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

A national clinical guideline

Consultation draft, 20 October 2022
Key to evidence statements and recommendations

Levels of evidence

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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 people. 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 individual.

Good-practice points

✓ Recommended best practice based on the clinical experience of the guideline development group.
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1 Introduction

1.1 The need for a guideline

Dementia is a clinical syndrome of cognitive decline which 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 inherent 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 50 million in 2018 to 152 million in 2050, an increase of 204 %.\(^4\)\(^5\) In the UK in 2015, around 850,000 people were estimated to be living with dementia;\(^6\) equivalent to 1 in 14 people over 65 or 1 in 79 of the whole population.\(^6\)\(^7\)

The number of people living with dementia in Scotland is expected to increase to approximately 164,000 by 2036,\(^8\) from a current estimate of 90,000,\(^9\) 3,000 of whom are under the age of 65 \(^10\) (people with young-onset dementia; see definitions below). Around two-thirds of these people are living at home, with the remainder in acute or residential care.\(^9\) The latter accounts for at least 66 % of the care home population in Scotland and continues to increase.\(^9\) The estimated annual diagnosed dementia incidence is 20,000, with roughly the same number of people dying with dementia each year.\(^9\)

1.1.1 Key policies and strategic drivers

The Charter of Rights for People with Dementia and their Carers in Scotland takes a human rights-based approach that aims 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 around dementia.\(^11\)

The Scottish Government’s National Dementia Strategy 2017–2020 has a shared vision for Scotland “where people with dementia and those who care for them have access to timely, skilled and well-coordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them.”\(^12\) This strategy maintains a focus on improving the quality of care for people living with dementia and their families through work on diagnosis, including postdiagnostic support; care co-ordination during the middle stages of dementia; end-of-life and palliative care; workforce development and capability; data and information; and research. This strategy recognises the importance of a person-centred and flexible approach to supporting all stages of the care journey. The delivery of the strategy is supported by the Promoting Excellence Education Framework, 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.\(^13\) A new dementia strategy for Scotland is anticipated in mid-2023.

The importance and recognition of the role of carers is supported in legislation.\(^14\) 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 well-being, 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 care support plans and statements.\(^14\)

The COVID-19 pandemic has had a profound impact not only on health services, but also on wider socioeconomic factors. The Dementia and COVID-19: action plan outlines the response to the COVID-19 pandemic and how to extend that response to continue to support recovery for people with dementia and their carers.
1.1.2 Socioeconomic impact

People with dementia are admitted to hospital more frequently than other people, often with illnesses that could be managed at home. People with dementia have died disproportionately during the COVID-19 pandemic. The current cost of dementia to the UK is £26 billion, consisting of informal care at £11.6 billion (44.2 %), social care £10.3 billion (39.0 %) and healthcare £4.3 billion (16.4 %). 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.

1.1.3 Risk factors for dementia

Important non-modifiable risks for dementia are age and family history (which, for the majority of people, is linked to genetic factors). A recent Lancet Commission paper (2020) identified the 12 most important potentially modifiable risk factors for dementia; less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution (Figure 1).

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

Source: Lancet commission 2020, permission to reproduce to be obtained.

1.1.4 Dementia and health inequalities

There are few large-scale studies that 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.
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.18

The care and support, including diagnostic pathways, for people of protected characteristics under the Equality Act (2010) requires further development.19 It is known that many of these groups are under-represented in terms of the numbers of people diagnosed with dementia, and current services do not fit well with their needs.19 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.19

### 1.1.5 Variations and excellence in practice

Despite its importance, there are deficiencies in the care of people with dementia in Scotland. The National Dementia Strategy recognises the importance of equality 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.

A scoping exercise of neurodegenerative disease clinics providing assessment and treatment of cognitive complaints (eg dementia services, older adult mental health services) in Scotland (2021);20 identified that services specialising in assessing primary clinical dementia syndrome showed significant variation across Scotland.20 This included variation in: i) cognitive clinics (also referred to as memory clinics); (which provide clinical assessment for individuals with cognitive complaints and/or suspected neurodegenerative diseases), with no standardised approach to the assessment of cognitive complaints and variation in the implementation of the assessment and care pathways ii) information about dementia made available on health board websites, and the ease of access to relevant information for dementia (occasionally, websites described disease pathology and provided signposting for post-diagnostic support information).20 From evaluation of responses, from approximately 58 clinics or services providing assessment and/or treatment for cognitive complaints, the majority of respondents did not mention the; involvement of psychiatry or neurology, home visit, postdiagnostic support, young-onset services, and remote appointment options; (psychiatry was referred to most often 36 %).20

A UK-wide survey identified the need for specialist services for young-onset dementia to be commissioned, and the importance of stability of these services for continuity.21-23 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 variation in age-appropriate services for young-onset dementia.

A further area of variation in Scotland is the treatment of cognitive and non-cognitive symptoms in dementia, including comorbid emotional disorders. Stress and distress behaviours are common in 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. Psychological approaches are recommended for first-line management, but there is variation and
uncertainty in terms of availability of resources, training and ongoing support and supervision.

Experience gained from quality improvement programmes in Scotland has shown that progress is being made. There is potential to improve clinical practice around dementia care by reducing variation in the assessment and non-pharmacological management of people with dementia. As dementia is common, 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 manage and monitor those in their care.

1.1.6 People with lived experience and carers' perspectives

People with lived experience and carers may have different perspectives on healthcare processes and outcomes from those of healthcare professionals. The involvement of people with lived experience in guideline development is therefore important to ensure that guidelines reflect their needs and concerns and address issues that matter to them. Family members can provide background information on an individual's history, changes in behaviour and early warning signs. Once diagnosed, people with dementia, their families and carers need information and support (see section 5).

Prior to the initiation of this guideline, the Scottish The Scottish Intercollegiate Guidelines Network (SIGN) Public Involvement Advisor invited a number of voluntary organisations to identify issues of importance for people with lived 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) and the Scottish Older People’s Assembly. Not all these organisations made a submission; some supported this by sharing resources or signposting to websites of case studies.

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

- Diagnosis – communicating and disclosing the diagnosis
  - Who should communicate a diagnosis of dementia?
  - Information lacking at diagnosis
- Support/education and training
  - Support and training for carers
  - Education and training for healthcare professionals (particularly GPs and hospital staff). The Dementia Champions Programme was identified as helpful.
- 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
  - Review appointments – frequency and how the person with dementia should be involved
- Coproduction and equality
  - Equal partnerships and involvement of person with dementia
- Transition between settings and support
- Physical activity
Keeping people mobile in care settings

- Age at onset of dementia
  - Young-onset dementia
- The impact of the COVID-19 pandemic

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 experience, their families and carers can be found in section 9.

1.1.7 Collecting lived experience data

Although there is a growing interest and awareness of the importance of integrating lived experience in health research, the development of this guideline development has exposed gaps. The section below references high-quality studies drawing on the perspectives of family carers of people living with dementia. However, the direct lived experience of people with dementia is, with a few small exceptions, noticeably absent from the research. The need to find other ways to draw on lived experiences in this guideline has therefore been even more important.

A range of resources highlighting lived 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 methodology. SIGN therefore identified and extracted themes, information and quotes from published qualitative syntheses, and, where possible, cross-referenced these with online experiences, stories and resources. Many of the key themes identified mirrored those from the consultation.

There was extensive qualitative literature in the area of dementia examining a wide range of aspects of experience. Commonly identified themes are detailed below.

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/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 informal 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. The information points included in this guideline are intended to aid shared decision-making.

1.2 Remit of the guideline

1.2.1 Overall objectives

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

The guideline relates to the adult population, as a true dementia in children is an incident,
progressive, neurodevelopmental disorder is extremely rare.

1.2.2 Comorbidities to consider when managing people with dementia

People living with dementia who are over 65 have on average four comorbidities, compared with people without dementia, who have two on average. Over 90% of people living with dementia have another health condition, the most common being hypertension (53%), painful conditions (34%) and depression (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
- learning disability
- neurological diseases, including Parkinson's disease and cerebrovascular disease
- cardiovascular disease
- vascular disease
- psychological/behavioural issues
- Down's syndrome/learning disabilities.

1.2.3 Definitions, classifications, terminology and considerations

Mild cognitive impairment

A diagnosis of mild cognitive impairment (MCI) is often given in the prodromal stage of Alzheimer's disease. 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). As MCI symptoms are so varied, it is difficult for clinicians to associate them with a single condition in the early stages. Studies suggest that around 8–15% of individuals with MCI will go on to develop dementia each year; 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. There are no clear guidelines for the diagnosis, treatment or follow-up of MCI, and the National Institute for Health and Care Excellence (NICE) dementia guideline (2018) did not include MCI. As such, there is a risk of lack of consistency and standards in MCI diagnostic practice. This guideline focuses on dementia and makes reference to MCI only in relation to diagnostic investigations.

Dementia

The International Classification of Diseases, version 11 (ICD-11) defines dementia as ‘an acquired brain syndrome characterised by a decline from a previous level of cognitive 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 judgement, psychomotor speed, visuoperceptual or visuospatial abilities). The cognitive impairment is not attributable to normal ageing and significantly interferes with independence in the person’s performance of activities of daily living. The symptoms are not better accounted for by disturbance of consciousness, altered mental status, delirium, substance intoxication, substance withdrawal, or another mental, behavioural, or neurodevelopmental disorder. Based on available evidence, the cognitive impairment is attributed or assumed to be attributable to a neurological or medical condition that affects the brain, trauma, nutritional deficiency, chronic use of specific substances or medications, or exposure to heavy metals or other toxins.'
Dementia due to Alzheimer’s disease

ICD-11 describes dementia due to Alzheimer’s disease as follows: ‘Onset is insidious with memory impairment typically reported as the initial presenting complaint. 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.’

Alzheimer’s disease (a pathological process) and Alzheimer’s dementia (a clinical phenotype)

People can be defined as having had definite Alzheimer’s dementia when they have both the pattern of illness outlined above and a postmortem examination that is demonstrative of the typical supporting pathological features of amyloid plaques and neurofibrillary tangles. In 2011 the National Institute on Aging and Alzheimer’s Association working group defined MCI due to Alzheimer’s disease as a cognitive concern reflecting a change in cognition by the individual or informant, with objective evidence of impairment in one or more cognitive domain but the preservation of independent functional abilities. It defined people meeting this clinical criterion who also demonstrate positive biomarkers for both amyloid-beta (Aβ) and neuronal injury as having the highest likelihood of MCI due to Alzheimer’s disease. Amyloid positron emission tomography (PET) and cerebrospinal fluid (CSF) Aβ were suggested as the markers of Aβ, whereas CSF tau, fluorodeoxyglucose (FDG)-PET or magnetic resonance imaging scan (MRI) were suggested as indicators of neuronal injury.

Some authors have argued, at least conceptually, that similar CSF and imaging biomarkers be used to diagnose preclinical Alzheimer’s disease. This is appealing from a research perspective, with the hope that disease-modifying treatments or preventative strategies might be more beneficial if administered at such a stage, but as yet there are insufficient longitudinal studies to confirm the validity of this view.

Vascular dementia

Vascular dementia is due to significant brain parenchyma injury resulting 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 considered sufficient to account for neurocognitive deficits in an individual’s history, physical examination and neuroimaging.

Dementia due to Lewy body disease

The precise etiology 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. These cognitive deficits are 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. The symptom presentation usually varies significantly over the course of days necessitating longitudinal assessment and differentiation from delirium. Spontaneous onset of Parkinsonism within approximately 1 year of the onset of cognitive symptoms is characteristic of the disease.

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.\textsuperscript{98}

**Other types of dementia**

Other types of dementia – including dementia due to psychoactive substances including medications, or other diseases, behavioural or psychological disturbances – are also described. It is acknowledged that dementia may also be due to an unknown or unspecified cause.\textsuperscript{99}

**Mixed dementia**

This guideline uses the ICD-11 research criteria\textsuperscript{40,41} and general clinical practice. This includes dementia presenting with both Alzheimer’s and vascular pathology contributing to the dementia.

**Young-onset dementia**

The terms ‘younger people with dementia,’ ‘early onset’ of dementia, ‘working-age dementia’ and ‘young-onset dementia’ are used interchangeably for people with dementia who are younger than 65 years. This guideline uses the term ‘young-onset dementia.’ There is not a biological reason for the age of 65, this is based on the usual age of retirement for many people.

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.

**The 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 the definitions from ICD-10 diagnostic criteria for research for staging, with the exception of advanced dementia, for which the definition from the European Palliative Project is adopted.\textsuperscript{42}

Mild dementia: the decline in memory or cognitive abilities is sufficient to interfere with everyday activities, though not so severe as to be incompatible with independent living. Complicated daily tasks or recreational activities cannot be undertaken.

Moderate dementia: the decline in memory loss or cognitive abilities causes serious handicap to independent living. The individual is unable to function without the assistance of another in daily living, including shopping and handling money. Activities are increasingly restricted and poorly sustained.

Severe dementia: the decline in memory loss or cognitive function is characterised by the complete inability to retain new information with an absence or virtual absence of intelligible ideation. Significant help and support is generally required.

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. Addressing advanced dementia-related health needs requires expert health care, nursing and palliative care assessments, together with insights provided by carers (see definition below).
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.\textsuperscript{42,43}

Within the Promoting Excellence Education Framework, the four stages of the dementia journey identified are:

- keeping well, prevention, and finding out it's dementia
- living well with dementia
- living well with increasing help and support
- end of life and dying well.

The progressive nature of dementia

Dementia is a progressive condition\textsuperscript{42,44} and as such all dementia care should be considered palliative. Not recognising dementia in this way drives the stigma and misrepresentation that dementia is a syndrome of old age.

Dementia and associated needs

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

Carers

‘Unpaid carers are people who provide care and support to family members, other relatives, friends and neighbours.’\textsuperscript{45} Other terms such as ‘informal carers,’ ‘unpaid carers’ and ‘caregivers’ are also used. The term ‘carers’ is used in this guideline. ‘You are not defined as a carer in the Carers Act if you are only providing care because of the person’s age (where they are under 18); or if you are caring because you have a contract or as voluntary work (ref).’\textsuperscript{13} Adult carers must meet the aforementioned criteria for a carer and are aged 18 or over, and not attending school. Young carers are under the age of 18; or 18 or over, but still attending school, providing (or intend to provide) care for another person.’\textsuperscript{13} The term ‘young carer’ will be used forthwith in this guideline and ‘adult carer’ or ‘young carer’ when both are referred to.

Formal paid workers and volunteers – defined as ‘paid carers’ – may also support the carer and the person living with dementia. The focus of this guideline is unpaid and informal, so these will be referred to forthwith as ‘carers.’

Healthcare professionals, multidisciplinary sector and team approach to dementia care

The majority of the literature reviewed for this guideline referred to healthcare professionals, so the content and recommendations reflect this terminology. A reason for this is the international context from which the evidence was derived. Within Scotland, and reflected throughout this guideline in good practice points, and when there was any supporting literature, a wider multiprofessional/sector approach is taken, in line with strategic drivers in Scotland around the integration of health and social care.

