grief disorder. The interventions in the studies all focused on participants who had not been assessed as having complicated grief.

One high quality RCT¹⁷⁸ highlighted the focus on grief being a normal reaction, for carers. The study incorporated grief into a wider intervention for carers of people with dementia, and for those experiencing 'normal grief' this might be the most feasible form of intervention.¹⁷⁸ } 1+

Only one study reported on harms, where a carers' programme in Singapore (including training workshops and carer support groups) worsened the effect of pre-death grief. The authors hypothesised that 'routine exploration of emotion in support groups, especially among carers with high grief and when emotions are not properly processed, may potentially overwhelm carers' and aggravate the impact of grief.¹⁷⁵ Harms were also reported in the assessment of pre-death grief (*see section 7.3*). } 3

R | Health and social care professionals should receive guidance and training on the assessment and support of pre-death grief for carers of people with dementia.

R | Assessment, support and management approaches for pre-death grief should be focused on carers and family units, as well as people with dementia, and could include coping skills for loss and grief.

R | To reduce the impact of pre-death grief in carers of people living with dementia, postdiagnostic support for carers could include psychoeducation using cognitive-based approaches on the role of grief and loss in the adjustment to caring for someone with dementia, and later for bereavement as part of a wider programme to support carers. Interventions should be individualised to carers' needs:

- consider face-to-face, online or telephone, individual and group delivery.

R | Psychotherapeutic support for grief should be delivered by practitioners trained in psychological approaches, with expert knowledge and experience of working with people with dementia and their carers.

Education and training resources for professionals working with people with dementia and their carers can be found in section 9.4.

✓ | Practitioners with appropriate knowledge skills and expertise (eg psychologists, nurses, occupational therapists, including the third sector workforce), defined in the [Promoting Excellence Framework in Dementia](#),¹¹ could deliver psychological approaches for grief.

Consider local services offered by both statutory and non-statutory sectors and carers' individual preferences for accessing these services.

7.7 Support for people with dementia following bereavement

Three qualitative studies were identified that described the experiences of people with dementia following the death of a spouse, relative or friend.^{171,181,182} All three rely on carer or professional descriptions of the experiences of people with dementia. } JBI
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One of the studies, from Japan, aimed to explore the mourning process of bereaved people with dementia who had lost a spouse and use the information to guide grief counselling.¹⁸² The sample consisted of seven pairs of family and paid carers. The sample was too small to make transferable conclusions about how to devise grief care for people with dementia, even in a Japanese context. However, it provides descriptions of the experiences of grief following a bereavement in people with mild, moderate and severe dementia.

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A high-quality, UK-based case study described one carer's experiences of caring for her mother in residential care.¹⁷¹ The carer describes her mother's re-experiencing of the grief associated with her husband's death each time she visited her and passed on this information (which her mother did not retain):

"Mum also asks about Dad. Invariably, when I go and see her, Mum will jump up, glad to see me, take my hand, and ask:

'Where's Dad?'

I try and fight back the tears explaining that Dad, her husband, has died. Mum has no recollection of the day of his funeral when she said she felt like crying, but couldn't. I smile, glad that my mother does not feel the pain as I do."¹⁷¹

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A US case study reported on two interventions for grief following bereavement in people with dementia.¹⁸¹ The group consisted of 13 members from the same care facility, ranging from 50 to 95 years of age. It also described the use of spaced retrieval to assist an older adult with dementia to retain information about the death of a loved one. Spaced retrieval involves recalling new information repeatedly, with each recollection elicited over a longer period of time.

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The studies conclude that people with dementia face a more complicated grieving process because of their cognitive and memory losses.^{181,182} For people with mild to moderate dementia, cognitive and memory impairment may result in a re-experiencing of the death each time they are told that their loved one has died. Difficulty retaining information about the death and re-experiencing grief can result in agitation, distress, depression, behavioural problems and confusion; it is also distressing for carers.^{171,181,182}

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People with dementia may require support after the death of a family member, spouse or friend, to process the loss and to manage the distress, agitation and confusion associated with the loss^{171,181,182} (see section 6). However, there is a lack of guidance, education and training for professionals on how to support people with dementia following the death of a spouse, relative or friend.^{181,182}

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R | Health and social care professionals should be aware that people with dementia may re-experience grief because of a failure to retain details of the loss of a spouse or family member.

R | People with dementia may require support from health and social care professionals with grief following a bereavement, to process the loss and to manage any distress, agitation and confusion associated with the loss.

✓ | Support for people with dementia experiencing grief should be delivered by professionals with appropriate training (as defined by the Promoting Excellence Framework in Dementia).¹¹

7.8 Grief following bereavement, and prolonged and complicated grief in carers of people with dementia

The term 'complicated grief' has been used to describe grief and associated painful emotions that are unusually persistent and disabling, yet the syndrome is not well defined.¹⁶¹ Prolonged grief disorder is defined in the fifth Diagnostic and Statistical Manual of Mental Disorders of the

American Psychiatric Association (DSM-5) and ICD-11. It is a persistent and pervasive grief response characterised by longing for the deceased or persistent preoccupation with the deceased that is accompanied by intense emotional pain (eg guilt, sadness, anger, denial, and blame).^{183,184} The grief response must have persisted for more than 6 months and cause significant impairment in functioning (personal, family, social, educational, occupational and so on) to warrant a diagnosis.¹⁸⁴

The experience of grief after the death of a loved one is a normal reaction, however, carers of people with dementia have often been exposed to a long period of emotional distress and multiple losses, related to the inevitable decline of the person with dementia.¹⁶² While many carers described a sense of relief at the time of the death of because of the end of the suffering of the person with dementia and the end of caring duties, for some people these feelings were complicated by guilt and loss.^{161,162,165} One qualitative systematic review concluded that dementia carers may be particularly vulnerable to a 'challenging grieving process' and 'intensified grief'.¹⁶²

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One study of 217 carers¹⁸⁵ (rated as high quality in a systematic review)¹⁶¹ found that approximately 20 % of carers for a person with dementia experienced complicated grief 12 months after the death of the person with dementia . A cross-sectional survey¹⁸⁶ of 138 carers of people with dementia and 38 carers of people with cardiac disease (within the same systematic review,¹⁶¹ rated as a moderate to low quality) found that the carers of people with dementia experience nearly twice the amount of loss as people caring for someone with cardiac problems.

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A mixed-methods systematic review concluded that being a spouse carer and being depressed are the strongest predictors of complicated grief after death in the carers of people with dementia.¹⁶¹ This conclusion was based on two USA-based prospective cohort studies, with a combined sample of 441 carers that was assessed as medium to high quality.¹⁶¹ The same review concluded that African American ethnicity and higher level of carer burden may also predict complicated grief.¹⁶¹ The early identification of modifiable risk factors (such as the need for person with dementia to move to long-term care, carer depression and carer burden) and the provision of appropriate support during the grieving period may help to prevent the development of complicated grief in carers.¹⁶¹ A qualitative synthesis of 11 studies concluded that carers who had experienced more feelings of guilt, commonly around the person with dementia moving to long-term care, were less likely to feel relief after the death of the person with dementia.¹⁶²

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Carers may also feel socially isolated and unable to access wider support services because of the belief that others will not be able to understand their experiences and their grief.¹⁶²

A US-based case study of two bereaved carers of people with dementia following the sudden death of their spouse (from choking and a fall)¹⁵⁵ and whose husbands had had particularly challenging types of dementias (progressive supranuclear palsy and frontotemporal dementia) described their experiences of group therapy for complicated grief.¹⁵⁵ No conclusions about the effectiveness were drawn, however, the authors suggest that, upon death and in the early weeks and months of mourning, clinicians must accurately assess the risks for complicated grief, screen carefully for complicated grief and refer to appropriate mental health care.

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R | **Health and social care professionals should be aware of the risk of complicated or prolonged grief in the carers of people with dementia following the death of the person with dementia.**

R | **Health and social care professionals should be aware that the experience of complicated grief or prolonged grief may be more likely in carers:**

- who are spouses
- when the person with dementia moves into long-term care, outside the home setting
- who have experienced high levels of guilt, depression, a lack of social support and a higher care burden.

- ✓ Health and social care professionals should be aware that carers of people with dementia may experience complicated grief, and should consider offering referral for psychological therapy, as appropriate. As grief is a very individual experience, the individual's informed consent must be obtained and circumstances that might affect their ability or wish to engage in such approaches should be taken into account.
- ✓ Practitioners with appropriate knowledge skills and expertise in dementia, defined in the Promoting Excellence Framework in Dementia,¹¹ could deliver psychological approaches to support people experiencing complicated grief. Local services offered by both statutory and non-statutory sectors, and carers' individual preferences for accessing these services, should be considered.

8 Changing needs of people with dementia

Dementia is a progressive condition^{38,187} and as such all dementia care may be considered palliative. Not recognising dementia in this way may drive the stigma and misrepresentation that dementia is a syndrome of old age.

Dementia affects an individual's wider physical and mental health, as well as their cognitive abilities, so a biopsychosocial approach is needed.

8.1 Assessment of changing and unmet needs

8.1.1 Assessment of changing and unmet needs in people with moderate, advanced and severe dementia

The progression of dementia is often separated into mild, moderate and severe, aligned to early, mid and late or advanced stages.¹⁸⁷ The middle to late stages of the disease often signal a loss of autonomy, independence and reduction in physical and cognitive function.¹⁸⁷ This stage has been described as the beginning of an extended, intensive palliative care phase.¹⁸⁸ Unlike other diseases such as cancer or organ failure, the disease trajectory for people with advanced dementia, is often characterised by a progressive decline over a long period of time making it difficult to identify or predict when death will occur.¹⁸⁹

An integrative review highlighted that there was no consistent definition of advanced dementia.¹⁸⁷ The term 'advanced dementia' was used as a short operational definition of the extended palliative phase this period can be more than twice as long as the early stages of the disease (up to 10 years).¹⁸⁸ There is a lack of literature on the psychological, spiritual and existential needs and preferences of people with advanced dementia and their family and carers.^{190,191}

As dementia progresses, living well requires increasing levels of support and care. People living with advanced dementia have complex health and social care needs, and are highly dependent, but may not yet be at the end stage of the condition. Symptoms may include difficulties with communication, mobility, eating and drinking and pain. Other symptoms may include psychosis, persistent confusion, withdrawal, lethargy, apathy, depressed mood, agitation or aggression.¹⁸⁷ People with dementia may also have other premorbid conditions and later life conditions, which require support and care, for example oral health, toileting and all activities of daily living.

