Dementias: supporting people with dementia and their carers

NICE-SCIE guideline

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If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.
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Introduction

Dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function, with some or all of the following features: memory loss, language impairment, disorientation, change in personality, difficulties with activities of daily living, self neglect, psychiatric symptoms (for example, apathy, depression, psychosis) and behaviour which is out of character (for example, aggression, sleep disturbance or disinhibited sexual behaviour, although such behaviour is only uncommonly the presenting feature of dementia).

Dementia is associated with complex needs and, especially in the later stages, high levels of dependency and morbidity. These care-needs often challenge the skills and capacity of carers and available services. As the condition progresses and especially in the later stages, people with dementia can present carers and social care staff with complex and challenging problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties which can lead to falls and fractures. The impact of dementia upon a person may be compounded by personal circumstances such as changes in financial status, accommodation, or bereavement.

This guideline makes recommendations for the identification, treatment and care of dementia. Settings relevant to these processes will include primary and secondary health care, and social care. Wherever possible and appropriate, agencies will need to work in an integrated way to maximise the benefit for people with dementia and their carers.
Person-centred care

This guideline offers best practice advice on the care of people with dementia.

Treatment and care should take into account people’s individual needs and preferences. People with dementia should have the opportunity to make informed decisions about their care and treatment. Where people with dementia do not have the capacity to make decisions, healthcare professionals should follow the Department of Health guidelines – Reference guide to consent for examination or treatment (2001) and Seeking consent: working with older people (2001) (both available from www.dh.gov.uk). The Mental Capacity Act 2005¹ is due to be implemented into full practice in April 2007. This Act will have implications for all people with dementia, their carers and those who work with them. The Act has five key principles.

1. Every adult has the right to make their own decisions and the capacity to do so unless proved otherwise.
2. An individual must be given all available support before it is concluded that they cannot make decisions for themselves.
3. Individuals must retain the right to make what might be seen as eccentric or unwise decisions.
4. Anything done for or on behalf of individuals without capacity must be in their best interests.
5. Anything done for or on behalf of individuals without capacity should be the least restrictive alternative to their rights and basic freedoms.

Good communication between care providers and people with dementia and their families and carers is essential. It should be supported by the provision of evidence-based information offered in a form that is tailored to the needs of the individuals. The treatment, care and information provided should be culturally appropriate and in a form that is accessible to people who have additional needs, such as people with physical, cognitive or sensory disabilities, and people who do not speak or read English.

¹ For a full explanation of the Mental Capacity Act 2005 – see www.dca.gov.uk
The views of the person with dementia concerning who should and should not be involved in his or her care are of paramount importance and should be respected. With the permission of the person with dementia, carers and relatives should normally have the opportunity to be involved in decisions about care and treatment. If the person with dementia objects to the involvement of carers and relatives, health and social care practitioners must consider the person's capacity to make such a decision and, when viewed against the background of the Mental Capacity Act 2005, if the person lacks capacity, act in his or her best interests.

Health and social care staff should take account of the views of all potential carers and relatives when they describe behaviour that could be in keeping with a diagnosis of dementia. This information, in conjunction with an assessment of the person concerned, will help with the process of deciding on diagnosis and management; but it will also help in the estimation of the extent of the person's capacity to make decisions for him or her self. For those areas in which the person with dementia retains capacity, his or her wishes should continue to be respected.

People with dementia, carers and relatives should also be provided with the information and support they need, and carers should be offered an assessment of their own needs.
Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

Non-discrimination

- People with dementia should not be excluded from any services because of their diagnosis, age (whether designated too young or too old) or a coexisting learning disability.

Structural imaging for diagnosis

- Structural imaging should be used to establish the diagnosis of dementia, to aid in the differentiation of type of dementia and to exclude other cerebral pathology. Either computed tomography (CT) scanning or magnetic resonance imaging (MRI) can be used, although MRI scanning is the preferred modality to assist with early diagnosis. Specialist advice should be taken regarding the interpretation of scans in people with learning disorders.

Valid consent

- Health and social care practitioners should always seek valid consent from people with dementia. This should entail informing the person of options, checking that he or she understands, agrees or does not object, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to consent, the provisions of the Mental Capacity Act 2005 should be followed.

Memory services

- Memory assessment services should be the single point of referral for all people with a possible or suspected diagnosis of dementia.

Behaviour that challenges

- People with dementia who develop behaviour that challenges should be assessed at an early opportunity to establish the likely causes and influences that may generate, aggravate and ameliorate challenging
behaviour. Assessment should be comprehensive and should include: the person’s physical health; possible presence of undetected pain or discomfort; side effects of medication; individual biography; psychosocial factors; physical environmental factors; and a specific behavioural analysis conducted by trained professionals in conjunction with family carers and care workers. Individually tailored care plans that help carers and staff address the challenging behaviour should be written in the notes and reviewed regularly, the frequency of which should be agreed by the carers and staff involved and written in the notes.