1.2.4 Target users of the guideline

This guideline will be of interest to primary and secondary healthcare professionals, community and care 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 with lived experience/carers

A version of this guideline for people with lived experience/carers is available from the SIGN website, www.sign.ac.uk. This will be developed after the content of this guideline is agreed.
1.3 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. 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.

1.3.1 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. *To be added post consultation.*

2.1 Section heading

<table>
<thead>
<tr>
<th>R</th>
<th>Rec 1</th>
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<tr>
<td></td>
<td>Rec 2</td>
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<td></td>
<td>Rec 3</td>
</tr>
</tbody>
</table>

Additional comment.

| R | Rec 1 |

Additional comment.

2.2 Section heading

| R | Rec 1 |

Additional comment.

| R | Rec 1 |

Additional comment.
3 Identification and diagnosis of dementia

3.1 Identification and assessment of suspected dementia

3.1.1 Cognitive tests that identify the need for specialist input in relation to a diagnosis of dementia, including utility and accuracy of remote use

**Brief cognitive tests**

A large number of brief cognitive tests are available which can be used in non-specialist settings, including primary care (Table 1). 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 encompass questions on temporal orientation and clock drawing.

Factors to be balanced in the selection of an appropriate instrument include adequate accuracy for identifying dementia; ease of administration and interpretation, including 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 groups.

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. The majority of studies on brief cognitive tests that compare directly with gold standard dementia diagnostic criteria 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.

**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. Based on systematic review evidence combining studies of varying quality across specialist and non-specialist settings, tests 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), Mini-Cog, Addenbrooke's Cognitive Examination (ACE), Six-item Cognitive Impairment Test (6-CIT), six-item screener, Montreal Cognitive Assessment (MoCA), Memory Impairment Screen, Clock Drawing Test (CDT), and Rowland Universal Dementia Assessment Scale (RUDAS).

For tests which rely on informant (someone with sufficient knowledge of the person with suspected cognitive problems, usually a family member or carer) questionnaires, the following were identified to have acceptable sensitivity and specificity: Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) and (NICE 2018) Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE). Test Your Memory (TYM), a tool requiring minimal assessor input, had acceptable accuracy.

No systematic reviews of the recently introduced Free-Cog were identified. The acceptable sensitivity and specificity of Free-Cog is supported by two studies from secondary-care settings. Neither compared to the gold standard dementia diagnostic criteria.

The acceptability of the General Practitioner Assessment of Cognition (GPCOG) is based on studies in mixed symptomatic and asymptomatic populations.
Remote testing

A Cochrane systematic review with literature search to June 2021 collated evidence on the accuracy of multidomain tools for remote cognitive testing by telephone.64 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.

Six test accuracy studies were identified for the primary analysis. Telephone-based tools examined 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).

No eligible 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 (TICSm) 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.

An overlapping systematic review included a wider group of studies, as it encompassed case–control designs.65 These study designs may overestimate test accuracy because of spectrum bias in comparing known cases with controls. 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).

The Cochrane systematic review identified one study that conducted video-based testing using the RUDAS and reported sensitivity of 80 % and specificity of 91 % for dementia.64 66

In the Cochrane review six studies compared the telephone version of the MMSE with various versions of the in-person test.64 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.

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

<table>
<thead>
<tr>
<th>Test</th>
<th>Time to complete (minutes)</th>
<th>Free of charge to NHS?</th>
<th>Formal specific training required?</th>
<th>Person requires written English/literacy skills?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rapid direct tests</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-CIT47</td>
<td>&lt;5</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>CDT54</td>
<td>&lt;3</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>GPCOG51-63</td>
<td>2–5</td>
<td>Yes</td>
<td>Minimal</td>
<td>No</td>
</tr>
<tr>
<td>Memory Impairment Screen(MIS)47</td>
<td>&lt;4</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Mini-ACE64,51</td>
<td>&lt;5</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Mini-Cog64,50</td>
<td>&lt;3</td>
<td>Yes</td>
<td>Minimal</td>
<td>No</td>
</tr>
<tr>
<td>Six-item Screener (SIS)47,52</td>
<td>1–2</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Extended direct tests</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addenbrooke's Cognitive Examination (ACE)47,51</td>
<td>10–30</td>
<td>Yes</td>
<td>Yesc</td>
<td>Yes</td>
</tr>
<tr>
<td>Free-Cog59,60</td>
<td>5–10</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Test Description</td>
<td>Time (min)</td>
<td>Completion</td>
<td>Access</td>
<td>Cost</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>------------</td>
<td>------------</td>
<td>--------</td>
<td>-------</td>
</tr>
<tr>
<td>Mini Mental State Examination (MMSE)¹⁷,⁴⁸,⁶⁷</td>
<td>10–15</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Montreal Cognitive Assessment (MoCA)³¹,⁴⁷,⁵³</td>
<td>10–20</td>
<td>Yes (training certification cost)</td>
<td>Training certification required</td>
<td>No</td>
</tr>
<tr>
<td>Rowland Universal Dementia Assessment Scale (RUDAS)⁴⁷,⁵⁵</td>
<td>10–15</td>
<td>Yes</td>
<td>Minimal</td>
<td>No</td>
</tr>
<tr>
<td>Informant questionnaires</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AD-8⁴⁷,⁵⁶</td>
<td>&lt;3</td>
<td>No (permission required)</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>IQCODE⁴⁸-⁷⁰</td>
<td>5–7</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Self-completion (minimal healthcare practitioner supervision)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Test Your Memory (TYM)⁴⁷</td>
<td>5–10</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td>Remote assessment⁴⁷,⁶⁴,⁶⁵</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tele-Free-Cog</td>
<td>15–20</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Telephone Interview for Cognitive Status – modified (TICSm)</td>
<td>15–20</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Telephone Interview for Cognitive Status (TICS)</td>
<td>10–20</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tele-MMSE</td>
<td>10–15</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

¹“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 June 2022.
²The assessment requires an informant interview for full scoring.
³Training available for NHS staff at [https://www.mvls.gla.ac.uk/aceiiitrainer/](https://www.mvls.gla.ac.uk/aceiiitrainer/)

Healthcare professionals should consider selecting 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), The 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), the Rowland Universal Dementia Assessment Scale (RUDAS) the 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):
  - The AD8 or IQCODE
- **Remote cognitive assessment** (where required):
  - The Telephone Interview for Cognitive Status (TICS), TICS modified, the Tele-MMSE and the Tele-Free-Cog

In addition to accuracy and time available, other factors to be considered by healthcare professionals when selecting a brief cognitive test include:
• cost to use the test
• training requirements
• 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.

3.1.2 People with dementia, and their carers,’ perspectives on remote assessment

There was insufficient qualitative literature to address the feasibility and acceptability of remote assessment in the diagnosis of dementia. There was, however, sufficient literature on remote assessment in the management of dementia. The evidence presented therefore relates to management only.

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 search and screening found one high-quality systematic review (n=9 included studies),71 and seven primary studies.72,73,74,75,76,77,78 The evidence reflected an international perspective, with studies from Israel, the UK, Europe, USA, Hong Kong and Taiwan. This represented 188 people with dementia in the systematic review, and 168 carers and 112 people with dementia in the primary studies. Although these countries are developed nations, differences in healthcare systems may limit the generalisability of the results. 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 included studies. All included literature focused on people with dementia and carers, although one study 74 included people with Alzheimer’s disease (n=32) and MCI (n=30). For the studies that included specific interventions (lasting between 8 weeks and 6 months), data collection was conducted shortly after the intervention. There were no long-term interventions identified, and 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.

A range of remote healthcare technologies was reported, with a focus on specific interventions for supporting people with dementia and their carers in the home setting. This ranged from health applications (apps) to remote consultations and in-home technology systems. This included: the eHM-DP (European eHealth Monitor Dementia Portal) providing a user-sensitive, interactive web portal for targeted support to informal carers;75 the TMSS (Telecare Medical Support System) integrating telecommunication systems with remote physiological monitoring devices for carers;72 the STAR-C-TM (STAR-C-Telemedicine) an evidence-based programme teaching family carers how to manage behavioural disturbances in people with dementia delivered by telemedicine;73 telecare services which included emergency detection, medicines and tasks reminders, cognitive stimulation, teleconsultation with professionals, and videoconference for carers, ADI and MCI;74 remote consultations via telephone calls;77 mobile health applications or ‘apps’ used on smartphones or tablet computers to enable and support health and well-being;71 unobtrusive in-home monitoring using surveillance systems providing 24-hour information on daily function, lifestyle and safety of people with dementia;78 and remote monitoring devices such as passive environmental home sensors, cognitive assessment puzzles, chat interfaces, smartwatches and physiological measurement devices.76

A recent high-quality systematic review investigated the experiences of people with dementia using mobile health applications (‘apps’) and the facilitators and barriers to implementation.71 It found technology appeared to improve some aspects of physical, mental and social health, but implementation issues should be considered including design, quality and information on device; digital knowledge and skills required; individual lifestyle, agency and health of people with dementia.
Seven primary studies focused on the management of people with dementia with technology. One study explored primary carers’ impressions of the Evercare Telecare Medical Support System (TMSS) as an aid in dementia homecare. It identified that carers had both positive and negative views on the TMSS for usefulness and ease of use.

A mixed-methods pilot study explored the feasibility, cost and satisfaction of the STAR-C-Telemedicine (STAR-C-TM). Findings reflected mixed views: increased carer access to health services and ease of use, but frustration with technical challenges and meetings that did not include the person with dementia.

A mixed-methods study explored the acceptance of home telecare technologies among people with dementia and their carers, and their willingness to adopt a system in their home. Overall, telecare services were perceived as useful by both people with dementia and families. People with dementia felt they would prefer contact with a person in an emergency, but the technology would increase their sense of security if they lived away from family. Concerns were raised about the complexity of devices and that people with dementia would prefer to use the telephone as it was more familiar. Other concerns related to privacy and cost. Carers reported feeling more reassured and about the person with dementia if they lived at a distance and improved quality of life. Carers’ concerns related to denying any need for help, cost, technical challenges and frustration and personalisation of system.

A mixed-methods study assessed the usefulness and impact of the eHealth Monitor Dementia Portal (eHM-DP) for carers. Benefits 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. Further improvements (improved portal design, personalisation of portal, further functionalities and improvement, integration of forum/chat area) were identified.

A mixed-methods approach explored the opportunities for care research and innovation using a remote monitoring device and cognitive test battery, which included with carers (n=10) and people with dementia (n=2). The following factors motivating or disengaging users were identified: preventing anxiety and frustration with technology, avoiding time-pressured tasks, increasing complexity gradually and using friendly vocabulary. Carers were interested in the location, physiological data and sleep of people with dementia. The system may not be suitable for advanced dementia. The devices were unfamiliar to participants, so resulted in low acceptance and compliance.

A qualitative study exploring the experiences of remote healthcare during the COVID-19 pandemic identified three themes: proactive care at the start of the pandemic (short calls, lacking purpose but reassuring). Some not contacted and would have liked practical advice; avoidance of healthcare settings (avoiding risk of COVID-19 transmission, did not want to trouble doctor, did not want to engage due to technology or impersonal issues); difficulties with remote healthcare (phone consultations issues if hard of hearing or memory issues, required carer organisation, preference for face-to-face, lack of visual changes being noticed, harder to convey changes over phone, issues arranging appointments, digital barriers, but some adult-child carers preferred online, benefit of shorter waiting times and quicker access.

A qualitative study explored benefits, barriers and needs around the concept of in-home monitoring by carers and paid carers. The main monitoring goals were fall detection and prevention, monitoring 24-hour rhythm, personal hygiene, nocturnal restlessness, and eating and drinking behaviour. Expected benefits included: cross-checking the self-report, extended independent living, objective communication, prevention of proactive measures, emotional reassurance, personalised and optimal care. Expected barriers included: information overload, privacy concerns, ethical concerns. Requirements for home monitoring included supporting prevention and proactive measures, preventing information overload, reducing privacy and ethical concerns.

Feasibility

People with dementia noted challenges to the feasibility of remote assessment in managing dementia. Key themes arising 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. Key positive themes among carers included ease of use and a preference for online consultations. 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. Some adult-child carers noted a preference for online consultations.

Key concerns expressed by carers were the skills required to use technology; lack of mental capacity for the person with dementia around remote technology; technical improvements; lack of internet connectivity; challenges for remote consultations (difficulties in conveying issues around new or increasing problems over the telephone, organisation of consultations over telephone to be suitable for carers, healthcare professionals' telephone calls required to have purpose and clarity for carers) and the requirements for in-home monitoring. 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. Barriers also included hearing or memory problems.

Acceptability

People with dementia reported a perceived reassurance of safety using remote technology. They found telecare services with healthcare professionals and family useful, and reported that a telecare system would allow them to feel more secure if they lived away from family. One study participant mentioned that they were comforted by the idea that someone is waiting to help at all times.

Concerns related to acceptance and compliance, 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. Face-to-face contact with healthcare professionals, was preferred by people with dementia, despite the potential use of remote technology in emergencies, they did not feel safe with machines.

For remote technology utility, 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.

Carers of people with dementia reported both positive and negative perceptions related to remote technology. Positives included: reduced stress in help-seeking, increased access to support and healthcare, with reduced travel requirements for carers (some felt it was easier to have a meeting from home rather than in person), reassurance from meetings and if the carer had to leave their home and monitoring of the person with dementia’s location, or physiological and sleep data helped reduce carer anxiety, improved communication with professionals for carers and reduced communication time and 24-hour access to support and information, an overview of caregiving activities resulted in increased carer awareness of personal tasks and support areas, avoidance of healthcare settings (carers felt it was better to have remote consultations during COVID-19 to reduce the risk of transmission) and cross-checking of information (self-care information reported by the person with dementia could be cross-checked using technology).

“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.”

"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.”

Negative experiences and concerns noted by carers produced the following key themes: exclusion of person with dementia, technology financial cost, a denial of help required, system flexibility, data privacy, ethical concerns, non-usage risk, lack of response by

JBI 4/10
5/10
7/10
the person with dementia, preference for face-to-face, information overload. Concern about meetings without the person with dementia present were expressed. Carers were also concerned about the cost of remote technology. Some carers denied there was a need for remote technology at that time, but acknowledged that it may be required in the future.

Some carers were concerned about the flexibility of remote systems when used by the person with dementia, who would have access to the data, the risk of infrequent or non-use of the technology by both carers and health professionals, and the person with dementia’s reluctance to respond to notifications or alerts. Dehumanising care was noted as a barrier by carers. 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.

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

Preferences:
- The person with dementia’s preference for face-to-face contact with healthcare professionals over technology.
- The carers’ preference for face-to-face contact to allow discussions, so that healthcare professionals can notice visual changes in the person with dementia.
- Some adult or child carers may prefer online consultation.

Skills, resources, usability and data protection:
- Skills (technical, digital literacy, mental capacity and competency), training and education needs of the person with dementia and their carer(s).
- Usability and ease of use for both the person with dementia and their carer(s).
- Physical changes required in the home environment.
- Cost, data security, ethical (eg informed consent) and privacy issues for the person with dementia and their carer(s).