No evidence was identified directly relating to assessment of approaches to address changing or unmet needs in people with moderate, advanced or severe dementia. Assessment of approaches were largely related to palliative or end-of-life care, with some evidence around transitional care.

8.1.2 Assessment and unmet needs of people with young-onset dementia and their carers

A systematic review of cross-sectional or longitudinal studies of carers examined factors related to quality of life, wellbeing and unmet needs in people with young-onset dementia or people with young-onset Alzheimer's disease, vascular dementia, mixed or frontotemporal dementia and dementia with other causes, at all stages of severity.¹⁹² One study included young carers aged 13–23 years, and studies originated from the UK (n=3) and Europe (n=5), with one international study. There was no critical appraisal of included studies, and there is a lack of detail on the search strategy.

The assessment instrument most frequently used to measure unmet needs was the Camberwell Assessment of Need for the Elderly (CANE), a semistructured interview consisting of 24 domains that cover social, physical, psychological and environmental needs of the person with dementia, as well as psychological needs of the carer. Quality of life was assessed most frequently using

the Quality of Life – Alzheimer Disease scale (QoL-AD), which covers 13 domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole.¹⁹² Evaluation instruments were challenging, with two studies reporting the inability of a large proportion of people with young-onset dementia to complete the assessment instruments as a limitation. The review authors commented that instruments widely used to assess quality of life, unmet needs and wellbeing of people with dementia may not be appropriate for people with young-onset dementia.¹⁹²

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Until further high-quality evidence is available, no recommendations on the assessment of unmet needs in people with young-onset dementia can be made.

8.2 Palliative and end-of-life care approaches

There is a lack of understanding of palliative care among front-line practitioners that relates to the lack of educational opportunities in advanced dementia care.^{190,191}

Palliative care is defined as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’¹⁹³

People with advanced dementia can benefit from a dementia-specific palliative approach to care, for example ‘Palliare’ approaches,¹⁹⁴ However people with dementia are less likely to receive palliative care, because of the complex and unpredictable disease trajectory. This can result in unmet needs and potentially burdensome interventions until death.¹⁹⁵

A Dementia Palliare best practice statement aims to promote a consistent and cohesive approach to advanced dementia care. It advocates a biopsychosocial spiritual model of dementia care that places the person and caring relationships at the centre of health care, with the management of symptoms encompassing the biopsychosocial, spiritual needs and preferences of the person with dementia, their family and friends.^{38,39}

The European Association of Palliative Care (EAPC) sought to define optimal palliative care in dementia by conducting a five-round Delphi study involving 64 experts across 23 countries.¹⁹⁶ It provided the first definition of palliative care in dementia, based on evidence and consensus, and presented a consensus-based framework consisting of 11 domains and 57 recommendations to provide guidance for clinical practice, policy and research. The final 11 domains were:

- applicability of palliative care
- person-centred communication and shared decision making
- setting care goals and advance planning
- continuity of care
- prognostication and timely recognition of dying
- avoiding overly aggressive, burdensome or futile treatment
- optimal treatment of symptoms and providing comfort
- psychosocial and spiritual support
- family care and involvement
- education of the healthcare team
- societal and ethical issues.¹⁹⁶

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A systematic review of 51 papers, reporting on 32 studies, explored the components of palliative care interventions in addressing the needs of people with dementia in long-term care, focusing on shared decision making and examining alignment to 10 of the 11 the EAPC domains of care (domain 11, societal and ethical issues, was not mapped to).¹⁹⁷ Included studies were quantitative,

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qualitative and mixed-methods, with one description of an advance care plan process. They were conducted in a range of geographical settings, including the UK, USA, Australia, Netherlands Canada, Italy, Belgium and Japan.

Eighteen interventions developed for people with advanced dementia were reported on. Studies included 16 to 688 participants (median 136 participants), including residents, family members, long-term care facility staff and healthcare professionals external to care facilities, with interventions targeting long-term care facility staff, family members or both. The review found that all 10 domains were addressed to varying extents, with interventions addressing on average five domains each. Domains 7 (symptom management, n=19), 6 (avoiding overly aggressive treatment, n=18) and 10 (education; n=17) were the most commonly addressed; domains 5 (prognostication, n=7) and 4 (continuity of care, n=2) were the least addressed.¹⁹⁷

This review indicated that a range of interventions that addressed the domains were being used in people with dementia receiving palliative care in long-term care. There was a focus on developing interventions that provide education and upskilling of healthcare teams, support optimal treatment of symptoms and comfort care, and seeking to prevent aggressive treatment at the end of life. Fewer interventions focused on prognostication and continuity of care. The authors proposed that the small number of interventions relating to prognostication is consistent with the EAPC white paper, in which prognostication was scored as the least important domain of interest. Given the uncertainty around prognosis, interventions that move from prognosis-driven palliative care and emphasise a needs-based model of care (identifying unmet palliative care needs) for people with dementia in long-term care settings are encouraging.¹⁹⁷

The following recommendation is reproduced from the NICE guideline on assessment, management and support for people living with dementia and their carers (NG97).²²

R | **From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.**
For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process. Involve the person and their family members or carers (as appropriate) as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.
 (In Scotland the [Adults with Incapacity \(Scotland\) Act 2000](#))

Advance and anticipatory care planning is covered in section 8.4.

R | **Review the person's needs and wishes** (including any care and support plans and advance care and support plans) **after every transition.**

8.2.1 Defining end of life

Prognostication in dementia care is difficult, with difficulty in identifying or predicting when death is likely.¹⁸⁹ A mixed-methods systematic review found that definitions of end of life varied in the 33 included studies.¹⁹⁵ These studies spanned a range of designs (cohort n=13, qualitative n=8, RCT n=5, evaluation designs n=4, mixed-methods n=2, quasiexperimental n=1) and countries of origin (USA n=15, UK n= 5, Europe n=3, other international n=8). The studies were conducted in nursing home (n=21), hospital (n=7), hospice (n=1) and home (n=1) settings, with two studies conducted across more than one setting (home and nursing home or hospital and nursing home). Eight different validated tools were used in 30 out of 33 studies to identify people living with dementia who were approaching the end of life, with nine studies using two or three scales interchangeably within the same study. The tools used were Global Deterioration Scale, Cognitive Performance Scale, Functional Assessment Screening Tool, MMSE, Functional Independence Measure, Clinical Dementia Rating, Australia-Modified Kamofsky Performance Status and Functional Autonomy Measurement

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System. The most commonly used tool was the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS), which assesses cognition, with cut-off scores of 5 for moderate and 7 for severe dementia. The second most commonly used tool was the Functional Assessment Screening Tool, which focuses on function stages ranging from 6a (requires physical assistance with clothing) to 7a (inability to hold the head up).¹⁹⁵ One study¹⁹⁸ within this systematic review recommended assessing the level of suffering in people dying with dementia; suffering being a state of psychological distress, spiritual concerns and various presentations of physical pain. They investigated the suffering of people with terminal dementia from admission to a geriatric ward to the last day of life, and found 63% of people with advanced dementia died with high levels of suffering and had shorter survival times.¹⁹⁸ Overall, the systematic review¹⁹⁵ concluded that the holistic needs of the individual were not considered. Three main themes were identified:

1. 'Limitations in existing measures to define end of life in dementia,' with the need for alternative measures to identify end of life, as current measures based on cognition and ambulatory function were ineffective at identifying end of life in dementia (based on six studies).
2. 'Family knowledge,' which identified that family carers had little understanding that people living with dementia can die from dementia
*"I don't think she [Mum] will die from dementia, I think she will die from a heart attack or stroke... some other medical condition but not dementia...do people die from dementia? I've never...heard of people dying [from it]"*¹⁹⁵
3. 'Staff knowledge,' finding that healthcare professionals also had limited knowledge of end of life in people with dementia (a lack of training in nursing homes was identified in two studies, one UK based).¹⁹⁵

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This systematic review concluded that end of life in people with dementia remains poorly defined, and unrepresentative of the general population with dementia.¹⁹⁵ Current measures based on cognition and ambulatory function are ineffective at identifying end of life in dementia and may fail to recognise other significant signs and unmet needs relevant to dementia at the end of life. It proposed that researchers and healthcare professionals in dementia care accept the complex nature of end of life between and within individuals with dementia and advocated for a transition beyond defining end of life by disease stage and to consider signs beyond cognitive and functional decline. Identifying the appropriate signs and the needs of individuals at the end of life could provide an improved response to end-of-life care for people with dementia and their families. The need for a multidisciplinary and palliative approach tailored to people living with dementia, encompassing physical, medical and psychosocial needs, was recommended.¹⁹⁵

- R** | **Healthcare professionals should be aware that existing measures to define end of life in people with dementia based on cognition and ambulatory function may be ineffective and may not recognise the unmet needs at end of life.**
Healthcare professionals should focus on the needs of the individual and consider moving away from a focus on defining end of life by disease stage.
- R** | **Family and carers of people with dementia should receive education, so that they understand how dementia can be the cause of death.**
- R** | **Healthcare professionals and those involved in the care of people with dementia should be aware that palliative care is ongoing from diagnosis to end of life.**

Information points

- i** | People living with dementia, and their family and carers, should be provided with information about the progressive course of the condition, that dementia can be a cause of death and that a palliative approach to care is appropriate at all stages.