Coordination and integration of health and social care

- Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers. This should include jointly agreeing written policies and procedures that relate to the treatment and care of people with dementia and their carers. Policies and procedures should clearly specify the roles, responsibilities and methods of integrated working of all professionals, practitioners and other care workers across all agencies. Particular attention should be given to increasing integrated working between health and social care practitioners and managers, streamlining and agreeing joint methods of assessment, and improving shared practitioner skills in both agencies. Joint planning should include local service users and carers so as to highlight and address problems specific to each locality.

- Care managers/care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This would be evidenced by:
  - a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and their carers
  - assignment of named health and social care workers to operate such a plan
endorsement by the person with dementia (if possible) and/or their carers
formal reviews and evaluations of care plans, with the frequency agreed with the person with dementia and their carers and recorded in the notes.

Training
- Health and social care managers should ensure that all staff working in close contact with older people in health, social care and voluntary sectors have access to dementia care training that is consistent with their role and responsibilities.

Mental health needs in acute hospitals
- Acute/general hospital trusts should plan and provide services that address the specific mental health needs of people with dementia who use acute hospital facilities for any reason.

Carers
- Health and social care managers should ensure that the rights of carers to an assessment of needs as set out in the Carers (Equal Opportunities) Act 2004\(^2\) are upheld.
- Health and social care practitioners who identify psychological distress and negative psychological impact in a carer of a person with dementia should arrange for the carer to be offered psychological therapy, including cognitive behavioural therapy, by a specialist practitioner.

The following guidance is evidence based. A summary of the evidence on which the guidance is based is provided in the full guideline (see section 5).

1 Guidance

This guideline draws on the best available evidence for the treatment and care of people with dementia. However, there are some significant limitations to the current evidence base, which have considerable implications for this guideline. These include the limited data on the differential responses of individuals to specific treatments, the long-term benefits of both pharmacological and psychosocial interventions, and limited data on quality of life and social functioning for all interventions. The guideline makes evidence-based recommendations for the diagnosis of dementia, and the treatment and care of people with this diagnosis. These approaches include psychological, pharmacological, service-level and self-help interventions.

1.1 Common aspects of care for all people with dementia

1.1.1 Diversity, equality and language

1.1.1.1 People with dementia should not be excluded from any services because of their diagnosis, age (whether designated too young or too old), or a coexisting learning disability.

1.1.1.2 Health and social care staff should treat people with dementia and their carers with dignity and respect at all times.

1.1.1.3 Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), personal care, frailty, ill-health, physical disability and learning disability. Care plans should both document and address these needs.

1.1.1.4 Social care and healthcare staff, especially in residential settings, should identify and, wherever possible, accommodate the individual preferences of people with dementia and their carers, including diet,
sexuality and religion. Care plans should both document and address these preferences.

1.1.1.5 People who are suspected of having dementia because of evidence of cognitive deterioration and decline from a previous level of functioning, but who do not have sufficient memory impairment to be diagnosed with dementia, should not be denied access to services and sources of help and support.

1.1.1.6 Where language may be a possible barrier to accessing or understanding services, treatment and/or care, health and social care practitioners should provide:

- all written information in the preferred language and in a format that is accessible to the person with dementia and/or their carer
- independent interpreters for the person with dementia and/or their carers where needed
- psychosocial interventions in the preferred language of the person with dementia.

1.1.2 Special considerations for young people

1.1.2.1 Younger (working age) people with dementia have special requirements, and specialist multi-disciplinary services should be developed to meet their needs with regard to assessment, diagnosis and ongoing management. Such services should be closely allied to existing dementia services, but younger people with dementia may require specific and separate support and therapeutic services to be developed and tailored to their particular needs.

1.1.3 Special considerations for people with a learning disability

1.1.3.1 Social care and healthcare staff working in care environments where younger people are at risk of developing dementia, such as those catering for people with learning disabilities, should be trained in dementia awareness.
1.1.3.2 People with learning disabilities and those supporting them should have access to specialist clinical advice and support regarding dementia.

1.1.4 Ethics, consent and advance decision making

1.1.4.1 Health and social care practitioners should always seek valid consent from people with dementia. This should entail informing the person of options, and checking that he or she understands, agrees or does not object, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to consent, the provisions of the Mental Capacity Act 2005 should be followed.

1.1.4.2 All health and social care practitioners should inform people with dementia and their carers about the availability and role of local and national advocacy services or voluntary support, and should encourage their use. If required, advocacy services and voluntary support services should be available for both people with dementia and their carers independently of each other.