Benefits and challenges:
- potential benefits, once the technology is set up, eg shorter waiting times and quicker access to healthcare support, reassurance from monitoring (monitoring of person with dementia’s location, or physiological and sleep data helps reduce carer anxiety), avoidance of healthcare settings/travel, potential to improve some aspects of physical, mental and social health
- potential challenges eg, internet connectively, potential anxieties and frustrations with the use of technology for 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.

i. 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.

i. The person with dementia and their carers’ should be aware of the benefits and challenges in using remote technologies, and consider and discuss with service providers/professionals their needs and preferences, to support informed decision-making around the use of remote technology.
3.2 Discussing a diagnosis of dementia

Four high-quality publications were identified: three systematic reviews [79,80,81] with 52, 54 and 23 included studies, respectively, and one qualitative phenomenological study [82]. These publications answered the ‘when’, ‘how’ and ‘who’ should be involved in a diagnosis of dementia discussion; ‘where’ the discussion should take place was not investigated.

A qualitative phenomenological study [82] interviewed informal carers or people with dementia. In one systematic review 16 of the 52 included studies focused on healthcare professionals, seven on informal carers, and four on people with dementia [79]. The other two systematic reviews included studies on people with dementia and/or carers [80] or focused on communication between healthcare professionals and people with dementia and their companions [81]. However, in one of these systematic reviews, only 8 out of 23 included studies focused on communication in dementia assessment and/or diagnosis meetings [81].

There was a relative under-representation of UK participants, with included studies originating from the UK ranging from 9% to 23% in the reviews [79,80,81]. The qualitative study [82] 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+; therefore, they would not include people with young-onset dementia.

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

There was consensus from the systematic reviews [79,80,81] and a qualitative study [82] that carers had an important role to play and should be present and fully engaged in meetings when a dementia diagnosis is communicated [79,81,82]. 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 [81]. 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’ [79]. The qualitative study also highlighted a need for education on involving carers in such meetings [82].

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 [79]. 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 [82]. Another systematic review found a person with dementia–carer dyad need ‘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 [80]. 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.

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% 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 [80]. The most recent systematic review found three included studies reporting that participants perceived that a dementia diagnosis had been delayed [79]. However, one study included in this review [83] 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.

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.’ 82

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.

3.2.3 How should a diagnosis of dementia be discussed?

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)79 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. 78 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 the person with dementia–carer dyad need for guidelines on dementia before and after diagnosis. 80 The aforementioned 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. 79

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. 81 A mixed systematic studies 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 well-being and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia. 79 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. 79

Who should be involved in the dementia diagnosis discussion

R Healthcare professionals with specialist expertise in dementia, GPs and the wider multidisciplinary team all have a role to play in the dementia diagnosis discussion. All healthcare professionals involved should be competent in discussing a diagnosis of dementia and knowledgeable about dementia.

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

When should a diagnosis of dementia be discussed

R Early discussion of a diagnosis of dementia should be considered, as this may be helpful for timely access to support and services.

R Healthcare professionals should consider delivering 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, consider whether the person with dementia has sufficiently processed and accepted the changes that are happening to them to ensure this discussion does not have a negative effect on their well-being.

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 where it can be competently made, even if there is co-existing delirium (see SIGN 157 Risk reduction and management of delirium).

Healthcare professionals should ensure that, when a diagnosis is delivered in any setting, the person with dementia and their carer(s) are informed about postdiagnostic support and services.

**How should a diagnosis of dementia be discussed**

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. This would allow for the elicitation of beliefs, expectations and potential misconceptions of people with dementia and their carers, in order for them to be adequately addressed. It may also allow for information to be better absorbed by people with dementia and their carers.

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 disclosure meeting.

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 well-being and how the person with dementia can continue with their life, maintain their sense of self and accept their identity as someone with dementia.

**INFORMATION POINTS**

- Encourage the person with dementia and their carer(s) to ask questions about the dementia diagnosis and allow sufficient time for answering. Examples of questions people may wish to ask are provided in section 9.4.
- Encourage the person with dementia and their carer(s) to ask about postdiagnosis support and services.
- Provide a positive message about living well with a terminal, life-changing diagnosis of dementia.
- Discuss the importance of making plans for the person’s financial and personal welfare as soon as possible (see section 9.4)
4 Investigative procedures

4.1 Fluid biomarkers

The NICE guideline on dementia (2018)\(^47\) recommends further tests after a standard dementia assessment and structural brain imaging, including fluid biomarkers for Alzheimer’s disease, if it would help diagnose a dementia subtype and knowing more about dementia subtype would change management. In this instance, NICE (2018)\(^47\) suggests that examining cerebrospinal fluid (CSF) biomarkers for 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 or functional brain imaging (FDG-PET or single-photon emission computerized tomography (SPECT)) be considered. It is also recommended by NICE that if a diagnosis cannot be made after one of these tests, the other test should be considered.\(^47\) This guideline examines evidence for established and emerging fluid biomarkers.

There are four core CSF biomarkers for the diagnosis of Alzheimer’s disease: amyloid-beta 40 and 42 (Aβ40, Aβ42), total tau (T-tau) and phosphorylated tau (P-tau). The term ‘established CSF biomarker’ is used as a descriptor for the use of a combination of Aβ42 and/or Aβ40 with either T-tau or P-tau. In Alzheimer's disease a reduction in CSF amyloid biomarkers (Aβ42, Aβ40) and elevated tau biomarkers (T-tau, P-tau) is usually expected. There are currently no established fluid biomarkers for any of the other subtypes of dementia.

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\(^84\) 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.\(^84\)

The clinico-pathological nature of an Alzheimer’s dementia diagnosis requires both clinical symptoms and typical neuropathological findings, which do not always directly correlate in practice.\(^85,86,87\) The gold standard for a diagnosis of Alzheimer’s dementia is confirmation of the typical neuropathological findings in people with symptomatic cognitive impairment.

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.\(^88,86\)

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),\(^69\) show good sensitivity (98 %) but low specificity (69 %) when compared with neuropathological confirmation.\(^87\)

Age is also a consideration, as the postmortem examinations of 20–40 % of asymptomatic people older than 80 years (depending on clinical criteria used) have the neuropathology of Alzheimer’s disease.\(^85,86,69\) Similar ratios of abnormal CSF Aβ/tau results are seen in asymptomatic people of this age.\(^90,88\)

4.1.1 Established CSF biomarkers and Alzheimer’s dementia neuropathology

Small neuropathology case series have shown a good degree of correlation between established CSF biomarker findings and Alzheimer’s dementia neuropathology when compared with people with non-Alzheimer’s disease dementia confirmed by neuropathology. One study found established biomarkers showed a high diagnostic accuracy for identifying Alzheimer’s disease pathology (AUC 0.94–0.97). This study (average age 82 years at death, biomarkers 2.9 years before death) included only 27 pathologically confirmed Alzheimer’s disease participants compared with 147 Aβ-PET negative controls.\(^91\) Another study of established CSF biomarker testing showed 94 %
sensitivity and 91% specificity in the largest of these series, including 89 controls, 30 participants with MCI, 92 with Alzheimer’s disease and 16 other people with dementia.⁹²

### 4.1.2 Established CSF biomarkers and amyloid PET findings

There is a moderate degree of correlation between CSF biomarker results and amyloid PET findings.

In a longitudinal cohort study of 377 older adults without dementia, with blood, imaging and CSF studies being undertaken serially, 135 were clinically diagnosed as having MCI. Reductions in CSF Aβ42, then CSF P-tau and CSF T-tau levels were noted to occur before the amyloid PET abnormalities.⁹³

Another study that compared 64 participants who had ¹⁸F amyloid PET and established CSF biomarkers undertaken for assessment of cognitive impairment reported that Aβ42 showed the highest correlation with ¹⁸F-flutemetamol PET with a cut-off value of 706.5 pg/mL, corresponding to sensitivity of 88% and specificity of 87%.⁹⁴

A further study (overall n=136) looked at 61 controls, 64 people with MCI, 63 with Alzheimer’s disease and 64 with non-Alzheimer’s disease. Concordance between ¹¹C-Pittsburgh compound B [¹¹C]PIB PET and CSF Aβ42 was 84%. When a combination of Aβ42 and tau was used, concordance with [¹¹C]PIB PET was 89%.⁹⁵

A meta-analysis of nine ¹⁸F amyloid PET studies including 662 participants (247 controls, 158 MCI, 244 Alzheimer’s disease, 13 other dementia) demonstrated slightly lower diagnostic values of individual CSF biomarkers with a sensitivity for CSF Aβ42 80% (95% CI 73% to 85%), specificity 82% (74% to 88%) compared with ¹⁸F amyloid PET with a sensitivity 90% (95% CI 82% to 95%), specificity 85% (68% to 94%).⁹⁶

### 4.1.3 Established CSF biomarkers and a clinical diagnosis of Alzheimer’s disease or MCI due to Alzheimer’s disease

A Cochrane meta-analysis to estimate the accuracy of CSF Aβ42 alone in differentiating Alzheimer’s disease from other dementia subtypes reported a sensitivity of 79% and specificity of 60% for Alzheimer’s disease versus all other forms of dementia.⁹⁷ There was better accuracy in diagnosing Alzheimer’s disease compared with specific dementia subtypes than in unclassified cases. In clinical practice people may present with less defined clinical phenotypes; however, CSF Aβ42 would not be used in isolation, CSF T-tau or P-tau would also be tested.⁹⁷

These findings indicate that CSF Aβ42 on its own should not be used to differentiate between Alzheimer’s disease and non-Alzheimer’s disease dementias.⁹⁷

In a meta-analysis with 15,669 Alzheimer’s participants and 13,018 controls, the core biomarkers (Aβ42, T-tau and P-tau) differentiated Alzheimer’s disease from controls with good performance: CSF T-tau (average ratio 2.54 (2.44 to 2.64), P-tau (average ratio 1.88, (1.79 to 1.97), and Aβ42 (0.56 (0.55 to 0.58)).⁹⁸ Differentiation between cohorts with MCI due to Alzheimer’s disease and those with stable MCI impairment (MCI defined as people with initial MCI progressing to a diagnosis of Alzheimer’s disease) was also strong (average ratio 0.67 for CSF Aβ42, 1.72 for P-tau and 1.76 for T-tau). The authors supported the use of CSF T-tau, CSF P-tau and CSF Aβ42 in differentiating between mild MCI due to Alzheimer’s disease and those with non-progressive MCI (over 2 years) as well as Alzheimer’s disease compared with controls.⁹⁸ However, as the biomarker reference ranges varied between the included studies it is difficult to interpret the relevance of these results to clinical practice.

A further Cochrane meta-analysis looking at CSF T-tau in diagnosis of Alzheimer’s disease in people with MCI showed a median sensitivity of 72% and 75% specificity.⁹⁷ MCI in this analysis was defined as meeting either the Petersen,⁹⁹ revised Petersen,¹⁰⁰ and/or Matthew’s¹⁰¹ criteria. Five studies evaluating the accuracy of CSF P-tau/Aβ ratio reported sensitivity ranging between 80% and 96% and specificity ranging between 33% and 95%. The authors concluded that biomarkers were more effective at ruling out Alzheimer’s disease in MCI than ruling it in.⁹⁷
Participants in these studies were identified in secondary and tertiary care settings. Before CSF testing, participants were clinically assessed using a version of the Petersen criteria for MCI or the NINDS-ADRDA criteria for Alzheimer's disease.89

A meta-analysis of 39 studies (n=5,000) looked at CSF Aβ42 levels to differentiate between Alzheimer’s disease and other dementia subtypes.102 The pooled estimates for differentiating Alzheimer’s disease from other dementia subtypes were:

- Alzheimer’s disease from non-Alzheimer’s disease: sensitivity 79 % (0.73 to 0.85), specificity 60 % (0.52 to 0.67) in 13 studies, 1,704 participants, 880 participants with Alzheimer’s disease.
- Alzheimer’s disease from vascular dementia: sensitivity 79 % (0.75 to 0.83), specificity 69 % (0.55 to 0.81), 11 studies, 1,151 participants, 941 participants with Alzheimer’s disease.
- Alzheimer’s disease from frontotemporal dementia: sensitivity 85 % (0.79 to 0.89), specificity 72 % (0.55 to 0.84), 17 studies, 1,948 participants, 1,371 participants with Alzheimer’s disease.
- Alzheimer’s disease from dementia with Lewy bodies: sensitivity 76 % (0.69 to 0.82), specificity 67 % (0.52 to 0.79), nine studies, 1,929 participants, 1,521 participants with Alzheimer’s disease.

The authors concluded that measuring Aβ42 levels in CSF may help differentiate Alzheimer’s disease from other dementia subtypes, but the test is imperfect and tends to misdiagnose those with non-Alzheimer’s disease as having Alzheimer’s disease.102 They caution against the use of CSF Aβ42 alone for dementia classification.

Participants were recruited in memory clinics, specialist services or research centres (suggesting specialist input prior to further investigation) with the authors indicating that ‘Aβ42 may have value as an adjunct to a full clinical assessment, to aid dementia diagnosis.’

The clinical context of all the above studies would suggest that CSF testing was preceded by specialist assessment. Participants from two studies were from specialist memory clinics.97,102 These participants had therefore undergone CSF investigations following a detailed clinical assessment, blood testing and initial imaging studies.

4.1.4 Considerations for use of biomarkers

The Alzheimer’s Association expert group (Shaw 2018) 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.

In people undergoing lumbar puncture, which included those with a diagnosis of MCI Alzheimer’s disease (28.4 %), and other dementia, adverse effects included back pain (17 %) and headache (19 %).103 Another study showed that 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).104

Consensus guidelines from the EU Joint Programme – Neurodegenerative Disease research consortium indicated the need for an examination, review of medications and potentially imaging to be undertaken before safe lumbar puncture (Table 2).105
<table>
<thead>
<tr>
<th>Contraindication</th>
<th>Assessment procedures</th>
<th>Action required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Space-occupying lesion with mass effect, posterior fossa mass, Arnold–Chiari malformation</td>
<td>Clinical neurological examination including fundoscopy</td>
<td>Perform brain imaging if:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• papilloedema</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• abnormal neurological examination</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• patient with reduced conscious level</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• patients with recent seizures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• patient is immunocompromised</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• patient with previous central nervous system disease</td>
</tr>
<tr>
<td>Anticoagulant medication</td>
<td>Check medication before lumbar puncture</td>
<td>Medication can be discontinued temporarily</td>
</tr>
<tr>
<td>Coagulopathy</td>
<td>Check recent full blood count and coagulation screen</td>
<td>Correct if possible</td>
</tr>
<tr>
<td>Uncorrected bleeding diathesis</td>
<td>Check recent full blood count and coagulation screen</td>
<td>Correct if possible</td>
</tr>
<tr>
<td>Congenital spina abnormality</td>
<td>Local inspection. Spinal imaging if suspicion of cord tethering</td>
<td>Imaging-guided lumbar puncture</td>
</tr>
<tr>
<td>Skin infection at puncture site</td>
<td>Local inspection</td>
<td>Treat skin infection</td>
</tr>
</tbody>
</table>

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. At present in Scotland, CSF biomarker tests are undertaken on a research basis, so the test batching means results can take a number of months. Further NHS laboratories would need to be established to allow for more regular testing than is presently offered.