8.3 Transitions between care settings

Although not specifically focused on assessment of changing needs in relation to disease stages, one systematic review focused on the management and experience of transitions over a long trajectory, the assumption being that this would incorporate changing stages of the disease and needs.¹⁹⁹ Thirteen papers reporting on 11 studies were included in the review (RCT n=8, quasiexperimental n=2, case series n=1). Participants were 1,861 older people with dementia (mean age 80 years) and 1,503 carers (mean age 69 years). Most studies were conducted in the USA, with one each in Australia and Europe. Interventions and data collection occurred over a variety of time periods (3 months to 16 years with a 12-month follow-up period most common). All studies included transitions from inpatient hospital settings, and/or residential aged care facilities, and/or outpatients/people living at home. Studies used outcome measures that were specific to cognitive status, behavioural symptoms, mental health, multimorbidity, physical functioning and quality of life. Six themes were identified for people with dementia and carers in relation to transitional care outcomes, as follows:¹⁹⁹

- Understanding the needs of older people living with dementia remains a priority, and complex interventions should address unmet needs of carers.
- Depression continues to be a significant area of need for people with dementia, as well as understanding carers' needs in emotional and mental wellbeing.
- Tailored education and support for older people living with dementia and better education for carers have more positive effects on transition experiences.
- Physical decline (falls, ADL, personal care and task assistance and balance) in older people living with dementia are important indicators.
- The importance of self-reported quality of life for people with dementia and poor quality of life of carers sees important components of caregiving come to light.
- With better service utilisation, which includes the need for a greater focus on carer-relevant services, transitions for older people living with dementia can be decreased/delayed.¹⁹⁹

Four included studies identified unmet needs as a primary goal of care for older people living with dementia and used unmet needs of the people with dementia as important outcome domains.²⁰⁰⁻²⁰³ Two studies identified that improvement in addressing unmet needs through better health service utilisation can lead to improvement in transitions for people with dementia.^{200,203} Models of care that assess people with dementia and their carers in a variety of areas and develop goals of care to address these needs can achieve improvements in unmet needs.²⁰² A Partners in Dementia Care intervention focused on holistic-centred care for people with dementia and saw a 44.1% decrease in unmet needs and cognitive impairment compared with a control decrease of 7.8%.²⁰¹ Overall, improvements related to better health service utilisation and prioritising the identification of care goals. Carers of people with dementia with more severe cognitive impairment were more likely to report severe unmet needs, but effective interventions resulted in greater improvements.²⁰⁴ The needs of carers are addressed elsewhere in this guideline (*see section 5 for carer needs relating to postdiagnostic support and section 7 for carer needs relating to grief*). The conclusion was that a holistic, autonomous and person-centred approach to transitional care is yet to be established.¹⁹⁹ Overall, transitions may be delayed with better health service utilisation, interhealthcare setting communication, and personalised care plans and goals of care, developed from assessments of older people. More research is needed into the methods to facilitate this effectively.¹⁹⁹

The findings of the studies included in this review may not be directly comparable or transferable to Scotland because of their predominantly non-UK settings. The main transition of care in the UK context is from home to long-term care (eg care home), usually when dementia is reasonably advanced; therefore, involving the person with dementia in goal-setting and care plans will be challenging.

- R** | **Health and social care professionals should consider holistic, person-centred approaches when people with dementia transition between care settings, that include the needs of people with dementia and their carers.**
- For people with dementia consider:**
- **identifying unmet needs such as depression, quality of life, physical decline** (such as falls and the ability to perform activities of daily living, such as walking and balance)
 - **setting person-centred goals and care plans to address unmet needs and signpost to or link with appropriate services that offer support for identified needs.**
- ✓ | In the advanced stages of dementia, when the transition from home to long-term care is more likely, it may be challenging to involve the person with dementia in goal-setting and care plans. This should be considered as part of anticipatory care planning discussions (see section 8.4).

Information points

- i** | Where transition to long-term care is anticipated, healthcare professionals should aim to have early discussions with the person with dementia and their family or carer(s) in relation to their expected needs (eg mental health and wellbeing, physical ability/decline), goals and plans for this transition. This should inform discussions at transition, considering the holistic needs of the person with dementia at that time.

8.4 Advance and anticipatory, or future, care planning

Advance care planning has been defined as a process ‘enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record these preferences if appropriate’.²⁰⁵

The term ‘anticipatory care planning’ (ACP) has been used in Scotland to refer to the support that people living with a long-term health condition (such as dementia) should receive to plan for an expected change in health or social status.²⁰⁶ The term ‘future care planning’ is to be used in the future and any references to advance or anticipatory care in this guideline should be interpreted under that term in future.²⁰⁷

Anticipatory care planning is widely used within health and social care in Scotland to describe a person-centred, proactive approach to help people consider what is important to them and plan for their future care.²⁰⁸ Anticipatory care planning has been shown to influence care practices, decrease hospitalisations, reduce length of stay and increase concordance between an individual’s end-of-life wishes and the care they are provided with, in a nursing home setting.²⁰⁹

The terms advance care planning and anticipatory care planning describe similar concepts. The term anticipatory care planning will be used in this guideline to encompass both advance and anticipatory care planning.

ACP discussions involving people with dementia may include conversations around a wide range of topics, including but not confined to acceptable levels of medical intervention and treatment, the use of artificial hydration and feeding, the scope of life preserving emergency interventions, and preferences around the type of and place of care. A report by the Care Quality Commission following the start of the COVID-19 pandemic emphasised that discussions about Do Not Attempt Cardiopulmonary Resuscitation may form part of an ACP, but should be part of a much wider conversation about future care and treatment preferences.²¹⁰

Informal carers, including family members play an important role in supporting someone with dementia to develop a person-centred ACP. It should be acknowledged that there is some evidence that there may be only low to moderate agreement between the person's actual care and treatment preferences and those assumed by family.²¹¹ As dementia progresses, people may lose the capacity to make decisions about future healthcare options. ACP allows a person to state how they do and do not wish to be treated, and what they would like to happen, when they are unable to communicate such wishes. However, when seeking to rely on wishes expressed in ACP it is always important to make sure insofar as it is possible that such wishes remain those of the person.

A 4-step approach to ACP has been developed by Healthcare Improvement Scotland which highlights the importance of clearly documenting ACP decisions and sharing these with relevant health and care professionals, and others (such as informal carers and family members) that need to know. ACP should provide a dynamic record, developed over time, which is reviewed and updated as the person's condition or situation changes.²⁰⁸

The following recommendation is reproduced from the NICE guideline on assessment, management and support for people living with dementia and their carers (NG97).²²

R Offer early and ongoing opportunities for people living with dementia and people involved in their care to discuss: the benefits of planning ahead, lasting power of attorney (for health and welfare decisions and property and financial affairs decisions), an advance statement about their wishes, preferences, beliefs and values regarding their future care, advance decisions to refuse treatment, their preferences for place of care and place of death. Explain that they will be given chances to review and change any advance statements and decisions they have made.

At each care review, offer people the chance to review and change any advance statements and decisions they have made.

8.4.1 Stages of dementia in relation to the person with dementia's decision-making capacity

There are challenges around defining the disease stages and trajectory of dementia (*see section 4*).

Most of the identified studies investigating ACP refer to the stages of dementia in relation to the person's decision-making capacity.²¹²⁻²¹⁴ People who are at an early stage in the illness, experiencing mild symptoms, and some at the moderate stage of disease progression are likely to have the capacity to contribute meaningfully to ACP discussions.²¹⁴ It is recognised that as the illness progresses, communication skills may diminish and the capacity for decision making may be lost, reducing or removing opportunities for the person with dementia to be directly involved.²¹⁵ If or when this happens, proxy decision makers may be involved in decisions about care and treatment.²¹⁵

In clinical practice, fluctuations in capacity can occur and the ability of the person to contribute to decision making can change. Whether the disease is in its earlier stages or is progressive all attempts must be made to support the person to overcome any decision-making challenges they may experience and communicate their wishes and feelings. Proxy decision makers involved in ACP must ensure that they are giving effect to the person's present and past ascertainable wishes and feelings.

There is less evidence on ACP during the earlier stages of dementia, despite recommendations for early ACP conversations with people affected by dementia.^{213,216} Most studies focused on the later stages of dementia (moderate to advanced, and severe) when care and treatment escalation decisions are increasingly called upon.^{209,212,214,217}

Studies identified included an umbrella review (n=19 reviews and n=11 additional primary studies);²¹⁴ two quantitative systematic reviews (n=8 studies);²¹⁵ and (n=30 studies);²⁰⁹ two qualitative systematic reviews (n=7 studies)²¹² and (n=84 studies);²¹⁷ a mixed-methods systematic

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review (n=33 studies);²¹⁶ and a review of guidelines, reviews and primary research aimed at developing clinical recommendations for applying ACP in practice in Belgium.²¹³ The evidence base was international, originating from the USA, Europe, UK and Australia.

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There was sufficient evidence to address when and with whom ACP discussions should take place and how to conduct ACP discussions. There was a lack of evidence about where ACP discussions should take place and on the specific views and preferences of people with dementia.^{212,217}

8.4.2 When should anticipatory care planning discussions take place?

One review of guidelines recommended starting ACP discussions as early as possible and to integrate them into daily care, ideally before cognitive decline is evident.²¹³ However, the most recent umbrella review found a lack of agreement on the best time,²¹⁴ with some included reviews recommending immediately after diagnosis and some recommending that people should be given time to become familiar with the dementia diagnosis first. There is consistency in recognising that ACP may be initiated in response to a trigger such as diagnosis, change in health status or place of residence.^{213,214} There is also consistency in the need for it to be person-centred and tailored to the needs of the person with dementia.^{213,214} In addition, it may need to take place over a series of conversations^{213,214} to allow clarification, reflection and updates to changing needs.²¹³ A precondition for families to be receptive to ACP discussions is understanding that dementia is a progressive and terminal condition.²¹²

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Late or 'crisis-triggered' ACP discussions were acknowledged as potentially stressful for the person with dementia,²¹⁶ and as such might be considered to be associated with harm. There is also evidence of family carer worry and regret if decision making about treatments and life-preserving interventions is left too late or undertaken in a crisis,²¹⁶ reducing or removing opportunities for the person with dementia to be directly involved because of a loss in decision-making capacity.²¹⁵

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8.4.3 Where should anticipatory care planning discussions take place?