1.1.4.3 People with dementia should be given the opportunity to convey information to professionals involved in their care in a confidential manner. Professionals should discuss with the person the need for information to be shared with colleagues and/or other agencies. Only in exceptional circumstances should confidential information be disclosed to others without the person’s consent. However, as dementia worsens and the person becomes more dependent on family or other carers, decisions about sharing information in the best interests of the person with dementia must be made.

1.1.4.4 Health and social care practitioners should discuss with the person with dementia, while they still have capacity, the use of advance decisions to refuse treatment (formerly known as advance directives or living wills) and lasting powers of attorney, which are made under
the provisions of the Mental Capacity Act 2005\(^3\), and the use of Preferred Place of Care documentation\(^4\), which allows decisions about future care choices and the place where they would like to die.

1.1.5 **Risk, abuse and neglect**

1.1.5.1 In light of the greater vulnerability of people with dementia to abuse and neglect, all practitioners supporting people with dementia should have access to information and training on adult protection and abide by the local multi-agency policy on adult protection.

1.1.5.2 At the time of assessment for diagnosis and when indicated thereafter, sensitive assessment of the impact of illness on relationships, including sexual relationships, should be routinely undertaken. When indicated, people with dementia and/or their carer should be given information about appropriate local support services in this area.

1.1.6 **Care management/care coordination**

1.1.6.1 Health and social care staff should ensure that all help, care and treatment provided for people with dementia and their carers should be planned and provided within the framework of care management/care coordination\(^5\).

1.1.6.2 Care managers/care coordinators should ensure that care plans are based on an assessment of an individual’s life history, social and family circumstance, preferences, as well as physical and mental health needs, and their current level of functioning.

1.1.6.3 Care managers/care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This would be evidenced by:

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\(^3\) The Stationery Office (2005).

\(^4\) http://www.cancerlancashire.org.uk/ppc.html

\(^5\) Care management/care coordination involves four elements: the coordination of a full assessment, agreeing a care plan, arranging action to deliver services, and reviewing changing need(s).
• a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and their carers
• assignment of named health and social care workers to operate such a plan
• endorsement by the person with dementia (if possible) and/or their carers
• formal reviews and evaluations of care plans, with the frequency agreed with the person with dementia and their carers and documented in the notes.

1.1.7 Funding arrangements for health and social care

1.1.7.1 People with dementia and their carers should have the same access to, and advice on, the deployment of direct payments and individual budgets as everybody else.

1.1.8 Workforce development and training

1.1.8.1 Commissioners/managers of health and social care should ensure that all staff, including those in the independent sector who routinely come into contact with older people, are trained in the use of this guideline.

1.1.8.2 Local mental health and learning disability services should set up consultation and communication channels for care homes and other services for people with dementia and their carers.

1.1.8.3 Liaison teams from local mental health and learning disability services should offer a regular consultation and liaison intervention for acute hospital staff within inpatient services in acute hospitals providing care for people with dementia.

1.1.8.4 Health and social care managers should ensure that all staff working in close contact with older people in health, social care and voluntary sectors have access to dementia care training that is consistent with their role and responsibilities.
When developing educational programmes for different health and social care professionals, trainers should consider the following elements, differentially combined according to the needs of the people involved (where staff care for people with learning disabilities the content of the training package should be adjusted accordingly):

- the early signs and symptoms suggestive of dementia and its major subtypes
- the natural history of dementia, its main signs and symptoms, progression/prognosis, and consequences for the person with dementia, their carers, their family, and their social network
- the assessment and pharmacological treatment of dementia including the administration of medication and monitoring of side effects
- applying the principles of person-centred care when working with people with dementia and their carers – in particular respect, dignity, learning about each person’s life story, and being sensitive to their culture and beliefs
- the importance of and use of communication skills for working with people with dementia and their carers – in particular pacing of communication and the use of language that is non-discriminatory, positive, and tailored for individual general ability
- assertive outreach techniques to support people who may not be engaged with services
- a clear description of the roles of all of the different practitioners and agencies involved in the delivery of care to people with dementia and basic advice on how they should work together in order to provide a comprehensive service
- basic introduction to local adult protection policy and procedures, including whistle blowing, in particular to know who to contact if there are concerns
- the palliative care approach (assessment of pain in advanced dementia).
1.1.8.6 An evidence-based educational intervention to improve the diagnosis and management of dementia should be made widely available and implemented in primary care.

1.1.9 Environmental design for people with dementia

1.1.9.1 When organising and/or purchasing living arrangements and/or residential placements for people with dementia, health and social care managers should ensure that the design of built environments for people with dementia comply with the Disability Discrimination Act 2000, as dementia is defined as a disability within the meaning of the Act.