There are minimal studies on the cost-effectiveness of CSF biomarker testing. However, one study outlined that any modelling of the cost-effectiveness of such testing is highly influenced by the pretest prevalence of Alzheimer's disease. This study suggested a pretest prevalence of 12.7% was required after clinical assessment and imaging to make the investigation cost-effective, and thus 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 they felt testing established CSF biomarkers was cost-effective. However, it is unclear if these assumptions are generalisable to the Scottish population and health care.

In people in whom Alzheimer's dementia or MCI due to Alzheimer's disease is suspected, but where the diagnosis remains uncertain after initial clinical and radiological assessment, CSF Aβ40 and/or Aβ42 combined with either T-tau or P-tau testing can be considered to support a clinical diagnosis.
CSF Aβ40 and or Aβ42 combined with either T-tau or P-tau are more valuable in ruling out Alzheimer’s disease as a cause of cognitive symptoms than in confirming a subdiagnosis.

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.

4.1.5 Emerging CSF biomarkers

A number of emerging serum and CSF biomarkers are currently unavailable for routine clinical use. Further clinical trials are required before their use in practice can be determined.\(^4\),\(^8\),\(^9\),\(^10\),\(^7\),\(^11\)

CSF alpha-synuclein RT-QuIC has the potential to be a pathology-specific biomarker for dementia with Lewy bodies\(^5\). One diagnostic study reported RT-QuIC identified people with MCI due to suspected Lewy body disease against cognitively unimpaired controls with 95% sensitivity and 97% specificity, and showed 98% specificity among neuropathological controls\(^6\). More research is required, in clinical practice, including comparison with available diagnostic tests before the clinical role of alpha-synuclein RT-QuIC can be established.

Similarly, RT-QuIC amplification techniques show high specificity (100%) and sensitivity (92%) in Creutzfeldt–Jakob disease\(^7\) and have the potential to be developed for other neurodegenerative conditions.

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.

4.2 Amyloid PET imaging in the diagnosis and management of suspected Alzheimer’s dementia

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 (Shetty 2014).\(^8\) 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 in use for dementia diagnosis. (NICE) Amyloid PET (aPET) utilises a ligand that binds selectively to amyloid plaques. Amyloid PET is not currently widely used in Scotland; although licensed for use, it is used only for research purposes and is not routinely available or funded. However, it may provide an accurate and early diagnosis of dementia or dementia subtype and identify biomarkers that can inform emerging antiamyloid treatments if they become available in the future\(^9\). There are also tau-specific PET ligands, which enable binding and visualisation of tau proteins in the brain. Tau PET is not considered here. Future research into novel PET ligands, including tau PET, is awaited with interest.

The NICE dementia guideline 2018\(^7\) states ‘amyloid imaging techniques have been licensed for use in the UK,’ but makes no recommendation for aPET use.

The Amyloid Imaging Taskforce report (2013)\(^10\) recommends appropriate-use criteria for aPET in selected patients with MCI, atypical Alzheimer’s disease, suspected mixed dementia or young-onset dementia.

4.2.1 Use of amyloid PET for the detection (or exclusion) of Alzheimer’s disease

Difficulties in interpreting studies\(^7\),\(^9\),\(^10\),\(^12\) investigating the utility of aPET include:

- A variety of tracers used, including PIB, which is a research ligand and not licensed for clinical use, and \(^18\)F tracers including florbetapen, florbetapir and flutemetanol (although one meta-analysis\(^9\) suggests pooled sensitivity and specificity values
are high for all tracers).

- The mode of imaging interpretation varies (visual versus automated reading/cut-offs).
- Variable populations (eg stages of dementia and age, age being crucial due to increasing accumulation of amyloid in normal individuals with age). Estimates of age-specific positivity rates for aPET <5% in those aged 50–60, 10% in 60–70, 25% in 70–80 and >50% in those aged 80–90 years). Some tracer studies reported inaccuracies in very advanced disease.123,125
- Some studies reported correlation of positive aPET with amyloid neuropathology; however, there was little neuropathological confirmation in actual clinical utility studies (a single study127 reviewed by other studies).67,96,126,129
- Dementia versus MCI, some studies looked at aPET utility in the clinical diagnosis of dementia, 67,96,124-126 whereas others looked at possible use in prediction of conversion from MCI to dementia (including the Cochrane review), 128 which advises against its use.129,132
- aPET in individuals with dementia versus normal controls or other-cause dementia; there was also variable comparison with either normal controls96,126,129 or other-cause dementia (the latter likely to be a more real-world clinical situation).67,128,124,125
- While aPET positivity may correlate well with amyloid brain pathology, amyloid brain pathology does not necessarily equate to Alzheimer’s disease dementia.123,125

A US study found aPET to be helpful in influencing changes in the management of individuals with suspected dementia.130

A systematic review reported that, following aPET in people with suspected Alzheimer’s disease, diagnosis was revised in more than one-third of cases, and aPET led to a change in management for 72% of those scanned.129 For differential diagnosis, a study reported sensitivity of 89.6% and specificity of 87.2% for identifying individuals with Alzheimer’s disease compared with healthy controls. In three studies in the systematic review comparing people with Alzheimer’s disease with those with non-Alzheimer’s disease dementia, sensitivities and specificities were between 61.6% and 96.7%, and 57.1% and 100%, respectively.128 A study of tracers used in aPET found that they performed well, but concluded that further evidence is needed to determine the use of aPET to support diagnosis of Alzheimer’s disease.96

A study confirming diagnosis of dementia at postmortem examination found that both aPET and FDG-PET had high accuracy for predicting intermediate-to-high Alzheimer’s disease neuropathology (sensitivity 96% vs 80%; specificity 86% vs 95%). When assessing people in the early symptomatic stages of dementia, aPET appeared more sensitive than FDG-PET (96% vs 75% for FDG, p=0.01) and specificity remained good (87% vs 92%, p=0.65). In people with established dementia, FDG-PET and aPET were similar. Where aPET and FDG-PET were incongruent, mixed pathology was more likely. Where aPET and FDG-PET were congruent, accuracy was very high (sensitivity 97%, specificity 98%).67 In another study, 6 out of 23 participants reported as normal on MRI were aPET positive.124

4.2.2 Amyloid PET use for prognostication in Mild Cognitive Impairment

A Cochrane review identified two studies with high sensitivity and specificity for identifying progression from MCI to Alzheimer’s disease with aPET; however, methodological flaws with the studies led the review to conclude that more studies were needed to determine the further utility of aPET.128

A retrospective database study using participants in the Alzheimer Disease Neuroimaging Initiative (ADNI) database (n=319, average age 72–73 years) looked at the predictive value of 18F-florbetapir and 18F-FDG-PET for conversion from MCI to Alzheimer’s disease. The authors concluded that the prediction benefited most from non-imaging variables, high risk apolipoprotein E and the MMSE, and suggested aPET did not add value to diagnostic prediction.129
4.2.3 Comparison of amyloid positron emission tomography with $^{18}$F-fluorodeoxyglucose (FDG) positron emission tomography (FDG-PET)

One diagnostic study ($n=101$) reported $^{11}$C-Pittsburgh compound B (PIB) PET had higher sensitivity than FDG-PET for intermediate–high Alzheimer’s disease neuropathological change with similar specificity. This study included 101 participants, including younger-onset cognitive impairment, who underwent both assessment during life and neuropathological assessment.  

A further cohort study ($n=319$) showed the $^{18}$F-FDG-PET model yielded a significantly higher predictive value than the aPET model when investigating the development of Alzheimer’s disease in people with MCI. However, the best prediction accuracy was reached by combining $^{18}$F-FDG-PET, aPET and non-imaging variables. The combined model yielded 5-years free-of-conversion rates of 100%, 64% and 24% for the low-, medium- and high risk groups, respectively.  

4.2.4 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 this may make it preferable to using CSF biomarkers. Amyloid PET does involve a scan with radiation exposure, and while there is no single figure for radiation exposure from FDG-PET, as it varies between scanners, aPET has at least two or three times higher radiation exposure than FDG-PET. MRI involves no exposure to radiation. Young people are more susceptible to the effects of radiation than older people, so the benefits and risks should be considered before any scans are undertaken.  

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

Studies identified were heterogeneous in terms of populations and mode of aPET used. Further research is required to determine whether aPET should be used routinely for the diagnosis of dementia.  

Two studies (one systematic review including people being evaluated for Alzheimer’s disease with an early-onset cohort, and one cohort study including young-onset dementia, atypical or potential multicause states) report a significant diagnostic revision rate of performing aPET, with impact on treatment and management.  

Routine use of amyloid PET in the diagnosis of dementia or MCI is not currently recommended, but 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 an atypical presentations or young-onset dementia.  

Any consideration of amyloid PET imaging should follow a full clinical assessment by a dementia specialist, and discussion of the potential risks from radiation.
5 Postdiagnostic support

‘People with dementia benefit from an earlier diagnosis and access to the range of postdiagnostic services.' 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. Healthcare Improvement Scotland’s Quality Improvement Framework for Dementia Post-Diagnostic Support in Scotland describes what is necessary for high-quality postdiagnostic support and the policies, principles, rights and standards that should underpin service provision. The Scottish Government’s local delivery plan standard states that ‘people newly diagnosed with dementia will be offered a minimum of one year’s postdiagnostic support, coordinated by a named link worker.’

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. GPs or family physicians (in the USA) are usually the first point of contact.

5.1 Experiences of postdiagnostic support

Carers’ experiences with seeking or engaging with formal health care and organised support services varied greatly. Evidence on the quality of services are equivocal. One systematic review reported people with dementia’s dissatisfaction with the information provided and postdiagnostic support; social health of participants was rarely attended to, with support groups occasionally mentioned (lack of signposting); and professional help with memory rarely described, and nor was support provided for speech pathology, communication difficulties or occupational therapy (maintaining independence).

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. One systematic review (n=11 papers) further reported that difficulties in receiving information and support, primarily thought to be because of poor co-ordination between services and carers’ preference for psychosocial support was not always accessible. Another systematic review (n=46 studies) highlighted the need for psychoeducation for carers. These may have an impact on the help-seeking experience of people with dementia and their carers. Likewise, people’s attitudes and beliefs have been shown to influence help-seeking and their subsequent use of formal care. Positive correlation among normative beliefs derived from the carer’s own standards and their relation to help-seeking.

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.

Healthcare 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.

5.2 Needs and unmet needs around postdiagnostic support

One systematic review (n=54 studies, 46 on the needs of person with dementia and their carers (mean age of person with dementia 77 years (58)) and eight on case management, mean age 79 (61)) was important because it categorised needs specifically to those of the person with dementia–carer dyad, the person with dementia or the carer. Whereas other reviews focused on the general needs of the carer or the person with dementia–carer dyad

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.

R  Service providers should consider carers’ preferences for psychosocial support and education.

✓  Healthcare 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.
from the perspective of the carer.\textsuperscript{135,136,140,141,144}

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 (facilitating ADL and independence see section 5.2.4) and meaningful activities, managing mood changes and stress and distress (see section 6.1), behavioural management, cognition management (memory loss and deteriorating cognitive functioning), safety and management of mood.\textsuperscript{80,135,140,144}

A systematic review\textsuperscript{145} identified that the person with dementia expressed safety needs within the social environment (concerns around stigma\textsuperscript{139,146,147} or feeling socially isolated) and emphasised the need to maintain normality.\textsuperscript{80,135,144} Normality included themes on self-concept/sense of self; to hold on to their identity; relationships; responsibility for others; continuing to live in their own home; continuing with social contacts; staying active and enjoy meaningful activities; health awareness (independent from the diagnosis of dementia); autonomy; usefulness; and religion and spirituality.\textsuperscript{145} Other reviews reported similar findings supporting around needs.\textsuperscript{139,147} One systematic review reported the desire for people with young-onset dementia 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.’\textsuperscript{146}

Some needs, such as education on the disease, were well addressed, whereas others, such as advance care planning and management of mood swings, were overlooked.\textsuperscript{80,135,144,146}

5.2.2 Carer-specific needs

Carer-specific needs included emotional support, in-home support (domestic), involvement in care planning, and capacity to provide care. These themes were consistent across multiple reviews.\textsuperscript{80,135,136,144,146} One systematic review also reported a lack of carer-specific support in the UK.\textsuperscript{141} Another systematic review (46 studies) also identified the need for psychoeducation for carers.\textsuperscript{142}

One of these reviews identified in advanced dementia, in the absence of verbal communication from the person with dementia, carers reported not being able to identify when something was wrong or causing distress to the person with dementia which was distressing.\textsuperscript{136}

5.2.3 Needs of the person with dementia–carer dyad

Within the needs of the person with dementia–carer dyad the following 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.\textsuperscript{80}

5.2.4 Safety issues

One systematic review discussed the challenges of striking a balance between safety issues and autonomy/independence amongst people with dementia and their carers.\textsuperscript{135} Negotiating tasks/skills associated with sense of self (eg walking alone, driving). This is supported by primary evidence within this review\textsuperscript{149} as to how professionals and support groups can 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.

One systematic review identified that the person with dementia and carers initiate discussions about medications and concerns such as safe driving.\textsuperscript{142}

Another systematic review\textsuperscript{144} quoted ‘home safety literature’ from one paper,\textsuperscript{150} which
described the following safety challenges of home care triads:

- 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 well-being 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).

As this is a Canadian study, the applicability to the UK setting needs to be considered.

Findings indicate that people with dementia, carers and providers struggle with the home care system. Home care models that are client/person-centred need to be considered to provide seamless, quality, sustainable home care.

One systematic review for people with dementia and their carers151 identified mitigating safety concerns (such as the person with dementia getting lost) from studies, which included people of ethnic minority, Asian and Chinese populations. Included 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.

Another systematic review for people with dementia and carers identified the need for help in managing falls and wander risk, ensuring home safety (eg a safe return programme) and minimising the risk of accidental self-harm.80
5.2.5 Communication and communication support needs

Two systematic reviews stated that carers reported difficulty of the person with dementia communicating their symptoms, resulting in uncertainty and distress. These reviews included 46 studies (30 qualitative interviews, 10 focus groups, 6 interviews and focus groups combined). These included people with dementia (7 studies), carers (25 studies), both (14 studies) in the UK, USA, Canada or Australia, and a meta-synthesis of qualitative findings (14 studies, n=265 participants). One review identified that in advanced dementia, in the absence of verbal communication from the person with dementia, carers reported not being able to identify when something was wrong or causing distress, which was upsetting. Although not stated in these reviews, this is suggestive that the person with dementia and their carers may also have needs around communication and support.

5.2.6 Considerations for healthcare professionals/service providers around needs

A systematic review (46 studies) supported the need for open communication, empathy when delivering information, and to value the perspectives of people with dementia and their carers. It proposed several clinical recommendations:

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

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). However, support does need to be flexible and sensitive, or tailored, to the needs of the individual, taking into account cultural needs. Findings across the reviews overlap, resulting in similar themes in terms of their recommendations for practice.