A variety of settings were represented in the evidence base. There is evidence that ACP conversations can be planned or opportunistic and take place in any setting, including the family home^{213,215} and care homes.²⁰⁹ A key finding from one systematic review was the importance for any goals developed in an acute care setting to be shared with ongoing care providers.¹⁹⁷

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8.4.4 Who should anticipatory care planning discussions involve?

There was consistency across the evidence base. The umbrella systematic review defined ACP as discussions between the individual and healthcare professional, the person with dementia and informal carer, or the person with dementia, carer and healthcare professional.²¹⁴ Although there was a lack of clarity on who should initiate the discussion, people with dementia, carers and healthcare professionals most frequently thought it was the role of the healthcare professional. A review of guidelines concurred, concluding that because research has shown that ACP conversations are not often initiated by the person living with dementia, the healthcare professional should initiate the discussion as soon as possible after diagnosis.²¹³ A mixed-methods systematic review concluded that a family's witness of a relative's decline was a facilitator for an ACP discussion, but that the healthcare professional should initiate the discussion; if not, then it may only happen when forced by a crisis situation.²¹⁶ GPs are reported to have an important role in ACP, and engaging doctors may result in higher completion rates of advance care directives.^{209,213,216} However, all healthcare professionals can be involved to some extent depending on their skills and knowledge of the disease trajectory.²¹³ The mixed-methods systematic review found that different disciplines were involved to varying degrees in different countries, including physicians, nurses, psychologists, social workers and spiritual care staff.²¹⁶ Informal carers, family and significant others should be involved as early as possible.^{213,214,216}

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Key themes arising were the need for a person- and family-centred approach;^{213,214,216} for people with dementia to be included and enabled to participate in ACP discussions;^{209,213-216} the importance of trusting relationships between healthcare professionals, people with dementia and their carers (formal or informal),^{212-214,217} and the need for healthcare professional education and training on palliative and dementia care, discussions on prognosis, treatment and care options, and how to enable people to engage in ACP discussions.^{214,217}

In support of trusting relationships:

"We had actually not spoken of it [goals and care] in those terms. I knew that they were trying to make her quality of life as good as possible and as functional as possible for as long as they could. And then near the very end, they switched to keeping her comfortable. But we didn't ever really need to have that conversation." [Daughter]²¹²

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In support of family-centred approaches:

"It's good to have the plan, but I also think you need the backup of your family to see that the plan is implemented to its best outcome." [Person with dementia]²¹⁷

"I actually think that before (clinicians) have family members fill out that [do-not-hospitalise] form, somebody should actually sit down and explain every little thing on the form, instead of, "do you want to do this, do you want to do that." They're doing it in a rush, and you don't know half the time what you're signing." [Carer]²¹⁷

- R | Anticipatory care planning discussions should:**
 - be tailored to the needs, readiness to engage and capacity of the person with dementia
 - consider the needs of family and carers
 - consider triggers for discussions, such as diagnosis, change or decline in health status or change in place of residence.
- R | Healthcare professionals should ensure that the person with dementia, and their family or carer(s), are aware of the progressive nature of dementia and what to expect at different stages of the illness.**
- R | Healthcare professionals should be aware that receptivity to anticipatory care planning discussions are increased when the person with dementia and their family have insight into the progressive and terminal nature of dementia.**
- R | The person with dementia, their family and carers and healthcare professionals should all have the opportunity to initiate, and be involved in, anticipatory care planning discussions.**
- R | If the person with dementia does not initiate anticipatory planning discussions, healthcare professionals should proactively initiate or enable person-centred anticipatory care planning conversations as soon as possible.**
- R | The person with dementia, their family and carers and healthcare professionals who are involved in anticipatory care planning discussions should all seek to build trusting relationships.**
- R | Anticipatory care planning may involve a series of conversations over time to allow clarification, reflection and updates to the plan to reflect any changing needs. Early discussions are beneficial, as the capacity of the person with dementia diminishes as the disease progresses.**

- R** | **Anticipatory care planning can take place in any care setting, including the family home, primary care, hospital or care home.**
- R** | **Healthcare professionals should receive education and training on communication skills, anticipatory care planning, the dementia disease trajectory, treatment and care options, and palliative care.**
- ✓ | Practitioners who support anticipatory care planning for people with dementia should be knowledgeable about dementia and dementia care.
- ✓ | All healthcare professionals leading on dementia-related anticipatory care planning should be at the enhanced or expert level of practice or above in dementia care as defined by the [Promoting Excellence Framework in Dementia](#).¹¹
- ✓ | Healthcare professionals with appropriate expertise should lead anticipatory care planning discussions that involve complex clinical needs and treatment considerations, such as artificial feeding.
- ✓ | Healthcare professionals should be aware of anticipatory care planning education and toolkits that are available.
- ✓ | Managers, clinical and professional leads should prioritise and support healthcare professionals to complete anticipatory care plans with people with dementia and to engage with available training.
- ✓ | Healthcare professionals should consider whether or not the person already has an anticipatory care plan; if so, their anticipatory care plan should be discussed and updated to consider their dementia diagnosis.
- ✓ | Healthcare professionals and others involved in anticipatory care discussions should allow sufficient time, and ensure a quiet location, free from distractions, that facilitates a supportive discussion and safeguards confidentiality.
- ✓ | It is important that the most up to date anticipatory care plan is shared with the people who are looking after the person with dementia. This should be easily accessible whenever health or care decisions are being made.
- ✓ | Anticipatory care planning decisions should be reviewed and updated; the frequency of this will be influenced by the pace of disease progression and any changing needs.

Education and training resources for professionals can be found in section 9.4.

Information points

- i** | The person with dementia, and their family or carer(s), should have the progressive and terminal nature of the condition explained to them.
- i** | Discuss the importance of the person with dementia and their carers participating in anticipatory care planning discussions
- i** | Explain to the person with dementia and their carers what anticipatory care planning is, why it is important and the benefits of an anticipatory care plan.

9 Provision of information

This section reflects the issues likely to be of most concern to people with dementia and their carers. These points are provided for use by healthcare professionals when discussing dementia with individuals and carers, and in guiding the development of locally produced information materials. Education and training resources for people living with dementia, their carers and healthcare professionals are highlighted to help promote person-centred conversations, care and self management.

9.1 Publications from SIGN

SIGN produce versions of guidelines that 'translate' guideline recommendations and their rationales, originally developed for healthcare professionals, into a form that is more easily understood and used by people with the condition, those with lived and living experience and the public. They are intended to:

- help people with the condition and carers understand what the latest evidence supports around diagnosis, treatment and self care
- empower individuals to participate fully in decisions around management of their condition in discussion with healthcare professionals
- highlight for people where there are areas of uncertainty.

A copy of the version of this guideline for people with lived and living experience and their carers is available from www.sign.ac.uk/patient-and-public-involvement/patient-publications.

9.2 Sources of further information

Citizens Advice Scotland

Tel: 0800 028 1456

www.cas.org.uk

The Citizens Advice Bureau can give free, confidential, impartial and independent advice and information on a wide range of subjects, including benefits, debt and money advice, consumer issues, work-related problems and housing.

Department for Work and Pensions (DWP)

www.gov.uk

The DWP provides information about benefits and claims forms.

NHS 24

Freephone 111

www.nhs24.scot

NHS 24 is an online and out-of-hours phone service providing access to health advice and information 24 hours a day, 365 days a year.

NHS Inform

Tel: 0800 22 44 88

www.nhsinform.scot

Scotland's national health information service provides people with information on medical conditions, self-help advice and a directory of local support groups.

9.3 Resources for people living with dementia and their carers

Age Scotland

Information and advice for people with dementia and their carers.

www.ageuk.org.uk/scotland/information-advice/dementia

The Alliance

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations

www.alliance-scotland.org.uk

Alzheimer Scotland

Resources for people living with dementia.

www.alzscot.org/living-with-dementia

Charter of rights for people with dementia and their carers in Scotland.

www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf

Online self-management resources.

www.alzscot.org/ahpresources

Webinars that examine how different allied health professionals support people with dementia.

www.alzscot.org/ahpinnovation

Alzheimer's Society

Information and support for people affected by dementia.

www.alzheimers.org.uk

British Deaf Association

Dementia-specific resources for people who are deaf and living with dementia.

bda.org.uk/dementia

Chartered Institute of Housing

Scottish housing and dementia framework, designed to help organisations support people to live well with dementia.

www.cih.org/policy/scottish-housing-and-dementia-framework

Connecting people, connecting support

Resources and activities online for people with dementia, their family members and supporters.

dementiatogether.online

Dementia Carers Count

Offers a range of free services that give family carers the opportunity to understand more about dementia and to connect with others in a similar situation. They offer practical advice on the reality and challenges of being a carer.

www.dementiacarerscount.org.uk

Dementia UK

Resources for people with dementia and their carers,

www.dementiauk.org/get-support

NHS Inform

Anticipatory care planning information.

www.nhsinform.scot/care-support-and-rights/decisions-about-care/anticipatory-care-planning-acp-thinking-ahead/

NHS Inform

Dementia: information and support resources.

www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/dementia

NHS Near Me

Near Me is a video consulting service that enables people to attend appointments from home or wherever is convenient.

www.nearme.scot

Police Scotland

Carers, family or friends of a vulnerable person, or the person themselves, can fill in a Herbert Protocol form, which provides information to help the police if the person goes missing.

www.scotland.police.uk/what-s-happening/missing-persons/the-herbert-protocol

The Scottish Dementia Working Group

A national, member-led campaigning and awareness-raising group for people living with a diagnosis of dementia in Scotland.

www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group/contact-sdwg

Sight Scotland

Dementia and sight loss guide.