1.1.9.2 When organising and/or purchasing living arrangements and/or care home placements for people with dementia, health and social care managers should ensure that built environments are enabling and aid orientation. Specific, but not exclusive, attention should be paid to: lighting, colour schemes, floor coverings, signage, garden design, and the access to, and safety of, the external environment.  

1.1.9.3 When organising and/or purchasing living arrangements and/or care home placements for people with dementia, health and social care managers should pay careful consideration to the size of units, the mix of residents, and the skill mix of staff to ensure that the environment is supportive and therapeutic.

1.1.10 Care for people with dementia in an acute hospital facility

1.1.10.1 Acute/general hospital trusts should plan and provide services that address the specific mental health needs of people with dementia who use acute hospital facilities for any reason.

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1.2 Integrated health and social care

1.2.1 Integrated health and social services for people with dementia and their carers

In November 2005 the Department of Health published ‘Everybody’s Business’, a service development guide for integrated mental health services for older adults. The SCIE-NICE Guideline and ‘Everybody’s Business’ are aimed at commissioners and practitioners in health and social care. ‘Everybody’s Business’ outlines current Department of Health policy on how these services should be delivered and identifies the foundations, models and key elements of a comprehensive mental health service for older people. This SCIE-NICE Guideline endorses the content of ‘Everybody’s Business’ and does not aim to duplicate it. It reviews the research evidence and best practice in relation to dementia.

1.2.1.1 Health and social care staff should use ‘Everybody’s Business’ in conjunction with this guideline as a framework for the planning, implementation and delivery of health and social care for all people with dementia and their carers, on the following aspects of health and social care:

- primary care
- home care
- day services (mainstream day services and specialist day care)
- housing (sheltered housing and extra-care housing)
- assistive technology and telecare
- care in residential settings
- intermediate care and rehabilitation
- care in the general hospital

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7 available at: [http://www.olderpeoplesmentalhealth.csip.org.uk/Home](http://www.olderpeoplesmentalhealth.csip.org.uk/Home)

8 ‘Everybody’s Business’, which gives good practice guidance on the development of older people’s mental health services, was published by the Department of Health while the SCIE-NICE Dementia Guideline was under development.
• specialist mental health services including community mental health teams, memory assessment services, psychological therapies and inpatient care.

1.2.1.2 Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers. This should include jointly agreeing written policies and procedures that relate to the treatment and care of people with dementia and their carers. Policies and procedures should clearly define the roles, responsibilities and methods of integrated working of all professionals, practitioners and other care workers across all agencies. Particular attention should be given to increasing integrated working between health and social care practitioners and managers, streamlining and agreeing joint methods of assessment, and improving shared practitioner skills in both agencies. Joint planning should include local service users and carers so as to highlight and address problems specific to each locality.

1.2.1.3 Health and social care practitioners should ensure that people with dementia and their carers are given up-to-date advice and written materials explaining the local arrangements, including any local agreements on integrated inter-agency working, for health, social care, the independent sector, and voluntary services, and how to access such services.

1.3 Risk factors, screening, preventive interventions and early identification

1.3.1 Screening for dementia

1.3.1.1 General population screening for dementia should not be undertaken.

1.3.2 Controlling risk factors for dementia

1.3.2.1 In middle-aged and older people, vascular risk factors associated with dementia (for example, smoking, diabetes, hypertension, obesity
and raised cholesterol) should be reviewed, and where appropriate, treated.

1.3.3 Genetic counselling and testing

1.3.3.1 Clinicians working with people thought likely to have a genetic cause for their dementia should offer referral for genetic counselling.

1.3.3.2 Regional genetic services should provide genetic counselling to people who are thought likely to have a genetic cause for their dementia (for example, familial autosomal dominant Alzheimer's disease, cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy [CADASIL], Huntington’s disease) and for their unaffected relatives.

1.3.3.3 Genotyping in other situations, including late onset dementia, should not be undertaken for clinical purposes.

1.3.4 Preventive measures

1.3.4.1 The following interventions should not be prescribed as specific treatments for the prevention of dementia:

- statins
- hormone replacement therapy
- vitamin E
- non-steroidal anti-inflammatory drugs.

1.3.4.2 In people with mild to moderate dementia, vascular risk factors (for example, smoking, diabetes, hypertension, obesity and raised cholesterol) should be reviewed, and where appropriate, treated.

1.3.5 Early identification of dementia

1.3.5.1 Primary healthcare staff should consider referring people who show signs of mild cognitive impairment (for example, impairments in memory, language, planning, visuospatial or other cognitive tasks) for assessment at memory assessment clinics to aid in early identification.
of dementia, as more than 50% of people with mild cognitive impairment later develop dementia.

1.3.5.2 Those undertaking health checks as part of health facilitation for people with learning disabilities should consider the possibility of dementia in those at risk.