A scoping review (8 papers) 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 relaying diagnosis (see section 3.2).

5.2.7 Postdiagnostic information and support needs, including signposting and accessing services

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’). Another systematic review noted that there was a lack of public-facing talks. Support services and voluntary services were also poorly signposted. Carers expressed the need for emotional support.

A systematic review of the burden, problems, needs and interventions of carers of people with frontotemporal lobe dementia (FTLD) described various interventions: 1) Carer support group, with topics comprising both educational (information on medical, legal, financial, insurance) and therapeutic elements (exchange of personal experience, encouragement, mutual support, facilitation of expressed emotion and development of coping strategies). Only 3/8 participants reported better outcomes; 2) 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. Outcomes at 2 years showed improved skills in all topics, better communication, and superior emotional coping; (3) Three-part series of conferences that provided educational lectures, introduction to the disease, support group sessions (semistructured setting where participants can share common coping strategies and practical tips) and clinician referral in crisis situations. Overall feedback was very positive; (4) Computer and online based technology to provide videoconferencing support group in a mutual self-help format. All carers were positive regarding this delivery method, for a support group, which facilitated access while balancing the demands of working full-time, household responsibilities and children. They felt they were not alone and found the emotional support they received to be beneficial but continued to be stressed albeit less burdened, and (5) day programme specialised for FTLD. This provided respite for carers and also educated them on the disease, ADL, behavioural management, and activation at home and long-term planning. No results were available; (6) Other short-term treatment programmes for FTLD and carers based on the concept of self-maintenance therapy have shown improved depression, chronic fatigue and restlessness for both FTLD and carers.

Another systematic review (46 studies) 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.\textsuperscript{142}

A further systematic review (19 papers) highlights the need for information to evolve with the stages of dementia.\textsuperscript{144} 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.\textsuperscript{135,144} Practical strategies included relying on family support, while emotional strategies included finding meaningful activities.\textsuperscript{135,144}
5.2.8 Attitudes and beliefs

A systematic review (14 papers) highlighted that attitudes and beliefs influence health-seeking behaviours, as 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 postdiagnostic support delivery for effective uptake. 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 which would include healthcare professionals and policy-makers.

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. Emotional well-being, consequences and duty of care demonstrated how perceptions of stigma 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.

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. There was also greater stigma among minority ethnic populations. Carers can also experience stigma.

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. (This was also found in young-onset dementia and young carers, see section 5.5).

5.2.9 Role of online resources and social media

Two systematic reviews (one of 21 papers, including 6 from the UK, with an age range of carers 6–35 years, and the other of 19 papers) found the use of internet resources and social media (blogs, online forums) beneficial in obtaining information and making contact with others with similar experiences.

One systematic review and one high-quality qualitative paper, which included people with dementia and carers, and service providers identified the need for better signposting to online resources and, separately, to third-party organisations, such as charities, which were widely considered important in terms of social and emotional support. The qualitative studies reported strong evidence of valuable support from voluntary organisations, although signposting needs to be improved.

Postdiagnostic support should address the needs of the person with dementia, carers, and the person with dementia–carer dyad.

The needs of people with dementia include:

- assistance with activities of daily living for maintaining their ‘normal life’ in the community; maintain their identity, relationships/partnerships; responsibility for others; continuing living in their own home; continuing with social connections; staying active; health awareness (independent from diagnosis of dementia); being useful and engaging in meaningful activities
- support for managing mood changes and stress and distress (agitation and aggression) (see section 6)
- support for memory loss, declining cognitive function (eg the ability to retain short-term information)
- support for safety needs, balanced with the need to maintain autonomy by facilitating normality and daily life
- education about the disease
• anticipatory care planning (see section 8.2).

The needs of carers include:
• emotional support
• psychoeducation
• information; timely information that relates to the stages of dementia, help to access the healthcare system (e.g., contacting healthcare professionals, knowing what services are available and how to access them) and practical strategies; such as knowledge of coping strategies, and strategies to preserve normality for both carers and the person with dementia, family support, and emotional strategies such as finding meaningful activity, use of online and social media for support
• domestic support at home
• involvement in care planning
• capacity to provide care.

The needs of the person with dementia–carer dyad include:
• communication and communication support. For the person with dementia to express their symptoms and needs. For carers to communicate with the person with dementia to understand their needs (e.g., when something is wrong or causing distress), particularly in the advanced stages of dementia and in the absence of verbal communication/education/counselling to manage stress and distress (e.g., agitation and aggression)
• self-management skills and resources, which requires appropriate support and signposting from healthcare professionals
• safety needs, e.g., the person with dementia walking outside alone/getting lost, safe driving, medication management, impaired judgement (e.g., appropriate seasonal dressing) and memory-related difficulties relating to activities of daily living, kitchen safety (e.g., flooding, fires, and food hygiene), in relation to stress and distress (extreme apathy or aggression), and achieving a balance between safety issues and autonomy/independence.
• anticipatory care planning (see section 8.2)
• a well-defined care pathway
• continuity of care
• access to GPs and healthcare professionals with specialist expertise in dementia care/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 Healthcare professionals should signpost people with dementia and their carers to
• non-statutory organisations (e.g., charities/voluntary organisations) that offer support, as this is important for social and emotional support
• information sources including internet resources and social media (blogs, online forums) (see section 9).
R Service providers and healthcare professionals delivering postdiagnostic support should consider and address: illness perception, cultural beliefs, lack of knowledge, stigma, and public acceptance; as attitudes and beliefs have shown to influence health-seeking behaviours, and uptake of care and
services, with negative views about residential and respite care associated with non-use of these services.

**R** Healthcare professionals need education about dementia and its management, including communication skills and person-centred approaches (see section 9.3).

- Healthcare professionals should consider the postdiagnostic support needs of the person with dementia as part of a holistic assessment; including any other risk factors and comorbidities that should be identified, considered and appropriately addressed.

- Healthcare professionals should be aware of potential communication difficulties for people in the advanced stages of dementia. Healthcare professionals may need enhanced communication skills training to communicate effectively with people with advanced dementia.

- The format of 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 POINT**

i Repeat information given at diagnosis on the long-term impact of dementia on the person with dementia and their carers, to ensure understanding.

### 5.3 Access to postdiagnostic support for ethnic minority groups

Only one systematic review (11 papers, in UK dementia services) 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.\(^{141}\) These findings suggest that current services are not equipped to deal with cultural differences.

A literature review (n=304 studies, mainly from the UK, Europe, the USA and Canada) looked at experiences of care and service requirements for people with young-onset dementia and discussed culturally appropriate services and subsequent needs in support for accommodations needed for minority groups or disadvantaged communities.\(^{147}\)

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.\(^{135}\) 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 than recognise them as an illness. In addition, 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, such as those with early-onset dementia or minority ethnic groups; it needs to take into account the needs for continuity of care; and it needs to manage care needs and safety while being aware of the person’s sense of identity and dignity.\(^{135}\)

Another systematic review (9 qualitative and 5 quantitative studies from the USA, UK, Australia, China, Hong Kong, Vietnam and Europe) found ethnicity was strongly associated with help-seeking (in Latin and Euro-American groups) and ethnicity was the only significant variable related to social network help-seeking.\(^{143}\) Despite the strength of these associations between ethnicity and help-seeking, the total model accounted for only 20 % of variance in social network seeking scores, which can be interpreted as a small effect size. As only two studies were from the UK, this may not be transferable to the UK NHS context setting.
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 and their carers from ethnic minority groups should consider language translation and culturally appropriate information that is tailored to individual cultural values and family dynamics.

Healthcare professionals should be aware of the potential 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, 80 carers (majority over 65, age range 26–90 years) 136 and young carers (6 to 35 years) 140 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. 136 Difficulties in receiving information and support experiences were primarily thought to be due to poor co-ordination between services. 141

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 dyad. 80 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 dyad. 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. Case managers also showed effects on the needs of carers as they 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.

Another systematic review advocated the introduction of services such as dementia care managers (case management) in primary care teams. 142

In one systematic review this need for a single point of contact was especially highlighted by young carers of family with dementia (see section 5.6), as 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. 140 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. 140 In addition, the issue arose of training professionals in the art of disclosing diagnosis 79 (see section 3.2).

A scoping review (n=8 papers) advocated for the role of a specialist key worker immediately after diagnosis for young-onset dementia. 152 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 also act as a co-ordinator of services, organisations and people, helping to connect the person living with young-onset dementia to a local group. They should also be available through a variety of organisations, depending on local infrastructure, such as primary care or the voluntary sector, or be based within local mental health teams or neurology services. 152

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 professional with appropriate skills, knowledge and expertise in dementia (link to NES framework), working with the GP, to ensure a tailored support package is delivered in a timely manner.
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.

Young carers and families of people with dementia should be offered support from one expert healthcare professional.

- People with young-onset dementia should be offered a key worker/case manager and postdiagnostic support information immediately after diagnosis.
- Input from multidisciplinary specialists (eg old age psychiatry, geriatrics and specialist care for any existing or identified comorbidities) should be considered within 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. 146,147,152-154 Three studies reported the process to diagnosis as confusing and distressing. 155 There were very few findings describing the experience of formal diagnostic support among people with young-onset dementia. In this population, there was a consistent theme of lack of age-appropriate support services (appropriate day services), programmes and financial problems were especially impactful. 146,147,153,154 A review specifically mentioned that interventions facilitating peer support, which allow people with young-onset dementia to engage in meaningful activities, should be developed. 146 Being with others in a similar situation was deemed an important means of support. The study explores the reaction of people with young-onset dementia to diagnosis and acknowledges how these needs can be different from those with late-onset diagnosis, which is a crucial point to consider.

A scoping review of lived experiences of people with young-onset dementia reported poor-quality information after diagnosis and a lack of explanation about the next steps. 152 It found that the accessibility of immediate emotional support was regarded as more beneficial in the short term than information provided via leaflets on dementia and postdiagnostic support. Similarly, another review found a paucity of information provision related to areas relating to prognosis, services and coping strategies. 154 Generally, information provision is valued highly. Carers recognised that the support for young-onset dementia is not on a par with 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.

An Australian review highlighted that effective service provision for people with young-onset dementia would only be possible if health services, care of older people services and disability service sectors work collaboratively to provide a holistic approach to supporting people with young-onset dementia and their carers and families. 147

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. 153 It may be related to stigma. 153 Carers encountered professionals with little awareness of young-onset dementia. 154

The young-onset dementia literature also highlighted the need for more empathetic communication, continuity of care, tailored care and better information provision. 146,147,152-154

One review referenced that grief was specific to people with young-onset dementia and their family 154 (see also section 7).
A systematic review of carers of people with FTLD (which is normally associated with onset at a younger age) highlighted poor overall well-being, neglected personal needs and increased social isolation among young carers. FTLD 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 FTLD.

A report by Young Dementia Network made recommendations for key workers for people with young-onset dementia. The key worker should (a) have specialist knowledge, skills and experience of the impact on 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. They should also (b) provide information, practical and emotional support for family members and (c) 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. The key worker should also (d) act as a co-ordinator of services, organisations and people, helping to link the person living with young-onset dementia to a local group and they should 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 that was highlighted as important in the literature search.

People with young-onset dementia need

- age-appropriate support services (appropriate day services) and programmes, tailored to individual needs, and support with accessing these
- continuity of care
- collaborative care
- peer support
- support to engage in meaningful activities
- support with financial problems
- immediate emotional support, in the short term, rather than information provision
- information on prognosis, services and coping strategies
- empathetic communication from all involved in the care of people with dementia, especially healthcare professionals.

Healthcare professionals need greater awareness of young-onset dementia and the needs of people with young-onset dementia (including grief) that people with young-onset dementia and their families experience (see section 7).

Healthcare professionals should be aware that a major barrier in the access of 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 of 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.
- Postdiagnostic support should be available throughout all stages of the disease, aligned to the needs of the person with dementia or their carers.

5.6 Postdiagnostic support for young carers of people with dementia

One systematic review’s findings relate to the young-onset dementia literature (see section 5.5), (n= 21 papers, including studies from the UK, USA, Europe and internationally, age
range of carers 6 to 35 years). There are consistent themes surrounding 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/case manager.

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/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. Idiosyncratic concerns include the ‘invisible’ nature of their experience. 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. Based on this systematic review, the condition and their caring role has a detrimental impact on their development and personal lives of these young carers in the following ways:

- hindered progress in studies or career due to interruptions from assuming care roles
- educational choices based on the need to stay close to family or spend time with a parent with dementia
- young carers at school highlighted 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 fulfill 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)

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.

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.

If the young carer is still in education, all professionals (e.g., healthcare professionals, case managers/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 cohesively to support the young carer’s needs and facilitate continuity of education (consider flexibility and support around education needs, e.g., the need to stay close to family or spend time with their parent) and look for and address any stigma and bullying.

All professionals (e.g., health visitor, teacher, healthcare professional/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 management of aggression, agitation and sleep problems

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, challenging behaviour and behaviours that challenge.\textsuperscript{157} The use of terminology around this is complex, with further work continuing.\textsuperscript{157}

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, non-compliance, 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 and/or social/environmental need(s)/unmet need(s).\textsuperscript{157}

Within the literature there is also variation in how distressed behaviour is measured and addressed. The recommendations in this guideline are based on three specific presentations of distressed behaviour, namely aggression, agitation and sleep disturbance, because these are frequently cited as reasons for a person with dementia being transferred to a care home, from their home, and/or being admitted to a specialist dementia unit.\textsuperscript{158-160}

Owing to the large number of interventions and heterogeneity of outcome measures, the primary focus of this evidence summary was high-quality systematic reviews of RCTs. Individual trials are included where they supersede relevant secondary analyses.

6.1 Assessment of distressed behaviours

A 2019 survey of UK specialists in distressed behaviours in people with dementia explored which instruments were used to evaluate their symptoms.\textsuperscript{161} A cascade approach was used to recruit 241 participants across the UK. Just over half (55\%) of the respondents worked in the community, and psychologists and nurses were the most represented professions in the survey. There were 102 (42\%) respondents who reported using an instrument to measure behavioural changes in dementia. The most frequently reported measure of behavioural symptoms was the Challenging Behaviour Scale (CBS) (n=54 participants) and the Neuropsychiatric Inventory (NPI) (n=38 respondents). Antecedent, behaviour, consequence (ABC) charts were reported as a functional analysis measure (n=44 respondents), with frequency charts recording the number of incidents (n=26 respondents). For agitation and aggression, the Cohen–Mansfield Agitation Inventory (CMAI) was reported by 17 respondents.\textsuperscript{161}

A systematic review with a literature search to 2013 identified 45 measures for assessing neuropsychiatric symptoms in people with dementia that had explicit psychometric data such as validity and reliability reported.\textsuperscript{162} 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 authors highlighted the NPI-C clinician rating scale because of its use in multiple clinical settings, validation in multiple countries and the range of versions and subscales available. The authors suggest that choice of measures should take into account:

- Measurement purpose – is it for a general screen or to measure a more targeted behaviour? It may be helpful to start with a more generic measure and use the results to inform more targeted measures.
- 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.\textsuperscript{162,164}
Another systematic review used similar inclusion criteria. These reviews were used as the basis for an updated synthesis focusing on measures of aggression, agitation and rejections of care. In summarising existing scales, the lack of consistency and consensus around the terminology and descriptors applied to each of the three behavioural constructs was highlighted. The authors noted a need for assessment instruments that can integrate descriptions of the context in which behaviours occur in order to assist in the design of treatment strategies.