sightscotland.org.uk/articles/information-and-advice/dementia-and-sight-loss-guide

Young Dementia UK

Information and support for younger people with dementia and their families

www.youngdementiauk.org

9.3.1 Resources for carers**Age Scotland**

Dementia carers' rights training.

www.ageuk.org.uk/scotland/what-we-do/dementia/age-scotlands-dementia-training-project/training-for-unpaid-carers-of-people-with-dementia

Alzheimer Scotland

Resources for carers.

www.alzscot.org/living-with-dementia/caring-for-someone-with-dementia/resources-for-carers

Alzheimer Scotland

NDCAN (National Dementia Carers Action Network), a campaigning and awareness raising group for carers of people with dementia.

www.alzscot.org/our-work/campaigning-for-change/have-your-say/national-dementia-carers-action-network

Carers Trust

Help and information for carers.

carers.org/help-and-info/introduction

NHS Education for Scotland

Caring for a Person Living with frontotemporal dementia: a supportive series of resources for carers.

www.nes.scot.nhs.uk/nes-current/caring-for-a-person-living-with-ftd-a-supportive-series-of-resources-for-carers

Scottish Dementia Research Consortium

Membership organisation including researchers, healthcare professionals, people living with dementia and anyone else with an interest in research.

www.sdrc.scot

Tide

Resources and information for carers.

www.tide.uk.net/resources

Living grief and bereavement. Resources for carers.

www.tide.uk.net/what-we-do/living-grief-and-bereavement

Moving Forward Toolkit. A guide for families and relatives involved in or supporting someone to move into a care home.

www.tide.uk.net/moving-forward

9.4 Education and training resources for professionals, people living with dementia and their carers

The British Psychological Society

Dementia and People with Intellectual Disabilities – Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.

explore.bps.org.uk/content/report-guideline/bpsrep.2015.rep77

Dementia Services Development Centre

Training and resources on general aspects of dementia and ageing through to more specialist areas of dementia care and design.

www.dementia.stir.ac.uk/training-events

Neuroprogressive disorders and Dementia Network (NDN)

Supports researchers from across a range of disciplines and deliver this research across Scotland in a wide range of healthcare settings, including primary and community care, mental health services and acute hospitals.

www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease

NHS Education for Scotland

Once for Scotland: Dementia learning site.

learn.nes.nhs.scot/24388

Scottish Government

Dementia in Scotland: Everyone's Story. The dementia strategy for Scotland.

www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story

Promoting Excellence Framework for all health and social services staff working with people with dementia, their families and carers.

www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers

Scottish Government and Alzheimer Scotland

Connecting People, Connecting Support – Transforming the allied health professionals' contribution to supporting people living with dementia in Scotland.

www.alzscot.org/sites/default/files/2019-07/AHP_Connecting%20People%20Connecting%20Support%20Report%202017.pdf

9.4.1 Diagnosis and postdiagnostic support

Healthcare Improvement Scotland

Information on diagnosis and postdiagnostic support including a quality improvement framework, dementia care co-ordination package and information on involving unpaid carers.

ihub.scot/improvement-programmes/focus-on-dementia/improving-diagnosis-and-post-diagnostic-support

9.4.2 Care delivery and communication

Alzheimer Scotland

Let's Talk About Dementia Blog.

letstalkaboutdementia.wordpress.com

British Deaf Association

Dementia-specific resources for healthcare professionals.

bda.org.uk/dementia/

British Psychological Society

Dementia and People with Intellectual Disabilities - Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.

explore.bps.org.uk/content/report-guideline/bpsrep.2015.rep77

Care Inspectorate

My life, my care home

Study on the experiences of people living with dementia in care homes in Scotland.

hub.careinspectorate.com/how-we-support-improvement/care-inspectorate-programmes-and-publications/my-life-my-care-home

Healthcare Improvement Scotland

A guide to making general practice dementia-friendly.

ihub.scot/media/8222/gp-df-a4-landscape_2021.pdf

Information and case studies on care co-ordination for people living with dementia and their carers.

ihub.scot/improvement-programmes/focus-on-dementia/care-co-ordination

Dementia in hospitals improvement toolkit.

ihub.scot/project-toolkits/specialist-dementia-units-toolkit/dementia-in-hospitals-improvement-toolkit

My new home - Guidance for staff supporting people with an intellectual/learning disability and advanced dementia moving into a care home.

ihub.scot/media/9648/supporting-people-with-a-learning-disability-and-advancing-dementia-guidance-for-staff-v20.pdf

Dementia-Friendly Dentistry: Good Practice Guidelines

Guidance for dental professionals to help understand dementia and its implications for dental practice, and adapt their patient management and clinical decisions accordingly.

cgdent.uk/dementia-friendly-dentistry/

LGBT Health and Wellbeing

A guide to support health and social care staff to develop their practice in working with lesbian, gay, bisexual and trans (LGBT) people with dementia.

www.lgbthealth.org.uk/resource/lgbt-dementia-toolkit/

Living with Dementia (Down's Syndrome Scotland)

A booklet about dementia for families and carers of a person with Down's Syndrome
www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LIVING-WITH-DEMENTIA_AW_WEB.pdf

NHS Near Me

Video and links to educational resources for healthcare professionals about using Near Me video consulting.

www.nearme.scot/information-about-near-me-for-professionals

Pavillion

Supporting People with Learning Disabilities and Dementia Self-study Guide.

www.pavpub.com/learning-disability/supporting-people-with-learning-disabilities-and-dementia-self-study-guide

Scottish Government

Evaluation of the effectiveness of the '8 Pillars' model of home-based support

ihub.scot/media/6283/evaluation-effectiveness-8-pillars.pdf

Supporting Derek

A practice development guide to support staff working with people who have an intellectual disability and dementia.

dementia.mvm.ed.ac.uk

9.4.3 Therapies and interventions

Music in Hospitals & Care

Community musicians who visit hospitals and care homes.

www.mihc.org.uk

The Kings Fund

Developing supportive design for people with dementia. A range of resources to enable hospitals, care homes, primary care premises and specialist housing providers to become more dementia-friendly.

www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia

NHS Education for Scotland

Educational and training resources for psychology and psychological interventions for people with Dementia.

www.nes.scot.nhs.uk/our-work/dementia-psychology-and-psychological-interventions/#trainingprogrammes2

Matrix: psychological therapies delivery guide.

www.nes.scot.nhs.uk/our-work/matrix-a-guide-to-delivering-evidence-based-psychological-therapies-in-scotland/#part1deliveringevidencebasedpsychologicaltherapies2

NHS Lothian Arts Therapies Service: Arts and Self Care Resources

Resources to support music, art and wellness interventions.

services.nhslothian.scot/artspychotherapies/arts-for-challenging-times

ReConnect, Scottish Chamber Orchestra

Music-making project for people living with dementia and their carers.

www.sco.org.uk/join-in/resources/all-resources/reconnect-resources

9.4.4 Anticipatory care planning

Healthcare Improvement Scotland

Anticipatory care planning toolkit.

ihub.scot/acp

NHS Inform

Anticipatory care planning information.

www.nhsinform.scot/care-support-and-rights/decisions-about-care/anticipatory-care-planning-acp-thinking-ahead

University of Edinburgh

Resources to Support Anticipatory Care Planning Conversations using the REDMAP (Ready, Expect, Diagnosis, Matters, Actions, Plan) framework.

www.spict.org.uk/red-map

9.4.5 Palliative care

Healthcare Improvement Scotland

Quick guide on palliative care identification tools for use with people living with dementia.

ihub.scot/media/8839/dementia-and-palliative-care-identification-tools-summary-table.pdf

Scottish Palliative Care Guidelines, provide a practical, evidence-based or best-practice guidance on a range of common clinical issues.

<https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/>

NHS Education for Scotland

Framework for Palliative and end of life care: enriching and improving experience.

learn.nes.nhs.scot/2450/palliative-and-end-of-life-care-enriching-and-improving-experience

9.4.6 Research

Neuroprogressive Research Network

Deliver cutting edge clinical research in neuroprogressive conditions and dementia across Scotland.

www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease

Scottish Dementia Research Consortium

Membership organisation including researchers, healthcare professionals, people living with dementia and anyone else with an interest in research.

www.sdrc.scot

9.4.7 School teaching resources

Alzheimer's Society

School teaching resources to make it easy to teach and learn about dementia.

www.alzheimers.org.uk/get-involved/dementia-friendly-communities/dementia-teaching-resources/schools

9.5 Checklist for provision of information

This section gives examples of the information people with dementia and their carers may find helpful at the key stages of their journey. The checklist was designed by members of the guideline development group, based on their experience and their understanding of the evidence base. The checklist is neither exhaustive nor exclusive.

Diagnosis
<p>Information provided should be accessible and culturally appropriate to the person with dementia and their carer(s).</p> <ul style="list-style-type: none"> • Ensure that the person is not alone when they receive the diagnosis. • If known, discuss the type of dementia the person has been diagnosed with, symptoms and how the condition might progress. • Offer tailored information based on the stage of dementia at the time of diagnosis. The information should be reiterated to ensure understanding. • Encourage the person with dementia and their carer(s) to ask questions and allow sufficient time for answering. Questions people may wish to ask include: <ul style="list-style-type: none"> - What is dementia? - What impact is the dementia diagnosis likely to have on the physical and mental health of the person with dementia and their carer(s)? - What impact is the dementia diagnosis likely to have on relationships with others, for example friends and family? - What can people with dementia and their carers expect and what are the potential care pathways? • If the carer is young, discuss the impact of the dementia diagnosis on their education or employment and other areas of their life. • Provide a positive message about living well with a terminal, life-changing diagnosis of dementia. Discuss the importance of the person with dementia continuing to do things they enjoy doing and how this can help them to live well. • Discuss the issue of stigma and how it can negatively impact the lives of people living with dementia and their families and carers, particularly as dementia progresses. Offer information on coping strategies. • Discuss the importance of the person with dementia and their carer(s) participating in anticipatory care planning discussions. • If appropriate, offer written information, such as leaflets, for people with dementia and their carers to read in their own time. • Signpost the person with dementia and their carers to third sector organisations, for example charities and voluntary organisations, where they can receive more information about dementia and the support available, including peer support. This includes information about accessing support for mental health (<i>see section 9.3</i>). • Signpost the person with dementia to free education courses, where they can learn more about dementia (<i>see section 9.4</i>). • Discuss the importance of making plans for the person's financial and personal welfare as soon as possible. Discuss the need for power of attorney and guardianship and explain the difference, as well as where to access help to appoint an attorney or guardian. • Signpost the person with dementia and their carer(s) to statutory and non-statutory organisations that can help with financial matters, such as claiming welfare benefits (<i>see section 9.2</i>).