1.3.5.3 Memory assessment services that identify people with mild cognitive impairments should offer follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage. This includes people with cognitive impairments not involving memory, as memory impairment may be absent in the earlier stages of non-Alzheimer’s dementias.

1.4 The recognition, diagnosis and assessment of dementia

1.4.1 Recognition of dementia

1.4.1.1 A diagnosis of dementia should only be made after a comprehensive assessment consisting of history, cognitive and mental state examination, physical examination and appropriate investigations.

1.4.1.2 Clinical cognitive assessment in those with suspected dementia should include examination of attention and concentration, orientation, short and long term memory, praxis, language and executive function. As part of this assessment, formal cognitive testing should be undertaken using a standardised instrument; the Mini-Mental State Examination (MMSE) has been frequently used, but a number of alternatives are now available, such as the 6-item Cognitive Impairment Test (6-CIT)\(^9\), The General Practitioner Assessment of Cognition (GPCOG)\(^10\) and the 7-minute screen\(^11\).

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1.4.1.3 Formal neuropsychological testing should form part of the assessment in cases of mild or questionable dementia.

1.4.2 Investigation of dementia

1.4.2.1 A basic dementia screen should be performed at time of presentation, usually within primary care, and should include:

- routine haematology
- erythrocyte sedimentation rate (ESR)/viscosity or C-reactive protein (CRP)
- biochemistry (including electrolytes, calcium, glucose, renal and liver function)
- thyroid function tests
- serum vitamin B12 and folate levels.

1.4.2.2 Testing for syphilis serology or HIV should not be routinely undertaken in the routine investigation of people with suspected dementia. These tests should only be considered in those with histories suggesting they are at risk or when the clinical picture dictates.

1.4.2.3 A mid stream urine (MSU) test should be undertaken in all cases where delirium is a possibility.

1.4.2.4 Clinical presentation will determine what, if any, other investigations (for example, chest X-ray and electrocardiogram [ECG]) are required.

1.4.2.5 Cerebrospinal fluid examinations should not be performed as a routine investigation for dementia.


1.4.3 Diagnosis of subtypes of dementia

1.4.3.1 A diagnosis of subtype of dementia should be made by clinicians with expertise in differential diagnosis using international standardised criteria (see Table 1).

Table 1: Diagnostic criteria for dementia

<table>
<thead>
<tr>
<th>Type</th>
<th>Criteria that can be used for diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's disease</td>
<td>NINCDS/ADRDA criteria are the preferred criteria.</td>
</tr>
<tr>
<td></td>
<td>Alternatives include ICD-10 and DSM-IV.</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>NINDS-AIREN criteria are the preferred criteria.</td>
</tr>
<tr>
<td></td>
<td>Alternatives include ICD-10 and DSM-IV.</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>International Consensus criteria for DLB</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>Lund-Manchester criteria, NINDS criteria for FTD</td>
</tr>
</tbody>
</table>

Note. NINCDS/ADRDA, National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association; NINDS-AIREN, Neuroepidemiology Branch of the National Institute of Neurological Disorders and Stroke – Association Internationale pour la Recherche et l'Enseignement en Neurosciences; DLB, dementia with Lewy bodies; FTD, frontotemporal dementia.

1.4.3.2 Structural imaging should be used to establish the diagnosis of dementia, to aid in the differentiation of type of dementia and to exclude other cerebral pathology. Either computed tomography (CT) scanning or magnetic resonance imaging (MRI) can be used, although MRI scanning is the preferred modality to assist with early diagnosis. Specialist advice should be taken regarding the interpretation of scans in people with learning disorders.

1.4.3.3 Perfusion hexamethylpropyleneamine oxime (HMPAO) single-photon emission computed tomography (SPECT) should be used to help differentiate between the diagnoses of Alzheimer's disease, vascular dementia and frontotemporal dementia when the diagnosis is in doubt. People with Down's syndrome may show SPECT abnormalities that resemble those in Alzheimer's disease throughout life, and this test is not helpful in this group.
1.4.3.4 When HMPAO SPECT is unavailable, 2-[18F]fluoro-2-deoxy-D-glucose (FDG) positron emission tomography (PET) can be used to help differentiate between the diagnoses of Alzheimer’s disease, vascular dementia and frontotemporal dementia when the diagnosis is in doubt, although PET scanning is more expensive.

1.4.3.5 Dopaminergic iodine-123-radiolabelled 2beta-carbomethoxy-3beta-(4-iodophenyl)-N-(3-fluoropropyl) nortropane (FP-CIT) SPECT should be used to establish the diagnosis in those with suspected dementia with Lewy bodies (DLB) when the diagnosis is in doubt.

1.4.3.6 Cerebrospinal fluid examination should be used when Creutzfeldt–Jakob disease or other forms of rapidly progressive dementia are suspected.