A descriptive study on the development of the Innovative Dementia-oriented Assessment (IdA®) used a literature review to identify a range of models for understanding distressed behaviour in people with dementia, including potential triggers. Examples were the Progressively Lowered Stress Threshold model, Treatment Routes for Exploring Agitation (TREA), Needs-driven dementia-compromised behaviour model (NDB model), Serial Trial Intervention (STI), Comprehensive model of behaviour, and the Antecedents–Behavior–Consequences (ABC) approach.

6.2 Comparison with pharmacological interventions

A network meta-analysis with literature search to July 2019 explored the effectiveness of non-pharmacological and pharmacological intervention for aggressive behaviour and agitation in people with dementia. Participants in the majority of studies were from nursing home settings and over 80% of studies included more women than men. Most treatment comparisons were at high risk of bias because of a lack of blinding and missing data. The most frequently used outcome measure across studies was the CMAI. Severity of dementia was not reported in a third of studies, and harms were not evaluated. When treatment rankings were analysed, several non-pharmacological interventions ranked highly and above pharmacological therapies. Outdoor activities ranked highest for combined aggression and agitation and for physical aggression. For verbal aggression outdoor activities and massage and touch therapy were the highest ranked treatments. For physical agitation the highest ranked treatment was exercise plus modification of ADL, and for verbal agitation anticonvulsants ranked highest. 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. It is possible that in some trials those receiving non-pharmacological therapies were also receiving medications. The analysis did not take into account the number of therapies used prior to study participation, which could be an effect modifier, particularly in that those recruited to pharmacological interventions may have previously received non-pharmacological approaches. Another potential effect modifier – tailoring of non-pharmacological interventions – was not explored in the analysis. The varied populations of the trials weaken the credibility of the indirect comparisons, so it is not possible to base a recommendation for a specific intervention on this analysis. However the finding that non-pharmacological interventions had greater efficacy than drug-based approaches seemed robust and had face validity. This is in keeping with the NICE guideline (2018) that recommends non-pharmacological treatments as first line. As such, the guideline development group agreed to focus on non-pharmacological interventions.

6.3 Comparisons with usual care or attention control conditions

A systematic review from the US Agency for Healthcare Research and Quality (AHRQ) with literature search to 2015 identified 67 trials that assessed individual resident-level non-pharmacological interventions for agitation and or aggression in residents of nursing homes and assisted living facilities. Of these, 40 were assessed as having an acceptable risk of bias. There was low-strength 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 when compared with the control. For most other comparisons with behaviour outcomes, including exercise, therapeutic touch, massage, simulated presence and reminiscence therapy, evidence was insufficient to draw conclusions on effectiveness. These findings are consistent with Cochrane systematic reviews on the individual interventions with respect to distressed behaviour outcomes. One trial on art
therapy for people with agitation or aggression in the community was identified. Evidence was insufficient to enable conclusions to be made. This is consistent with a more recent Cochrane systematic review.169

The AHRQ systematic review also 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. Nineteen trials were assessed as having an acceptable risk of bias. For the majority of interventions and comparisons evidence was insufficient to draw conclusions. There was low-strength evidence that neither dementia care mapping (three trials) nor person-centred care (two trials) was more effective than usual care in reducing agitation or aggression. Evidence was also insufficient to make conclusions around interventions that aimed to reduce antipsychotic and psychotropic medication use.

The WHELD (Well-being and Health for People with Dementia) study175 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; or education around antipsychotic use and review. Outcome assessors were blind to treatment allocation. WHELD led to a statistically significant improvement in mean CMAI (secondary outcome) of –4.13 (n=296) from baseline to 9 months compared with a mean worsening of 0.14 in the treatment-as-usual (TAU) group (n=257), between-group difference 4.27, 95% CI –7.39 to –1.15, p=0.0076). The authors note 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 NPI-NH of –2.64 compared with a mean worsening of 1.91 in the TAU group. Antipsychotic use was stable at a low baseline across both groups.

The TIME (Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms) study randomised 33 nursing homes (n=229) 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.176 The interventions 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. The primary outcome was the difference in the change between the intervention and control groups in agitation or aggression at 8 weeks from baseline using the NPI-NH. Assessors were blinded to allocation. 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).176

The MARQUE (Managing Agitation and Raising Quality of Life) cluster RCT was conducted across 20 UK care homes (n=492).177 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. Assessors were blinded to group allocation. 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).177

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.178 The primary outcome was agitation in individuals with dementia at 16 months as measured by the CMAI. There was no evidence of any difference between treatment arms (mean difference –2.11, 95% CI –4.66 to 0.44, p=0.10). Similarly, there was no difference when assessors blinded to the intervention allocation undertook CMAI observer scoring. Implementation of the intervention was described as poor with full completion of the protocol by only four of the care homes.178

The US AHRQ review identified 27 RCTs, of which 20 were assessed at acceptable risk of
bias, looked at carer interventions for managing agitation or aggression in community-dwelling individuals with dementia. Interventions variously focused on addressing carer knowledge, skills and affect.\textsuperscript{167} Trials were heterogeneous in outcomes and comparators, so a meta-analysis was not possible. There was low-strength 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 (one trial, n=239) and reducing carer distress (three trials, n=685). 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.

An overlapping Cochrane systematic review examined interventions for people with dementia which incorporated a functional analysis approach to understanding the possible purpose of an individual’s distressed behaviour.\textsuperscript{179} 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 and depression. The literature search to 2011 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 post intervention or at follow-up. Carer reaction (such as distress, upset and bother) was reduced after 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.

### 6.4 Effect of tailoring activities

A Cochrane systematic review with meta-analysis 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.\textsuperscript{180} The primary outcomes were distressed behaviour and quality of life. 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. For quality of life, two studies were incorporated, both of which involved proxy ratings by family carers. Meta-analysis was not possible. There was low-certainty evidence of 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.\textsuperscript{181} 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 $0.08$, $p=0.15$).

A systematic review with meta-analyses examined the effect of degree of personalisation of tailored activities on outcomes relating to reducing distressed behaviour in people with dementia.\textsuperscript{182} 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 $0.14$, $p=0.076$).
6.5 Sleep problems

6.5.1 Light therapy

A Cochrane systematic review with literature search to January 2014 examined the effects of bright-light therapy on sleep outcomes in people with dementia. Based on six studies, there was no statistically significant effect on total sleep after 10 days and to 10 weeks of treatment. There was no statistically significant effect on sleep efficiency (three studies) or number of night-time awakenings (three studies).

6.5.2 Multicomponent approaches

NICE (2018) systematically reviewed RCTs of multicomponent interventions for people with dementia who experienced sleep problems. Based on evidence from three RCTs undertaken in the community and residential settings, multicomponent interventions resulted in improved total night-time sleep, 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. Interventions encompassed sleep hygiene, education for carers, additional sunlight exposure, lightbox use and exercise. An additional RCT examined the effect of individualised social activity on people with dementia in nursing homes who had sleep–wake pattern disturbance (n=139). 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.

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.

For the management of agitation and aggression in care homes a multicomponent programme, including staff training and support, as well as interventions tailored to the needs of the person with dementia, may be considered.

For people with dementia who have sleep disturbance, consider a multicomponent approach that includes sleep hygiene education, exposure to daylight, exercise and personalised social activities.

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.

When people with dementia present with distressed behaviour, a holistic assessment should be undertaken which includes consideration of the possible reasons underlying the person's distress. Structured/objective measures can assist in the identification of distressed behaviour. Functional analysis can aid identification of possible triggers/reasons for the behaviour.

Staff training around the management of distressed behaviours, to improve the quality of life for people with dementia, should be linked to the Promoting Excellence Education Framework. Training should be part of ongoing multidisciplinary skills
development and supported by appropriate leadership, infrastructure and resources to facilitate sustained implementation and staff engagement.
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. In the context of this guideline, grief is defined by the key terms ‘anticipatory grief’ (section 7.1.1), ‘pre-death grief,’ (section 7.2.2) 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. A small but significant proportion of the bereaved do experience complicated/prolonged grief, and thus can benefit from psychological interventions. 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 and pre-death grief

7.1.1 Anticipatory grief

The bereavement experience or ‘anticipatory grief’ for informal carers of people with dementia commences 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. 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. Anticipatory grief can be experienced by both carers and people with terminal conditions.

People with dementia, as well as their carers, experience multiple losses over the course of the dementia. Early losses include cognitive decline, such as decline in memory and communication function, followed by losses in personality and self-care follow. 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’ well-being. 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 postdeath grieving. Below a carer describes their experience of anticipatory grief:

'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.'

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. 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.

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. 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 endure a ‘tragic variant’ of anticipatory grief.
7.1.2 Pre-death grief

The term ‘pre-death grief,’ defined by Lindauer and Harvath (2014), attempts to capture this phenomenon that applies specifically to the carers of people with dementia:

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 (e.g., sorrow, anger, yearning, and acceptance) that can wax and wane over the course of 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.

Their definition captures the elements of pre-death grief in carers of people with dementia described in the wider literature.

The term ‘pre-death grief’ blurs with the concept of anticipatory grief in many of the studies reviewed. Authors frame their definitions around Rando’s (1986) definition of anticipatory grief, suggesting that pre-death grief and anticipatory grief share conceptual boundaries. The terms 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). People with dementia experience progressive losses related to their sense of personal identity that can result in experiences that are grief-like, and that they may think about their death and the impact of their diagnosis on their future. These findings were based on three primary qualitative interview studies in younger people (age range 35–68 years) with dementia, which 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 and one in the USA; all three were of high quality. In total they interviewed 36 people (16 women, 19 men and one person for whom the gender is not known). The US study recommends that ‘there is a need for counselling, especially grief counselling, for both the person [with dementia] and family members.’

One high-quality qualitative study of 30 people with dementia–carer dyads 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. 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. The authors recommend ongoing education, support and psychotherapeutic interventions beginning from the diagnostic phase for people with dementia.

R Health and social care professionals should be aware that people with dementia may have experiences that are grief-like. These can take the form of:
7.3 Pre-death grief in the carers of people with dementia

A number of qualitative systematic reviews, 154,190,200 mixed-methods systematic reviews and other reviews, examined the experiences of carers with pre-death grief.189,191 Reviews included studies on only younger people with dementia and their carers, 154 and one focused only on the carers of people with young-onset dementia. 200 The representation of UK studies ranged from 0% to 36% in these reviews, with the majority based in the USA (ranging from 0% to 87%).

There was consensus across the reviews that the experience of pre-death grief in carers can start at diagnosis. 154,187,189-191,200 While it can fluctuate across the course of the dementia, it usually worsens as the dementia becomes more severe and the losses associated with the dementia mount.50,198-191 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. 189,190,200-202

Adult children and spouses may experience grief in different ways throughout the course of the 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.187,189,191 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.189 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.200 The children of a person with young-onset dementia may grieve the loss of normality and for some a parent they never fully had.200 In the quote below an adult-child carer of a person with young-onset dementia describes this type of pre-death grief:

'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.' 200

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:

- Pre-death grief in carers often worsens as dementia becomes more severe.
- Pre-death grief in carers often worsens 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.203 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.203 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.203

Pre-death grief in carers is varied and influenced by individual circumstances and the losses carers experience during the course of the dementia; therefore, 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. 187,190,191,201 It is difficult for carers of people with dementia to ‘recognise’ and talk about their experiences of pre-death grief.204 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. 190,204

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

### 7.5 Pre-death grief and depression in carers

Carer depression increases as anticipatory grief increases. 189 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<.001 (Liew, 2020 #206) Pre-death grief may have a worse impact on well-being and be associated with worse outcomes than depression for carers.205

While the experience of pre-death grief may be associated with depression, they are not equivalent.189,193 Two US-based, cross-sectional surveys suggest that what appears to be clinical depression in this group may sometimes be pre-death grief.189 The cohort study from Singapore suggested that pre-death grief is likely to act on well-being 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.205

**Healthcare professionals should be aware that pre-death grief in 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.
- Pre-death grief experienced by the carers of people with dementia can be distressing and disabling, and has an impact on well-being.

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

There is evidence that care professionals should support carers and the family unit, as well as the person with dementia, including offering interventions aimed at developing coping skills for loss and grief.187,189,191,193,200,201 Nursing staff were the professionals most often described as active providers of support aimed at helping carers cope with psychosocial aspects of dementia and grief.190,193,200,201

There is a lack of guidance and training for professionals on the assessment and support of carers experiencing pre- (and post-) death grief.187,189,190,193,200,201 With no clear knowledge and skills framework or evidence-based guidance to support grief-focused work with carers, this often depends on descriptions of practice and professionals' experience instead. 207 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.'190

The authors of a non-randomised controlled trial that 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 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.206

The reviews mentioned several areas where professional support for pre-death grief could focus, including:
• psychoeducation on illness trajectory, caregiving skills and self-help strategies\textsuperscript{187,193,207,208} 7/10 1+

• investing in other relationships and activities\textsuperscript{190,192,200} JBI 8/10 9/10 3/10 6/10 1-

• accessing consistent social support before and after death of the care receiver\textsuperscript{187,189,190,192} 1-

• cognitive behavioural support strategies\textsuperscript{204,207,208,208} 1-

Two RCTs also investigated the role of CBT for pre-death grief in carers of people with dementia.

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 (\(p=0.003\))\textsuperscript{207}. 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.\textsuperscript{207}

Another small RCT did find benefit from a grief intervention programme\textsuperscript{208}. 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.\textsuperscript{208}

A qualitative study of nine male carers in Norway described the grief and loss experienced by men as dementia progressed.\textsuperscript{209} 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 assuage the loneliness and isolation they were experiencing. One man said:

‘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.’\textsuperscript{209}

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.\textsuperscript{206} 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 with 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.\textsuperscript{206}

A non-randomised controlled feasibility study showed short–but not long-term benefits from a group-based multicomponent chronic grief management intervention.\textsuperscript{210} 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, or 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 and depression. 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.

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 a diagnostic criteria within ICD-11 of prolonged grief disorder. The interventions in the studies all focused on participants who had not been assessed as having complicated grief, and one RCT (Meichsner 2018) highlighted the focus on grief being a normal reaction for carers. The highest quality 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. 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. Harms were also reported in the assessment of pre-death grief (see section 7.4).

| Healthcare professionals should receive guidance and training on the assessment and support of pre-death grief for carers of people with dementia (see section 9.3). |
| 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 (see section 7.6). |
| To reduce the impact of pre-death grief in carers of people living with dementia, postdiagnostic support for carers could include psychoeducation on 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/telephone, individual and group delivery. |
| Consider local services offered by both statutory and non-statutory sectors and carers’ individual preferences for accessing these services. |

7.7 Support following bereavement for people with dementia

Three primary qualitative studies were identified that described the experiences of people with dementia following the death of a spouse, relative or friend. All three rely on carer or professional descriptions of the experiences of people with dementia.