After diagnosis

- Repeat the information given at diagnosis on the long-term impact of dementia on the person and their carer(s) to ensure understanding.
- Discuss any new support needs, such as counselling, for the person with dementia and their carer(s) and how to access these.
- When discussing support needs with carers, be mindful that male carers may be less likely to engage. Reiterate the importance of support needs for both them and the person living with dementia. Carers from ethnic minority groups and those with additional support needs, such as the deaf community, have specific needs around language during discussions.
- When discussing support needs with LGBTQ+ groups and young carers, highlight sources of support relevant to these specific groups (*see section 5*).
- Discuss the following with the person with dementia and their carer(s):
 - symptom management
 - employment issues
 - safety issues, such as safe driving and kitchen safety
 - where to receive financial support.
- Discuss with the person that they will have access to free personal care, should they need and wish to access it
- Discuss living grief with carers and where they can access support.
- If appropriate, inform the person with dementia and their carer(s) that as the condition progresses there could be times when the person with dementia may need to be sectioned under the Mental Health (Care and Treatment) (Scotland) Act (2003).
- Inform the person with dementia and their carer(s) that there is no situation where they should not be included in do-not-resuscitate conversations.
- Highlight the availability of self-directed support and how this can be accessed.
- Continue to signpost the person with dementia and their carer(s) to third sector organisations, for example charities and voluntary organisations (*see section 9.3*), where they can receive more information about dementia and support, including peer support.
- Sources of further information, such as helplines, video guides, written material and websites, should be made available (*see section 9.3*).

10 Implementing the guideline

This section provides advice on the resource implications associated with implementing the key clinical recommendations, and advice on audit as a tool to aid implementation.

10.1 Implementation strategy

Implementation of national clinical guidelines is the responsibility of each NHS board, including health and social care partnerships, and is an essential part of clinical governance. Mechanisms should be in place to review care provided against the guideline recommendations. The reasons for any differences should be assessed and addressed where appropriate. Local arrangements should then be made to implement the national guideline in individual hospitals, units and practices.

Implementation of this guideline will be encouraged and supported by SIGN. The implementation strategy for this guideline encompasses the following tools and activities.

10.2 Resource implications of key recommendations

Currently there are no laboratories in Scotland offering established CSF biomarker testing for diagnosis of dementia. At present biomarker testing is only recommended in this guideline if the diagnosis is uncertain and Alzheimer's disease is suspected. These samples are sent to a neuroimmunology laboratory in London, or alternatively a laboratory in Sweden, for processing. Medicines coming to market may require CSF biomarker testing as a component of diagnosis to confirm whether or not a patient will benefit from the treatment. Set up of such a service would have resource implications for NHSScotland.

10.3 Auditing current practice and improving services

A first step in implementing a clinical practice guideline is to gain an understanding of current clinical practice. Audit tools designed around guideline recommendations can assist in this process. Audit tools should be comprehensive but not time consuming to use. Successful implementation and audit of guideline recommendations requires good communication between staff and multidisciplinary team working.

The new dementia strategy for Scotland, *Dementia in Scotland: Everyone's Story*, calls for a greater access to and sharing of data across government, public bodies and academia.¹⁰ Of the data suggested in the strategy, the following may be a useful starting point:

- How many people have a formal diagnosis of dementia.
- The number of people under 65 years receiving a diagnosis of dementia.
- How many people are accessing high-quality postdiagnostic support, the length of time they receive support and how long they wait from referral to receiving support.
- The outcomes post diagnostic support delivers for people and their care partners/unpaid carers, captured by embedding the Healthcare Improvement Scotland-led Single Quality Question for postdiagnostic support into service evaluation methods.
- Protected characteristics breakdown.

Organisations may wish to consider a quality improvement approach to understanding current practice and the implementation of the guideline recommendations.²¹⁸

11 The evidence base

11.1 Systematic literature review

The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Information Scientist. Databases searched include Medline, Embase, PsycINFO and the Cochrane Library. The year range covered was 2000–2021. Internet searches were carried out on various websites for relevant guidelines. The main searches were supplemented by material identified by individual members of the development group. Each of the selected papers was evaluated by two Evidence and Information Scientists using standard SIGN methodological checklists before conclusions were considered as evidence by the guideline development group.

The search strategies are available on the SIGN website, www.sign.ac.uk.

11.1.1 Literature search for person-centred issues

At the start of the guideline development process, a SIGN Evidence and Information Scientist conducted a literature search for qualitative and quantitative studies that addressed person-centred issues of relevance to the management of people with dementia. Databases searched include Cochrane, Medline, Embase, and PsycINFO, and a qualitative synthesis was produced by a Health Services Researcher. Themes were drawn from the results, which feature in the guideline.

11.1.2 Appraisal of qualitative and mixed-methods studies

For key questions addressed by a range of evidence types (eg qualitative systematic reviews, mixed-methods systematic reviews, systematic reviews of observational studies, mixed-methods studies and qualitative studies) critical appraisal was conducted independently by two experienced researchers using Joanna Briggs Institute (JBI) critical appraisal tools (systematic review; qualitative [Critical Appraisal Tools | JBI](#)) or the Mixed Methods Appraisal Tool (MMAT).²¹⁹

For systematic reviews it was decided beforehand that studies scoring 8–10 (out of 10) would be considered high quality, 5–7 moderate quality and 4 or below low quality. Although the JBI tool has 11 items, item 9 (assessment of publication bias) was not considered applicable for the review types being appraised. For mixed-methods studies it was decided beforehand that studies scoring 8–10 (out of 10) would be considered high quality, 5–7 moderate quality and 4 or below low quality. For qualitative studies it was decided beforehand that studies scoring 8–10 (out of 10) would be considered high quality, 5–7 (out of 10) moderate quality and 4 or below low quality. Studies were then summarised by an experienced researcher by extracting descriptive information and data relevant to the key question and presenting it in tabular form.

11.1.3 Literature search for cost-effectiveness evidence

The guideline development group identified key questions with potential cost-effectiveness implications, based on the following criteria, where it was judged particularly important to gain an understanding of the additional costs and benefits of different treatment strategies:

- treatments which may have a significant resource impact
- opportunities for significant disinvestment or resource release
- the potential need for significant service redesign
- cost-effectiveness evidence could aid implementation of a recommendation.

Economic evidence was identified for fluid biomarkers and aPET. Each of the selected papers was evaluated by a Health Economist, and considered for clinical relevance by guideline group members.

Interventions are considered to be cost effective if they fall below the commonly accepted UK threshold of £20,000 per quality-adjusted life year (QALY).

11.2 Recommendations for research

The guideline development group was not able to identify sufficient evidence to answer all of the key questions asked in this guideline.

Overall there was a gap in the research of the views people living with dementia, across all key questions.

Until such research is among the mainstream of health research, only a partial view of the experiences of people living with dementia can be presented.

The following areas for further research have been identified:

Dementia diagnosis and discussion of diagnosis

- Perceptions of people with dementia on timing and processes of dementia diagnosis discussions.
- UK-based studies in relation to dementia diagnosis.
- Timing of diagnosis and role of prediagnostic counselling.
- Where the dementia diagnosis discussion should take place.
- The role of the MDT in dementia diagnosis.
- The impact of training in communication about disclosure and methods of communication on people with dementia and their carers.

Brief screening tools

- More research on telephone and video-based screening tools. These studies should assess accuracy, feasibility and acceptability in real-world populations.
- Research on the accuracy, feasibility and acceptability of new screening tests, such as Free-Cog and Oxford Cognitive Screen.

Remote assessment

- The feasibility, acceptability and supportiveness of remote assessment in the diagnosis of dementia.

Fluid biomarkers

- Evaluation of emerging tau PET tracers against alternatives.
- Long-term follow-up of people with different clinical diagnoses and positive or negative CSF biomarkers for A β 42, T-tau, and P-tau, including eventual postmortem examination validation. In particular, more data is required on biomarkers' diagnostic value in older people who are more likely to have Alzheimer's disease copathology.

Postdiagnostic support

- Postdiagnostic support that relates to the stages of dementia and specific populations.
- Research into the experiences of postdiagnostic support in minority groups, those with protected characteristics, those with young-onset dementia and young carers.
- Postdiagnostic support specific to people with advanced dementia.
- How to achieve person-centred care.
- Models of care and the various multidisciplinary contributions.

Distressed behaviours

- Research of a shift in focus to the assessment of, and process for, arriving at a decision on person-centred interventions for each individual who experiences distress.
- Better evidence for non-pharmacological therapies and the effectiveness of such therapies for distressed behaviours.
- Research focussed on how carers communicate and interact with a person when they are distressed, including communication style, method and de-escalation.
- Grief and dementia
- Research into acceptability of the grief interventions and management for men and minority ethnic groups.
- People with dementia's experience of pre-death grief and bereavement and how to support them with managing this.
- How people with mild to moderate dementia experience grief and how to help them retain the pertinent information about their loss and process the loss.
- Interventions to support carers with grief before and after death.
- Healthcare professionals' experiences around grief in dementia before and after death.
- Changing needs in people with dementia
- Assessment of approaches to address changing or unmet needs in people with moderate, advanced or severe dementia.
- Unmet needs of people with young-onset dementia.
- Regular assessment of newly developed comorbidities and cardiovascular risk factors, and the implications of holistic or integrated care assessment.