1.4.3.7 The electroencephalogram (EEG) should not be performed as a routine investigation in people with dementia.

1.4.3.8 The EEG can be used when a diagnosis of delirium, frontotemporal dementia or Creutzfeldt–Jakob disease is suspected, or in the assessment of associated seizure disorder in those with dementia.

1.4.3.9 Brain biopsy for diagnostic purposes should only be considered in highly selected people whose dementia is thought to be due to a potentially reversible condition which cannot be diagnosed in any other way.

1.4.3.10 At the time of first diagnosis of dementia, and at regular intervals thereafter, assessment should be made for medical comorbidity and other key psychiatric features associated with dementia, including depression and psychosis, to ensure that there is optimal management of coexisting conditions.

**1.4.4 Specialist services for dementia assessment**

‘Everybody’s Business’ supports the development and integration of memory assessment services which should aim to provide early identification,
maximise quality of life, promote independent functioning, and offer a single point of referral and coordination of services for people with dementia and their families and carers throughout the lifespan. Memory assessment services may be focused as a memory assessment clinic or be a part of community mental health teams.

1.4.4.1 Memory assessment services should be the single point of referral for all people with a possible or suspected diagnosis of dementia.

1.4.4.2 Memory assessment services should offer a responsive service to aid early identification and should include a full range of assessment, diagnostic, and therapeutic services to accommodate the different needs of people with different types and severities (from mild to severe) of dementia and the needs of their carers and families.

1.4.4.3 Memory assessment services should also ensure a properly integrated approach to service provision for health and social care of people with dementia and their carers, and should do so in partnership with local health, social care, and voluntary organisations.

1.4.5 Addressing needs that arise from the recognition, diagnosis and assessment of dementia

1.4.5.1 Providing and receiving a diagnosis of dementia is a difficult and challenging experience for clinicians, people with dementia and family members. Clinicians should therefore, following a positive diagnosis of dementia, give adequate time at an appropriate opportunity to discuss the diagnosis and its implications with both the person with dementia and family members. People with dementia and family members may need ongoing support to cope with the difficulties that this diagnosis presents.

1.4.5.2 Following a positive diagnosis, health and social care practitioners should, unless the person with dementia clearly indicates to the contrary, provide them and their family with written information about:

- the signs and symptoms of dementia
- the course and prognosis
- treatments
- local care and support services
- support groups
- sources of financial and legal advice, and advocacy
- voluntary organisations (that may also be a useful source of information and advice).

Any advice and information given should be clearly documented in the person’s notes.

1.4.5.3 Clinicians who regularly diagnose dementia and discuss this with patients and carers may wish to consider mentoring, coaching or clinical supervision to support less experienced clinicians in undertaking this difficult and challenging work.

1.5 Strategies for promoting and maintaining the health and independence (including mobility) of people with dementia

1.5.1 Promotion and maintenance of independent functioning (including mobility)

1.5.1.1 Health and social care practitioners should aim to promote and maintain independence. Care plans for people with dementia should address activities of daily living (ADLs) that maximise independent activity, enhance function, adapt and develop skills, and minimise the need for support. Essential components include:

- consistent and stable staffing
- retaining a familiar environment
- minimising relocations
- flexible care plans to accommodate fluctuating abilities
- assessment and care planning advice regarding ADLs, and ADL skill training from an occupational therapist
• assessment and care planning advice regarding independent toileting skills from a continence specialist
• environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist and/or clinical psychologist
• care plans that address physical exercise, with assessment and advice from a physiotherapist when needed
• allowing people to go at their own pace and participate in activities they enjoy.

1.6  Therapeutic interventions for people with dementia – cognitive symptoms and maintaining function

1.6.1 Assessment

1.6.1.1 Assessment prior to the use of cognitive enhancers in the treatment of cognitive symptoms in people with dementia should include the MMSE as part of a comprehensive clinical and social assessment. However, for people with a learning disability, the MMSE should not be used.

1.6.1.2 For people with learning disorders, assessment tools should be sensitive to their level of competence. Options include:

• Cambridge Cognitive Examination (CAMCOG)\textsuperscript{12}
• modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)\textsuperscript{13}
• Dementia Questionnaire for Mentally Retarded Persons (DMR)\textsuperscript{14}


\textsuperscript{14} Evenhuis, H. M., Kengen, M. M. F., & Eurlings, H. A. L. (1990) \textit{Dementia Questionnaire for Persons}
• Dementia Scale for Down Syndrome (DSDS)\textsuperscript{15}, which can be useful in diagnosis of dementia in the non-Down's population with learning disabilities.