One of the studies, from Japan, aimed to explored the mourning process of bereaved people with dementia who had lost a spouse to use the information to guide grief counselling.
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.

A high-quality, UK-based case study described one carer’s experiences of caring for her mother in residential care. 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.’

A US case study reported on two interventions for grief following bereavement in people with dementia. This study describes one complete cycle of group therapy for grief following bereavement. 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.

The studies conclude that people with dementia face a more complicated grieving process because of their cognitive and memory losses. 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.

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. 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.

**R** Healthcare 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 healthcare professionals with grief following a bereavement; to process the loss and to manage the 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*](#)).
Grief following bereavement, and prolonged and complicated grief in carers of people with dementia

The term ‘complicated grief’ has been widely used in clinical practice to describe grief and associated painful emotions that are unusually persistent and disabling, yet the syndrome is not well defined.\textsuperscript{189} Prolonged grief disorder is defined in the fifth Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association (DSM-5) and the 11th International Classification of Diseases (ICD-11).\textsuperscript{213,214} Prolonged grief disorder 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 (e.g., guilt, sadness, anger, denial, and blame). 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.\textsuperscript{214}

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.\textsuperscript{190} 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.\textsuperscript{189,190,193} One qualitative systematic review concluded that dementia carers may be particularly vulnerable to a ‘challenging grieving process’ and ‘intensified grief’\textsuperscript{190}

One study of 217 carers\textsuperscript{215} (rated as high quality in a systematic review)\textsuperscript{189} 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 survey\textsuperscript{216} of 138 carers of people with dementia and 38 cardiac carers (within the same systematic review,\textsuperscript{189} rated as a moderate to low-quality survey) found that the carers of people with dementia experience nearly twice the amount of loss as people caring for someone with cardiac problems.

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.\textsuperscript{189} This conclusion was based on two US-based prospective cohort studies, with a combined sample of 441 carers that was assessed as medium to high quality.\textsuperscript{189} The same review concluded that African American ethnicity and higher level of carer burden may also predict complicated grief.\textsuperscript{189} The early identification of modifiable risk factors (such as the need to institutionalise the person with dementia, 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 dementia carers.\textsuperscript{189} A qualitative synthesis of 11 studies concluded that carers who had experienced more feelings of guilt, commonly around institutionalisation, were less likely to feel relief after the death of the person with dementia.\textsuperscript{190}

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.\textsuperscript{190}

A US-based case study of two bereaved dementia carers following the sudden death of their spouse (from choking and a fall)\textsuperscript{183} whose husbands had had particularly challenging types of dementias (progressive supranuclear palsy and frontotemporal dementia) described their experiences of complicated grief group therapy.\textsuperscript{183} No conclusions about the effectiveness of complicated grief group therapy for dementia carers 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.

**R** Healthcare professionals should be aware of the risk of complicated/prolonged grief in the carers of people with dementia following the death of the person with dementia.

**R** Healthcare professionals should be aware that the experience of complicated grief/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.

✓ Healthcare 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, any intervention offered must be done with the individual’s informed consent and awareness of circumstances that might affect their ability or wish to engage in such approaches.

✓ Practitioners with appropriate knowledge skills and expertise in dementia, defined in the Promoting Excellence Framework in Dementia, 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 and palliative approaches

8.1 Palliative and end-of-life care approaches to changing and unmet needs, including transitional care

8.1.1 Assessments and approaches to identifying 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. The middle to late stages of the disease often signals a loss of autonomy, independence and reduction in physical and cognitive function. This stage has been described as the beginning of an extended, intensive palliative care phase. 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.

An integrative review highlighted that there was no consistent definition of advanced dementia. 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). There is a lack of literature on the psychological, spiritual and existential needs and preferences of people with advanced dementia and their family carers. There is also a lack of understanding of palliative care among front-line practitioners that relates to the lack of educational opportunities in advanced dementia care.

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 impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' 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 impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

As dementia progresses, living well requires increasing levels of support and care. People living with advanced dementia have complex health and social care needs, are highly dependent, but may not yet be at the terminal end stage of the condition. People with advanced dementia can benefit from a dementia specific palliative approach to care (Palliare), that assists them to live the best life possible for the months and often years of living with advanced dementia. However people with dementia are less likely to receive palliative care, due to the complex and unpredictable disease trajectory. This can result in unmet needs and potentially burdensome interventions until death.

A Dementia Palliare best practice statement in 2016 aimed to promote a consistent and cohesive approach to advanced dementia care, advocating 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.

No evidence directly relating to assessment and approaches for changing or unmet needs in people with moderate, advanced or severe dementia was identified. Assessment and approaches were largely related to palliative or end-of-life care, with some evidence around transitional care. Evidence subsequent to the 2018 NICE guideline on dementia was reviewed.

Palliative care evidence and recommendations previously presented in the NICE dementia guideline (2018) are as follows:

NICE 2018 (section 1.10, Palliative care)

- 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, see also recommendation 1.1.12, on advance care planning. 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.

NICE 2018 (section 1.12, Moving to different care settings)

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

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, well-being and unmet needs in people with young-onset dementia and/or people with young-onset Alzheimer’s disease, vascular dementia, mixed or frontotemporal dementia and dementia with other causes, at all stages of severity. 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. 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 well-being of people with dementia may not be appropriate for people with young-onset dementia.

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

8.1.3 Defining end of life, assessments, and approaches for palliative care for people with dementia

Prognostication in dementia care is difficult, with difficulty identifying or predicting when death is likely. A mixed-methods systematic review found that definitions of end of life varied in the 33 included studies. These studies spanned a range of designs (cohort n=13, qualitative n=8, RCT n=5, evaluation designs n=4, mixed-methods n=2, quasi-experimental 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 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). One study 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. Overall, the systematic review 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’

3. ‘Staff knowledge,’ finding that healthcare professionals also had limited knowledge of end of life in dementia (a lack of training in nursing homes was identified in two studies, one UK based).

This systematic review concluded that end of life in dementia remains poorly defined, and unrepresentative of the general population with dementia. 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 end of life. It proposed that researchers and healthcare professionals in dementia care accept the complex nature of end of life in dementia between and within individuals 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.

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. 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.

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 EAPC domains of care (domain 11, societal and ethical issues, was not mapped to). Included
studies were quantitative, 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.

This review indicated that a range of interventions that addressed the domains were being utilised for people with dementia receiving palliative care in long-term care, with a focus on developing interventions that provide education and upskilling of healthcare teams, support optimal treatment of symptoms and comfort care, and seek 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.

Healthcare professionals should be aware that existing measures to define end of life in 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.

Family and carers of people with dementia should receive education, so that they understand that dementia can be the cause of death.

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 POINT

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.

8.1.4 Needs, unmet needs and approaches to transitions between care settings for people with dementia

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. Thirteen papers reporting on 11 studies were included in the review (RCT n=8, quasi-experimental 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,
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 well-being.

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. Carer physical decline was not considered a priority for intervention.

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.

Decreases in transitions for older people living with dementia with better service utilisation and prioritises the need for a greater focus on carer-relevant services.

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. Two studies identified that improvement in addressing unmet needs through better health service utilisation can lead to improvement in transitions for people with dementia. 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. 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%. 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. 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. 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.

The findings of the studies included in this review may not be directly comparable or transferable to Scotland because of their predominantly non-UK data. 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.

**Healthcare professionals should consider holistic, person-centred approaches when people with dementia transition between care settings, which 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 (consider falls and the ability to perform activities of daily living, such as walking and balance)
  - setting goals or 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 8.2).

**INFORMATION POINT**

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...
Discussing anticipatory care plans

Since 2010 the term ‘anticipatory care planning’ 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.\textsuperscript{234}

Anticipatory care planning is now 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.\textsuperscript{235} 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.\textsuperscript{236} 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.\textsuperscript{237}

The terms Advance Care Planning (used in most other countries) and Anticipatory Care Planning (used in Scotland) are synonymous. The term Anticipatory Care Planning (ACP) will be used in this guideline to encompass both Advance and Anticipatory Care Planning.

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 1.2.3).

Most of the identified studies investigating ACP refer to the stages of dementia in relation to the person’s decision-making capacity.\textsuperscript{238-240} 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.\textsuperscript{240} It is recognised that as the illness progresses verbal 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.\textsuperscript{241} If or when this happens, proxy decision-makers may be involved in decisions about care and treatment.\textsuperscript{241}

There is less evidence on ACP during the earlier stages of dementia, despite recommendations for early ACP conversations with people affected by dementia.\textsuperscript{239,242} Most studies focused on the later stages of dementia (moderate to advanced, and severe) when care and treatment escalation decisions are increasingly called upon.\textsuperscript{236,238,240,243}

The NICE guideline on dementia (2018)\textsuperscript{47} makes the following recommendations about ACP, using the term ‘advance care planning.’

Advance care planning (NICE 2018, section 1.1.12)

- Offer early and ongoing opportunities for people living with dementia and people involved in their care (see also NICE recommendation 1.1.7) 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 (NICE 2018, section 1.1.13).\textsuperscript{47,51}

Studies identified in the review for this SIGN guideline included an umbrella review\textsuperscript{240} (n=19 reviews and n=11 additional primary studies); two quantitative systematic reviews (n=8 studies)\textsuperscript{241}; and (n=30 studies)\textsuperscript{236}, two qualitative systematic reviews (n=7 studies)\textsuperscript{238} and (n=84 studies),(Sellars et al, 2019); a mixed-methods systematic review (n=33 studies), van der Steen et al, 2014); and a review of guidelines, reviews and primary research aimed at
developing clinical recommendations for applying ACP in practice in Belgium (Piers et al., 2018). The evidence base was international, originating from the USA, Europe, UK and Australia.

There was sufficient evidence to address the questions of when and with whom ACP discussions should take place and how to conduct ACP discussions. There was a lack of evidence specific to where ACP discussions should take place and on the specific views and preferences of people with dementia,238,243

8.2.2 When should anticipatory care planning discussions take place?

The evidence was equivocal. 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.238 However, the most recent umbrella review242 found a lack of agreement on the best time, 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.239,240 There is also consistency in the need for it to be person centred and tailored to the needs of the person with dementia.239,240 In addition, it may need to take place over a series of conversations 239,240 to allow clarification, reflection and updates to changing needs.239 A precondition for families to be receptive to ACP discussions is understanding that dementia is a progressive and terminal condition.238

Late or ‘crisis-triggered’ ACP discussions were acknowledged as potentially stressful for the person with dementia242, and as such might be considered to be associated with harm. There is also evidence of family carer worry and regret if decision-making regarding treatments and life-preserving interventions is left too late or undertaken in crisis,242 reducing or removing opportunities for the person with dementia to be directly involved because of a loss in decision-making capacity.241

8.2.3 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 home239,241 and care homes.236

8.2.4 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.240 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.239 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.242 GPs are reported to have an important role236,239,242 noted that engaging doctors in ACP may result in higher completion of advance care directives. However, all healthcare professionals can be involved to some extent depending on their skills and knowledge of the disease trajectory.239 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.242 Informal carers/family/significant others should be involved as early as possible.239,240,242

Key themes arising were the need for a person- and family-centred approach239,240,242, for people with dementia to be included and enabled to participate in ACP discussions;236,239-242 the importance of trusting relationships between healthcare professionals, people with
dementia and their carers (formal or informal); 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.

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]

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]

‘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]

**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/carer(s)
- consider triggers for discussions, which include diagnosis, change/decline in health status or change in place of residence.

**Healthcare professionals** should ensure that the person with dementia, and their family or carer(s), have awareness of the progressive nature of dementia and what to expect at different stages of the illness.

**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.

The person with dementia, their family/carer(s) and healthcare professionals should all have the opportunity to initiate and be involved in anticipatory care planning discussions.

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.

The person with dementia, their family/carer(s) and healthcare professionals who are involved in anticipatory care planning discussions should all seek to build trusting relationships.

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

Anticipatory care planning can take place in any care setting, including the family home, primary care, hospital or care home.

Healthcare professionals should receive education and training on communication skills, anticipatory care planning, the dementia disease trajectory, treatment and care options, and palliative care.

All professionals and people involved in the care of people with dementia should be aware of the importance of anticipatory care discussions and plans, and the inclusion of healthcare professional(s) with specialist dementia expertise.
All healthcare professionals leading on dementia-related anticipatory care planning should be at the enhanced level of practice or above in dementia care as defined by the Promoting Excellence Framework in Dementia, (NES 2021).

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 (see section 9.3).

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 ensure a quiet location, free from distractions, that facilitates a supportive discussion and safeguards confidentiality.

INFORMATION POINTS

i The person with dementia, and their family or carer(s), should have awareness of the stages of dementia and the progressive and terminal nature of the condition.

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 and care.

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/lived 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 experience and their carers is available from [www.sign.ac.uk/patient-publications.html](http://www.sign.ac.uk/patient-publications.html) - to be developed after this guideline.