Anticipatory care planning

- ACP during the earlier stages of dementia.

11.3 Review and updating

This guideline was issued in 2023 and will be considered for review in three years. The review history, and any updates to the guideline in the interim period, will be noted in the update request report, which is available in the supporting material section for this guideline on the SIGN website: www.sign.ac.uk.

Comments on new evidence that would update this guideline are welcome and should be sent to the SIGN Executive, email: sign@sign.ac.uk.

12 Development of the guideline

12.1 Introduction

SIGN is a collaborative network of clinicians, other healthcare professionals. SIGN guidelines are developed by multidisciplinary groups of practising healthcare professionals and organisations that include and represent the views of those with lived and living experience using a standard methodology based on a systematic review of the evidence. Further details about SIGN and the guideline development methodology are contained in ‘SIGN 50: A Guideline Developer’s Handbook,’ available at www.sign.ac.uk.

This guideline was developed according to the 2019 edition of SIGN 50.

12.2 The guideline development group

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Ms Ray Fallan	Network and Growth Officer, Tide (Together in dementia everyday), Glasgow
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Ms Marion Ritchie	Lay Representative, Committee Member National Dementia Carers Action Network and former carer
Dr Joanna Shim	Allied Health Professions Research Fellow, School of Health Sciences, Robert Gordon University, Aberdeen
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Ms Jacqueline Thompson	Nurse Consultant, Older People, Rowanpark HSCP offices, Glasgow City Health and Social Care Partnership
Dr Katharine Thompson	Consultant in Palliative Medicine, Lead Clinician, Tayside Specialist Palliative Care Services, Roxburghe House Hospice, NHS Tayside
Ms Lorna Thompson	Health Services Researcher, Healthcare Improvement Scotland
Professor Debbie Tolson	Alzheimer Scotland Professor of Dementia, Director Alzheimer Scotland Centre for Policy and Practice, University of West Scotland

The membership of the guideline development group was confirmed following consultation with the member organisations of SIGN. All members of the guideline development group made declarations of interest. A register of interests is available in the supporting material section for this guideline at www.sign.ac.uk.

Guideline development and literature review expertise, support and facilitation were provided by SIGN Executive and Healthcare Improvement Scotland staff. All members of staff make yearly declarations of interest. A register of interests is available on request from the SIGN Executive.

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Molly Dobson	Project Officer
Karen Graham	Patient and Public Involvement Advisor
Ailsa Halliday	Project Officer
Meryl Heggeland	Health Economist
Paul Herbert	Health Information Scientist
Kirsty Littleallan	Project Officer
Karen MacPherson	Lead Health Services Researcher
Gaynor Rattray	Guideline Co-ordinator
Domenico Romano	Publications Designer
Carolyn Sleith	Health Information Scientist

12.2.1 Acknowledgements

SIGN would like to acknowledge the following guideline development group members who contributed during the early stages of guideline development.

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12.3 Consultation and peer review

A report of the consultation and peer review comments and responses is available in the supporting material section for this guideline on the SIGN website. All expert referees and other contributors made declarations of interest and further details of these are available on request from the SIGN Executive.

12.3.1 National open meeting

A national open meeting is the main consultative phase of SIGN guideline development, at which the guideline development group presents its draft recommendations for the first time. The national open meeting for this guideline was held on 27 October 2022 and was attended by 190 representatives of all the specialties relevant to the guideline. The draft guideline was also available on the SIGN website for a limited period at this stage to allow those unable to attend the meeting to contribute to the development of the guideline.

12.3.2 Specialist reviewers invited to comment on this draft

This guideline was also reviewed in draft form by the following independent expert referees, who were asked to comment primarily on the comprehensiveness and accuracy of interpretation of the evidence base supporting the recommendations in the guideline. The guideline group addresses every comment made by an external reviewer, and must justify any disagreement with the reviewers' comments.

SIGN is very grateful to all of these experts for their contribution to the guideline.

Professor Judith Carrier	Professor of Nursing, Co-Deputy Director Wales Centre for Evidence Based Care, Cardiff University
Maria Drummond	Senior Clinical Studies Officer, NHS Tayside
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12.3.3 Public consultation

The draft guideline was also available on the SIGN website for a month to allow all interested parties to comment.

12.3.4 SIGN editorial group

As a final quality control check, the guideline is reviewed by an editorial group comprising the relevant specialty representatives on SIGN Council to ensure that the specialist reviewers' comments have been addressed adequately and that any risk of bias in the guideline development process as a whole has been minimised. The editorial group for this guideline was as follows. All members of SIGN Council make yearly declarations of interest. A register of interests is available on the SIGN Council page of the SIGN website www.sign.ac.uk.

Dr Roberta James	SIGN Programme Lead; Co-Editor
Professor Angela Timoney	Chair of SIGN; Co-Editor
Dr Safia Qureshi	Director of Evidence, Healthcare Improvement Scotland
Dr Shridevi Gopi-Firth	Royal College of Psychiatrists
Ruth Stark	Scottish Association of Social Workers
Dr Antonia Torgersen	Royal College of Pathologists

Abbreviations

6-CIT	Six-item Cognitive Impairment Test
Aβ	amyloid-beta
aPET	amyloid PET
ABC	antecedent, behaviour, consequence
ACE	Addenbrooke's Cognitive Examination
ACP	anticipatory care planning
AD	Alzheimer's disease
AD8	Eight-item Informant Interview to Differentiate Aging and Dementia
ADL	activities of daily living
ADNC	Alzheimer's disease neuropathological change
ADNI	Alzheimer Disease Neuroimaging Initiative
CBT	cognitive behavioural therapy
CBS	Challenging Behaviour Scale
CDT	Clock Drawing Test
CI	confidence interval
CMAI	Cohen-Mansfield Agitation Inventory
CSF	cerebrospinal fluid
CT	computerised tomography
DaT	dopamine transporter
DSM-5	Diagnostic and Statistical Manual fifth edition
DWP	Department for Work and Pensions
EAPC	European Association of Palliative Care
EPIC	Enhancing Person-centred care In Care homes
FDG	fluorodeoxyglucose
GDS	Global Deterioration Scale
GPCOG	General Practitioner Assessment of Cognition
ICD-10, ICD-11	International Classification of Diseases version 10, version 11
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
JBI	Joanna Briggs Institute
LGBTQ+	lesbian, gay, bi, trans, queer, questioning and ace
MARQUE	Managing Agitation and Raising Quality of Life
MCI	mild cognitive impairment
MDT	multidisciplinary team

MIS	Memory Impairment Screen
MMAT	Mixed Methods Appraisal Tool
MMSE	Mini Mental State Examination
MoCA	Montreal Cognitive Assessment
MRI	magnetic resonance imaging
NDB	needs-driven dementia-compromised behaviour
NICE	National Institute for Health and Care Excellence
NPI	Neuropsychiatric Inventory
NPI-NH	Neuropsychiatric Inventory-Nursing Home Version
PET	positron emission tomography
PIB	¹¹ C-Pittsburgh compound B
P-tau	phosphorylated tau
QALY	quality-adjusted life year
RCT	randomised controlled trial
RUDAS	Rowland Universal Dementia Assessment Scale
SIGN	Scottish Intercollegiate Guidelines Network
SIS	Six-item Screener
SMC	Scottish Medicines Consortium
SMD	standardised mean difference
SPECT	single-photon emission computed tomography
STI	serial trial intervention
TIME	Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms
TICS(m)	Telephone Interview for Cognitive Status (modified)
TMSS	Telecare Medical Support System
TREA	Treatment Routes for Exploring Agitation
T-tau	total tau
TYM	Test Your Memory
USA	United States of America
WHELD	Wellbeing and Health for People with Dementia

Annex 1

Key questions used to develop the guideline

This guideline is based on a series of structured key questions that define the target population, the intervention, diagnostic test, or exposure under investigation, the comparison(s) used and the outcomes used to measure efficacy, effectiveness, or risk. These questions form the basis of the systematic literature search.

The remit :

- **Includes:** adults with dementia across all settings (home, long-term care, hospital (acute, community and specialist dementia units), and hospice).
- **Excludes:** dementia secondary to alcohol and illicit substances use.
- **Comorbidities to consider:** critical illness, other types of dementia, delirium, depression, frailty, head injury, learning disabilities, Down's Syndrome, neurological diseases including Parkinson's disease, cerebrovascular disease, cardiovascular disease, vascular disease, psychological/behavioural issues, premorbid severe and enduring mental health.

Guideline section	Key question
3.2	<p>1. When, where and how should a diagnosis of dementia be discussed and who should be involved?</p> <p>Population:</p> <ul style="list-style-type: none"> • people with suspected dementia (all ages) • carers, family, friends • healthcare professionals and multidisciplinary teams <p>Phenomena of interest:</p> <ul style="list-style-type: none"> • the process of receiving assessment and diagnosis, eg pathways and information • diagnosis approaches and communication • needs and outcomes in relation to assessment and diagnosis • who should be involved, eg people with dementia, carer/family and healthcare professional and multidisciplinary teams • who should give the diagnosis • how should this be approached • acceptability of approaches to assessment and diagnosis (eg lumbar puncture) • what is the role of postdiagnostic support? • young onset of dementia, assessment and referral and experience as above <p>Context:</p> <ul style="list-style-type: none"> • types of care, ages and when, how • appropriateness and meaningfulness <p>Outcomes:</p> <ul style="list-style-type: none"> • understanding • knowledge • confidence • empowerment • sense of being supported; family or carers

- satisfaction
- improved experience for patient, family, carers, healthcare professional
- compassion and empathy
- approach
- referral to appropriate services
- appropriate management and as appropriate engagement with pharmacological and non-pharmacological management
- independence
- quality of life
- appropriate management of comorbidities
- better and appropriate process around diagnosis and onward management

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2. What postdiagnostic support do people with dementia and their families and carers need after dementia is diagnosed?