1.6.1.3 At the time of diagnosis of dementia in a person with a learning disability, an Assessment of Motor and Process Skills (AMPS) assessment carried out by an occupational therapist may be used as part of the development of an appropriate care plan. Monitoring of change in functioning with time may be achieved with the Dementia Questionnaire for Mentally Retarded Persons (DMR), and Dalton's Brief Praxis Test (BPT)\textsuperscript{16}.

1.6.2 Pharmacological interventions for the cognitive symptoms of Alzheimer's dementia

1.6.2.1 The clinical effectiveness and cost effectiveness of cholinesterase inhibitors and memantine for people with Alzheimer's disease are the subject of a NICE technology appraisal currently in development. The appraisal recommendations will be added here when finalised.

1.6.3 Pharmacological interventions for the cognitive symptoms of other dementias\textsuperscript{17}

1.6.3.1 For people with vascular dementia, cholinesterase inhibitors should not be used for the treatment of cognitive decline, except as part of properly constructed clinical studies.


\textsuperscript{17} For the treatment of cognitive and non-cognitive symptoms of dementia in people with Parkinson's disease, please see the NICE guideline on Parkinson's disease (http://www.nice.org.uk).
1.6.3.2 For people with vascular dementia, memantine should not be used for the treatment of cognitive decline, except as part of properly constructed clinical studies.

1.6.3.3 For people with mild cognitive impairment (MCI), cholinesterase inhibitors should not be used, except as part of properly constructed clinical studies.

1.6.3.4 For people with DLB, cholinesterase inhibitors should not be used for the treatment of cognitive decline, except as part of properly constructed clinical studies.

1.6.4 Non-pharmacological interventions for the treatment of cognitive symptoms and maintaining function

1.6.4.1 People with mild/moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any antidementia drug received by the person with dementia.

1.7 Therapeutic interventions for people with dementia – non-cognitive symptoms and behaviour that challenges

1.7.1 Non-pharmacological interventions for non-cognitive symptoms and behaviour that challenges

1.7.1.1 People with dementia who develop behaviour that challenges should be assessed at an early opportunity to establish the likely causes and influences that may generate, aggravate and ameliorate challenging behaviour. Assessment should be comprehensive and should include: the person’s physical health; possible presence of

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18 Mild cognitive impairment is a syndrome defined as cognitive decline greater than expected for an individual’s age and education level which does not interfere notably with activities of daily life. It is not a diagnosis of dementia of any type, although it may lead to dementia in some cases.
undetected pain or discomfort; side effects of medication; individual biography; psychosocial factors; physical environmental factors; and a specific behavioural analysis conducted by trained professionals in conjunction with family carers and care workers. Individually tailored care plans that help carers and staff address the challenging behaviour should be written in the notes and reviewed regularly, the frequency of which should be agreed by the carers and staff involved and written in the notes.

1.7.1.2 People with all types and severities of dementia who have comorbid agitation should have access to a range of interventions tailored to the individual’s preferences, skills and abilities. People may respond better to one treatment modality than another, therefore response to each treatment should be monitored so that the care plan can be adapted accordingly. The range of approaches that may be considered, depending on availability, include:

- aromatherapy
- multisensory stimulation
- therapeutic use of music and/or dancing
- animal-assisted therapy
- massage.

This list is not exhaustive. These approaches can be delivered by a range of health and social care workers/volunteers, with appropriate training and supervision. Clinicians and practitioners in the NHS and social care should work with the voluntary sector to ensure that some of these options are available, as there is some evidence of their clinical effectiveness, although more research is needed into their cost effectiveness.

1.7.2 Pharmacological interventions for non-cognitive symptoms

Non-cognitive symptoms include hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviour.
1.7.2.1 For people with dementia with mild non-cognitive symptoms, a non-pharmacological intervention should be used as a treatment of first choice before a pharmacological intervention is used.

1.7.2.2 A recommendation on the use of cholinesterase inhibitors for people with DLB is to be inserted at a later stage.

1.7.2.3 For people with DLB, antipsychotic drugs should be avoided for the treatment of mild to moderate non-cognitive symptoms, because people with DLB may be particularly sensitive to severe adverse reactions.

1.7.2.4 A recommendation on the use of cholinesterase inhibitors for non-cognitive symptoms in people with Alzheimer’s disease will be formulated following the publication of the NICE Technology Appraisal ‘Alzheimer’s disease – donepezil, rivastigmine, galantamine and memantine’.

1.7.2.5 For people with vascular dementia, cholinesterase inhibitors should not be used for the treatment of non-cognitive symptoms, except as part of properly constructed clinical studies.

1.7.2.6 For people with Alzheimer’s disease, vascular dementia and mixed dementias, antipsychotic drugs should be avoided for the treatment of mild to moderate non-cognitive symptoms because of the possible increased risk of cerebrovascular adverse events and death.