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 Education and training resources

9.3.1 Resources for professionals working with people with dementia people living with dementia and their carers

Overarching resources

NHS Education for Scotland
Once for NES: Dementia learning site
https://learn.nes.nhs.scot/24388

Scottish Government
National Dementia Strategy

Scottish Government
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-framework-health-social-services-staff-
working-people-dementia-families-carers/pages/2/

Diagnosis and postdiagnostic support

Healthcare Improvement Scotland
Information on diagnosis and postdiagnostic support
https://ihub.scot/improvement-programmes/focus-on-dementia/improving-diagnosis-and-
post-diagnostic-support

Communication and care delivery

British Deaf Association
Dementia-specific resources for healthcare professionals
https://bda.org.uk/dementia/

Healthcare Improvement Scotland
A guide to making general practice dementia friendly
https://ihub.scot/media/8222/gp-df-a4-landscape_2021.pdf

Healthcare Improvement Scotland
Information and case studies on care co-ordination for people living with dementia and their
carers
https://ihub.scot/improvement-programmes/focus-on-dementia/care-co-ordination/
Healthcare Improvement Scotland
Dementia in hospitals improvement toolkit
https://ihub.scot/project-toolkits/specialist-dementia-units-toolkit/dementia-in-hospitals-improvement-toolkit/

Healthcare Improvement Scotland
Guidance for staff supporting people with an intellectual/learning disability and advanced dementia moving into a care home

LGBT Health and Well-being
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/

NHS Cumbria
Northumberland, Tyne and Wear
Communication and Interaction Training (CAIT): an online person-centred training programme designed to help staff acquire greater ‘dementia care literacy’
www.cntw.nhs.uk/services/cait/

NHS Near me
Informative video and links to educational resources for healthcare professionals
www.nearme.scot/information-about-near-me-for-professionals

Scottish Government
Evaluation of the effectiveness of the ‘8 Pillars’ model of home-based support
https://ihub.scot/media/6283/evaluation-effectiveness-8-pillars.pdf

Care Inspectorate
My life, my care home
Study on the experiences of people living with dementia in care homes in Scotland

Psychological therapies and interventions

NHS Education for Scotland
Educational and training resources for psychology and psychological interventions in Dementia
Anticipatory care planning

Healthcare Improvement Scotland
Anticipatory care planning toolkit
https://ihub.scot/acp

NHS Inform
Anticipatory care planning information

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/

Palliative care

Healthcare Improvement Scotland
Quick guide on palliative care identification tools for use with people living with dementia

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

Research

Scottish Dementia Research Consortium
Membership organisation including researchers, healthcare professionals, people living with dementia and anyone else with an interest in research.
https://www.sdrc.scot/

School teaching resources
Alzheimer's Society
School teaching resources to make it easy to teach and learn about dementia
School teaching resources | Alzheimer's Society (alzheimers.org.uk)

9.3.2 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/

Alzheimer Scotland
Resources for people living with dementia
www.alzscot.org/living-with-dementia

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

Alzheimer’s Society
Information and support for people affected by dementia
www.alzheimers.org.uk/

British Deaf Association
Dementia-specific resources
https://bda.org.uk/dementia/

Chartered Institute of Housing
Scottish housing and dementia framework
www.cih.org/policy/scottish-housing-and-dementia-framework

Dementia UK
Resources for people with dementia and their carers
www.dementiauk.org/get-support/

NHS Inform
Dementia: information and support resources
www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/dementia

NHS Inform
Anticipatory care planning information
Anticipatory Care Planning (ACP): Thinking ahead | NHS inform

NHS Near me
Information on Near me and instructions for use
www.nearme.scot
Sight Scotland
Dementia and sight loss guide

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/

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

Young Dementia UK
Information and support for younger people with dementia and their families
www.youngdementiauk.org/

Alzheimer’s Society
School teaching resources to make it easy to teach and learn about dementia
School teaching resources | Alzheimer’s Society (alzheimers.org.uk)

Carer-specific resources

Age Scotland
Dementia carers’ rights training

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

Carers Trust
Help and information for carers
https://carers.org/help-and-info/introduction

NHS Education for Scotland
Caring for a Person Living with FTD: a supportive series of resources for carers
https://www.nes.scot.nhs.uk/nes-current/caring-for-a-person-living-with-ftd-a-supportive-series-of-resources-for-carers/

Tide
Resources and information for carers
https://www.tide.uk.net/resources/

Tide
Living grief and bereavement
Resources for carers
www.tide.uk.net/what-we-do/living-grief-and-bereavement/

Tide
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/#:~:text=With%20carers%2C%20we%20have%20created,moving%20into%20a%20care%20home

Scottish Dementia Research Consortium
Membership organisation including researchers, healthcare professionals, people living with dementia and anyone else with an interest in research.
https://www.sdrc.scot/

9.4 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.

<table>
<thead>
<tr>
<th>Diagnosis</th>
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<tbody>
<tr>
<td>- Ensure that the person is not alone when they receive the diagnosis.</td>
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<tr>
<td>- If known, discuss the type of dementia the person has been diagnosed with, symptoms and how the condition might progress.</td>
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<tr>
<td>- Offer tailored information based on the stage of dementia at the time of diagnosis. The information should be reiterated to ensure understanding.</td>
</tr>
<tr>
<td>- 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:</td>
</tr>
<tr>
<td>- What is dementia?</td>
</tr>
<tr>
<td>- What impact is the dementia diagnosis likely to have on the physical and mental health of the person with dementia and their carer(s)?</td>
</tr>
<tr>
<td>- What impact is the dementia diagnosis likely to have on relationships with others, for example friends and family?</td>
</tr>
<tr>
<td>- What can people with dementia and their carers expect and what are the potential care pathways?</td>
</tr>
<tr>
<td>- If the carer is young, discuss the impact of the dementia diagnosis on their education and other areas of their life.</td>
</tr>
<tr>
<td>- Provide 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.</td>
</tr>
<tr>
<td>- 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.</td>
</tr>
<tr>
<td>- Discuss the importance of the person with dementia and their carer(s) participating in anticipatory care planning discussions.</td>
</tr>
</tbody>
</table>
• If appropriate, offer written information, such as leaflets, for people with dementia and their carers to read in 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 (see sections 9.2 and 9.3).
• Signpost the person with dementia to free education courses, where they can learn more about dementia (see section 9.3).
• 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 (see section 9.2).

Information provided should be accessible and culturally appropriate to the person with dementia and their carer(s).

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 LGBT 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 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 Act (1983).
• 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. This section will be completed after consultation.

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

No recommendations are considered likely to reach the £5 million threshold which warrants resource impact analysis.

OR Short summary of the budget impact report if there is one.

Table 3: Implementation, audit and potential resource implications of the recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>section</th>
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<tbody>
<tr>
<td>Rec 1</td>
<td>2.1</td>
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<tr>
<td>Rec 2</td>
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<tr>
<td>Rec 3</td>
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10.3 Auditing current practice

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 guideline development group has identified the following as key points to audit to assist with the implementation of this guideline:

- How many people with suspected cognitive problems are assessed with brief screening tools prior to specialist referral
- How many brief screening tools are used in a service
- How often are pharmacological interventions used when a person with dementia has behaviours indicating stress or distress

To be updated further/added to post consultation feedback.
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 Evidence and Information Scientist. Databases searched include Medline, Embase, Cinahl, PsycINFO and the Cochrane Library. The year range covered was July 2021-May 2022. 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 Appraisal of qualitative and mixed-methods studies

For key questions addressed by a range of evidence types (e.g. 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 JBI critical appraisal tools (systematic review; qualitative Critical Appraisal Tools | JBI) or the mixed-methods appraisal tool, Cargo M, Dagenais P, Gagnon, M-P, Griffiths F, Nicolau B, O’Cathain A, Rousseau M-C, Vedel I. Mixed Methods Appraisal Tool (MMAT), version 2018. Registration of Copyright (1148552), Canadian Intellectual Property Office, Industry Canada; http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf].

For systematic reviews it was decided a priori 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 considered not applicable for the review types being appraised). For mixed-methods studies it was decided a priori 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 a priori 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.

11.1.2 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 Medline, Embase, Cinahl and PsycINFO, and the results were summarised by the SIGN Patient Involvement Advisor and presented to the guideline development group.

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 (see Annex 1). The following areas for further research have been identified:

Overall there was a gap in the research, of the views people living with dementia, across all key questions. This is an important deficit of existing published research. There is growing interest and prioritisation of the involvement of people with lived experience and the public in health research, with the Neuro Progressive Network undertaking groundbreaking work to involve people living with dementia, that was sadly absent when the literature searches for this guideline were undertaken. Until such research is among the mainstream of health research, only a partial view of experiences can be presented.

**Dementia diagnosis and discussion of diagnosis**

- Perceptions of people with dementia on timing and processes of dementia diagnosis discussions.
- UK-based studies are needed 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.
- Training in communication around disclosure, methods and impact 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**

- New tau PET tracers are emerging and evaluation is needed alongside alternatives.
- Long-term follow-up of people with different clinical diagnoses and positive or negative CSF biomarkers for Ab42, T-tau, and P-tau are needed, including eventual postmortem examination validation. In particular, more data is required on biomarkers’ value in older people more likely to have Alzheimer’s disease co-pathology.

**Postdiagnostic support**

- Postdiagnostic support that relates to the stages of dementia and specific populations.
- Postdiagnostic support specific to advanced dementia.
- How to achieve person-centred care.
Grief and dementia

- 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.
- Guidance, training and support for healthcare professionals.

Changing needs in people with dementia

- Assessment and approaches for changing or unmet needs in people with moderate, advanced or severe dementia.

Anticipatory care planning

- ACP during the earlier stages of dementia.

11.3 Review and updating

This guideline was issued in 2017 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, Gyle Square, 1 South Gyle Crescent, Edinburgh, EH12 9EB (email: sign@sign.ac.uk).
12 Development of the guideline

12.1 Introduction
SIGN is a collaborative network of clinicians, other healthcare professionals and organisations that include and represent the views of those with lived experience and is part of Healthcare Improvement Scotland. SIGN guidelines are developed by multidisciplinary groups of practising healthcare professionals 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
Dr Adam Daly (Chair) Consultant (Old Age) Psychiatrist, NHS Lanarkshire, Associate Medical Director (Mental Health, Learning Disabilities and Addictions), North Lanarkshire Health and Social Care Partnership
Dr Lyndsay Alexander Reader, School of Health Sciences, Robert Gordon University, Aberdeen, Deputy Director, the Scottish Centre for Evidence-based, Multi-professional Practice: a JBI Centre of Excellence
Dr Paul Baughan GP, Dollar Health Centre, Clackmannanshire National Clinical Advisor for Ageing and Health, Chief Medical Officer Directorate, Scottish Government
Professor Kay Cooper Clinical Professor Allied Health Professions, Robert Gordon University and NHS Grampian, Director, the Scottish Centre for Evidence-based, Multi-professional Practice: A JBI Centre of Excellence, Robert Gordon University
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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 on request from the SIGN Executive.

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

12.2.1 Acknowledgements

SIGN would like to acknowledge the contribution of the guideline development group responsible for the development of SIGN X: Assessment, diagnosis, care and support for people with dementia and their carers. SIGN would also like to acknowledge the following guideline development group members who contributed during the early stages of guideline development.

Dr Caroline Gallacher

**GP, North Berwick, NHS Lothian**
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 27th October 2022 and was attended by XX representatives of all the key 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.

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Professor Karen Watchman  
*Professor in the Faculty of Health Sciences and Sport and Senior Fellow of the Higher Education Academy, University of Stirling, Scotland*

Dr Thomas Welsh  
*Consultant Geriatrician at Royal United Hospital, Bath, England*

### 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 request from the SIGN Executive.

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*
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC</td>
<td>antecedent, behaviour, consequence</td>
</tr>
<tr>
<td>ACP</td>
<td>anticipatory care planning</td>
</tr>
<tr>
<td>ADL</td>
<td>activities of daily living</td>
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<tr>
<td>ADNI</td>
<td>Alzheimer Disease Neuroimaging Initiative</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
</tr>
<tr>
<td>CAIT</td>
<td>communication and interaction training</td>
</tr>
<tr>
<td>CBT</td>
<td>cognitive behavioural therapy</td>
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<tr>
<td>CMAI</td>
<td>Cohen–Mansfield agitation inventory</td>
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<tr>
<td>CSF</td>
<td>cerebrospinal fluid</td>
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<tr>
<td>DWP</td>
<td>Department for Work and Pensions</td>
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<tr>
<td>EAPC</td>
<td>European Association of Palliative Care</td>
</tr>
<tr>
<td>EPIC</td>
<td>Enhancing Person-centred care In Care homes</td>
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<tr>
<td>FDG</td>
<td>Fluorodeoxyglucose</td>
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<tr>
<td>FTLD</td>
<td>Frontotemporal dementia</td>
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<tr>
<td>GDS</td>
<td>Global Deterioration Scale</td>
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<tr>
<td>GPCOG</td>
<td>General Practitioner Assessment of Cognition</td>
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<tr>
<td>JBI</td>
<td>Joanna Briggs Institute</td>
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<tr>
<td>LGBT</td>
<td>lesbian, gay, bisexual and trans</td>
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<tr>
<td>MARQUE</td>
<td>Managing Agitation and Raising Quality of Life</td>
</tr>
<tr>
<td>MCI</td>
<td>mild cognitive impairment</td>
</tr>
<tr>
<td>MDT</td>
<td>multidisciplinary team</td>
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<tr>
<td>MIS</td>
<td>Memory Impairment Screen</td>
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<tr>
<td>MMAT</td>
<td>Mixed Methods Appraisal Tool</td>
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<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<tr>
<td>MoCA</td>
<td>Montreal Cognitive Assessment</td>
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<tr>
<td>NDB</td>
<td>needs-driven dementia-compromised behaviour</td>
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<tr>
<td>NDCAN</td>
<td>National Dementia Carers Action Network</td>
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<tr>
<td>NES</td>
<td>NHS Education for Scotland</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<tr>
<td>NPI</td>
<td>Neuropsychiatric Inventory</td>
</tr>
<tr>
<td>PET</td>
<td>positron emission tomography</td>
</tr>
<tr>
<td>PIB</td>
<td>$^{11}$C-Pittsburgh compound B</td>
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<tr>
<td>QALY</td>
<td>quality-adjusted life year</td>
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<tr>
<td>RCT</td>
<td>randomised controlled trial</td>
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<tr>
<td>REDMAP</td>
<td>Ready, Expect, Diagnosis, Matters, Actions, Plan</td>
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<tr>
<td>RUDAS</td>
<td>Rowland Universal Dementia Assessment Scale</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>SDWG</td>
<td>Scottish Dementia Working Group</td>
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<tr>
<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
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<tr>
<td>SIS</td>
<td>Six-item Screener</td>
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<tr>
<td>SMC</td>
<td>Scottish Medicines Consortium</td>
</tr>
<tr>
<td>SMD</td>
<td>standardised mean difference</td>
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<tr>
<td>SPECT</td>
<td>single-photon emission computed tomography</td>
</tr>
<tr>
<td>TIME</td>
<td>Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms</td>
</tr>
<tr>
<td>STI</td>
<td>serial trial intervention</td>
</tr>
<tr>
<td>TMSS</td>
<td>Telecare Medical Support System</td>
</tr>
<tr>
<td>TREA</td>
<td>Treatment Routes for Exploring Agitation</td>
</tr>
<tr>
<td>TYM</td>
<td>Test Your Memory</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>WHELD</td>
<td>Well-being and Health for People with Dementia</td>
</tr>
</tbody>
</table>
# 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.

<table>
<thead>
<tr>
<th>Guideline section</th>
<th>Key question</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2</td>
<td>1. When, where and how should a diagnosis of dementia be discussed and who should be involved?</td>
</tr>
<tr>
<td>5</td>
<td>2. What postdiagnostic support do people with dementia and their families and carers need after dementia is diagnosed?</td>
</tr>
<tr>
<td>3.1</td>
<td>3. Which tools and assessments are effective in the identification of dementia?</td>
</tr>
<tr>
<td>4.1</td>
<td>4. What are the role of biomarkers in the diagnosis of and management of suspected dementia?</td>
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<tr>
<td>3.1</td>
<td>5. What is the utility and accuracy of remote assessment in the diagnosis and management of dementia?</td>
</tr>
<tr>
<td>3.1</td>
<td>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?</td>
</tr>
</tbody>
</table>
| 6               | 7. a) What approaches are effective in identifying distress, challenging behaviours and behavioural symptoms in people with dementia?  
               | b) What non-pharmacological interventions and approaches are effective in preventing distress, challenging behaviours and behavioural symptoms in people with dementia?  
               | c) What non-pharmacological interventions and approaches are effective in managing distress, challenging behaviours and behavioural symptoms in people with dementia? |
| 7               | 8. What interventions and approaches are effective in supporting grief associated with dementia? |
| 7               | 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? |
| 8.1            | 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? |
| 8.2            | 11. When, where and with whom should advanced care planning discussions in relation to the stages of dementia take place? |
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