Population:

- people with suspected dementia (all ages)
- carers
- family
- friends
- healthcare professionals and multidisciplinary teams

Phenomena of interest:

- views opinions and experiences of support
- the process of postdiagnostic support including pathways, information provision, screening in primary care, onward referral and referral pathways
- approaches, how postdiagnostic support should be approached, acceptability of approaches
- communication, compassion, empathy
- needs and outcomes in relation to postdiagnostic support
- who should be involved, including people with dementia, carers, family and healthcare professionals, multidisciplinary team
- what is the role of postdiagnostic support?
- young onset of dementia, and experience of postdiagnostic support as above

Context:

- types of care
- ages and when
- how
- appropriateness and meaningfulness

Outcomes:

- understanding
- knowledge
- confidence
- empowerment
- sense of being supported; family or carers

- satisfaction
- improved experience for patient, family, carers, healthcare professional
- compassion and empathy
- approach
- referral to appropriate services
- appropriate management and as appropriate engagement with pharmacological and non-pharmacological management
- independence
- quality of life
- appropriate management of comorbidities
- better and appropriate process around diagnosis and onward management

3.1

3. Which tools and assessments are effective in the identification of dementia in primary care or non-specialist settings?

Population:

- people with suspected dementia

Interventions:

- 6-item cognitive impairment test (6-CIT)
- Clock drawing test (CDT)
- General Practitioner Assessment of Cognition (GPCOG)
- Memory Impairment Screen (MIS)
- Mini-Cog
- Six-item Screener
- Addenbrooke's Cognitive Examination (ACE)
- Free Cog
- Mini-mental State Examination (MMSE)
- Montreal Cognitive Assessment (MoCA)
- Rowland Universal Dementia Assessment Scale (RUDAS)
- Eight-item Informant Interview to Differentiate Aging and Dementia (AD8)
- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)
- Test Your Memory (TYM)
- Carer's questionnaires (eg the Addenbrooke's behaviour inventory)
- Tools suitable for remote assessment
- Neuropsychological assessment
- Clinical assessment

Comparators:

- Diagnostic and Statistical Manual (DSM 5) or International Classification of Diseases (ICD-10) defined diagnosis
- Between tools/tests/assessments

Outcomes:

- test accuracy,
- prediction value

	<ul style="list-style-type: none"> • feasibility • applicability in clinical practice (time required for completion, need for training, need for special equipment, test burden/ease of use) • cost
4	<p>4. What is the role of investigative procedures and biomarkers in the diagnosis of and management of suspected dementia?</p> <p>Population:</p> <ul style="list-style-type: none"> • people with suspected dementia (Alzheimer’s disease, vascular dementia, dementia with Lewy bodies (DLB), frontotemporal dementia, mixed dementias, Parkinson’s disease dementia) <p>Interventions:</p> <ul style="list-style-type: none"> • Fluorodeoxyglucose (FDG)-PET • amyloid PET imaging • CSF biomarkers (total tau, total tau and phosphorylated-tau 181 and amyloid beta 1-42 or amyloid beta 1-42 and amyloid beta 1-40, neurofilament), • perfusion SPECT • MRI • CT • I-MIBG cardiac scintigraphy <p>Comparators:</p> <ul style="list-style-type: none"> • Diagnostic and Statistical Manual (DSM-5) or International Classification of Diseases (ICD-10) defined diagnosis or recognised classification criteria for dementia subtypes • between tools <p>Outcomes:</p> <ul style="list-style-type: none"> • test accuracy, sensitivity and specificity • applicability in clinical practice • cost • feasibility • test burden • added value over conventional assessment
3.1.5, 6.5.2	<p>5. What is the utility and accuracy of remote assessment in the diagnosis and management of dementia?</p> <p>Population:</p> <ul style="list-style-type: none"> • people with suspected dementia • carers/family/friends • healthcare professionals who carry out remote assessment <p>Interventions:</p> <ul style="list-style-type: none"> • video consultations • telephone consultations/tests • telehealth memory services • postal questionnaires

	<p>Comparators:</p> <ul style="list-style-type: none"> • Diagnostic and Statistical Manual (DSM 5) or International Classification of Diseases (ICD-10) defined diagnosis • video or telephone assessment versus face to face <p>Outcomes:</p> <ul style="list-style-type: none"> • diagnostic accuracy , sensitivity and specificity • applicability in clinical practice • cost • feasibility • test burden
6.5.2	<p>6. Do people with dementia, and their carers, feel that remote assessment is a feasible, acceptable and supportive in the diagnosis and management of dementia?</p> <p>Population:</p> <ul style="list-style-type: none"> • people with suspected dementia • Carers/family/friends • healthcare professionals who carry out remote assessment <p>Considerations :</p> <ul style="list-style-type: none"> • views, opinions and experiences of symptoms of remote assessments <p>Comparators:</p> <ul style="list-style-type: none"> • settings (urban/rural) • types of assessment used • different subgroups of people with dementia <p>Outcomes:</p> <ul style="list-style-type: none"> • understanding • knowledge • confidence • empowerment • satisfaction • improved experience for patient, family, carers, healthcare professionals • referral to appropriate services • appropriate management and engagement with pharmacological and non-pharmacological interventions • independence • quality of life • appropriate management of comorbidities
6	<p>7. (a) What approaches are effective in identifying distress, challenging behaviours and behavioural symptoms in people with dementia?</p> <p>(b) What non-pharmacological approaches are effective in preventing distress, challenging behaviours and behavioural symptoms in people with dementia?</p> <p>(c) What non-pharmacological interventions and approaches are effective in managing distress, challenging behaviours and behavioural symptoms in people with dementia?</p>

Population:

- People with dementia

Interventions:

- psychological interventions
- self management
- befriending/peer support
- caregiver support interventions
- psychological assessment
- approaches to care
- individual interventions eg art therapy, doll therapy, light therapy, music therapy, exercise, sensory stimulation, reminiscence therapy, aromatherapy, reality orientation, simulated presence
- formulation-led approaches eg functional analysis
- staff training, person-centred care planning approaches

Comparators:

- usual care
- other non-pharmacological and pharmacological interventions

Outcomes:

- reduction in anxiety and distress for carer
- improved quality of life for people with dementia/carers
- reduced behavioural and psychological symptoms eg aggression, anxiety, agitation, apathy, depression
- delayed institutionalisation
- sleep quality
- wellbeing
- reduction of use of pharmacological therapies

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8. What interventions and approaches are effective in supporting grief associated with dementia?

Population:

- people with dementia (eg Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mixed dementias, Parkinson's disease dementia)
- carers, family members, friends
- healthcare professionals, caregiver with experience of supporting others

Phenomena of interest:

- the process and experience of the identification, support and management of grief in people with dementia and their family, friends, and carers.
- who should be involved and when?
- approaches to care and management
- information needs
- experiences of interventions

	<p>Outcomes:</p> <ul style="list-style-type: none"> • identification and acknowledgment of grief for people with dementia, friends, family, and carers • impact on: <ul style="list-style-type: none"> - mental health - physical health - psychological wellbeing - quality of life • improved and sustained outcomes for people with dementia, family, friends, and carers
7	<p>9. What are people with dementia, their families, carers and healthcare professionals' views and experiences of grief management approaches throughout all stages of dementia and after death?</p> <p>Population:</p> <ul style="list-style-type: none"> • people with moderate, advanced and severe dementia (eg Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mixed dementias, Parkinson's disease dementia) • carer, family and healthcare professional, caregiver with experience supporting others <p>Phenomena of interest :</p> <ul style="list-style-type: none"> • the process and experience of the identification, support, and management of grief in people with dementia and their family, friends, and carers • practical skills • who should be involved and when? • information • delivery and experiences of interventions • physical and mental wellbeing <p>Comparators:</p> <p>Outcomes:</p> <ul style="list-style-type: none"> • identification and acknowledgment of grief for people with dementia, friends, family, and carers • impact on: <ul style="list-style-type: none"> - mental health - physical health - psychological wellbeing - quality of life • improved and sustained outcomes for people with dementia, family, friends, and carers
8.1	<p>10. Which assessments and approaches are most helpful, feasible and appropriate in identifying changing and unmet needs in people with 'moderate,' 'advanced' and 'severe' dementia?</p>

Population:

- people with moderate, advanced and severe dementia (eg, Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mixed dementias, Parkinson's disease dementia)

Interventions:

- history taking
- assessments
- tools
- symptom change

Comparators:

- no identification of palliative care needs or use of tools
- no recognition of people dying with dementia

Outcomes:

- progressive and anticipatory care planning throughout all stages of dementia.
- appropriate identification of changes in symptoms linked to changes of stages in dementia and triggers for next stage care planning.
- end-of-life care planning that is person centred and begins as early as possible in the care pathway (ensuring all ACP remains relevant, symptoms are assessed and monitored).
- patient-centred, holistic care (physical, psychological, social and spiritual)
- family supported as equal partners in care
- co-ordination of care between all health and social care professionals involved
- communication, with family and between health/social care professionals involved

8.4

11. When, where and with whom should advanced care planning discussions in relation to the stages of dementia take place?

Population:

- people with moderate, advanced and severe dementia (eg Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mixed dementias, Parkinson's disease dementia)
- carer, family and healthcare professional, caregiver with experience supporting others

Phenomena of interest :

- the process of advance care planning
- end of life care expectations
- what are people with dementias and carers needs, views and experiences
- who should be involved?
- approaches to supporting care/delivery of interventions
- communication - how and who?

Comparators:

- usual care
- no ACP

Outcomes:

- identifying appropriate triggers for end-of-life care planning
 - understanding of when initial ACP discussion should be held in relation to diagnosis
 - how ACP should be managed
 - how patient-centred, holistic care (physical, psychological, social and spiritual) with family can be offered
 - how care can be co-ordinated between all healthcare professionals involved
 - improved communication - with family and between health/social care professionals involved
 - education needs of the care team
-

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