1.7.2.7 For people with Alzheimer’s disease, vascular dementia, mixed dementia or DLB, with severe non-cognitive symptoms (psychosis and/or agitated behaviour), antipsychotic drugs may be considered and used after the following conditions have been met:

- there has been full discussion with the person with dementia and/or their carers about the possible benefits and likely risks of treatment; in particular, after cardiovascular risk factors have
been assessed and discussion regarding possible increased risk of stroke/transient ischaemic attack

- target symptoms are identified, quantified and documented
- changes in target symptoms are assessed and documented at regular intervals
- the choice of antipsychotic is made after an individual risk–benefit analysis
- starting dose is low and then titrated upwards
- treatment is time limited and regularly reviewed (every 3 months or according to clinical need)
- for people with DLB, clinicians should monitor carefully for the emergence of severe untoward reactions; in particular, neuroleptic sensitivity reactions and extrapyramidal side effects.

1.7.2.8 For people with dementia where there is significant risk of harm because of behaviour that challenges, the immediate management should be conducted by staff with specialist training who should follow the NICE guideline on ‘Violence: the short-term management of disturbed/violent behaviour in psychiatric inpatient settings and emergency departments’ with due consideration for dosage adjustments because of age and the presence of dementia. Once the immediate risk has been reduced, a comprehensive assessment and review of treatment options should be carried out.

1.8 Therapeutic interventions for people with dementia – comorbid emotional disorders

1.8.1 Psychosocial interventions for people with dementia and comorbid emotional disorders

1.8.1.1 For people with dementia, any care package should include assessment and monitoring for depression and/or anxiety.

19 http://www.nice.org.uk/CG025NICEguideline
1.8.1.2 For people with dementia who also have depression and/or anxiety, cognitive behavioural therapy should be offered as part of the treatment approach. This may involve active participation of their carers.

1.8.1.3 For people with dementia who also have depression and/or anxiety, a range of tailored interventions should be available, which may include multisensory stimulation, animal-assisted therapy, exercise and other approaches.

1.8.2 Pharmacological interventions for people with dementia and comorbid emotional disorders

1.8.2.1 For people with dementia who also have depression that has not responded to non-pharmacological treatment, antidepressants may be considered. Treatment should be initiated by staff with specialist training who should follow the NICE guideline on ‘Depression: management of depression in primary and secondary care’ after a careful risk–benefit assessment. A full explanation of the need for compliance, time to onset of action and risk of withdrawal effects should be given at the start of treatment.

1.9 Palliative care, pain relief and care at the end of life for people with dementia

1.9.1 Palliative care and end of life issues

Dementia care should incorporate a palliative care approach (see, for example, The Gold Standards Framework and the Liverpool Care Pathway for the Dying Patient) from the time of diagnosis until death. The use of advance refusals of treatment, or other forms of advance care planning,

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20 http://www.nice.org.uk/CG023NICEguideline
should help the person with dementia to retain some control over their care. The ultimate aim should be to allow people with dementia to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may well both anticipate and follow death.

1.9.1.1 Palliative care professionals and health and social care practitioners should ensure that palliative care services are available and accessible to people with dementia who are dying, in the same way that such services are available to people who do not have dementia.

1.9.1.2 Primary care teams should ensure that the palliative care needs of people with dementia who are close to death are assessed and that the information is communicated within the team and with others.

1.9.1.3 Health and social care practitioners should encourage people with dementia to eat and drink by mouth for as long as possible. Specialist assessment and advice concerning swallowing and feeding in dementia should be available. Artificial (tube) feeding should not generally be used in people with severe dementia, although it may be used in circumstances where dysphagia is considered to be a transient phenomenon rather than a manifestation of the severity of the disease process.

1.9.1.4 Where the person with severe dementia has a fever, especially in the terminal stages, health and social care staff should ensure that a clinical assessment is undertaken. Simple analgesics, antipyretics and mechanical means of cooling the person may suffice. The use of antibiotics in the terminal stages of dementia can also be considered as a palliative measure, but this requires assessment on an individual basis.

1.9.1.5 Cardiopulmonary resuscitation is unlikely to succeed in cases of cardiopulmonary arrest in people with severe dementia. Policies in hospitals and long-stay residential, nursing or continuing care units should reflect this fact. The views and wishes of all those concerned, however, should be considered in an empathic manner, as should the
possibility that discussions about resuscitation may be upsetting to family and friends. Decisions about resuscitation should be recorded in the medical notes and care plans.

1.9.2 Pain relief

1.9.2.1 If people with dementia have unexplained changes in behaviour, health and social care practitioners should assess whether the person with dementia is experiencing pain. An observational pain assessment tool may help in this regard. However, the possibility that distress might have some other cause should be considered.

1.9.2.2 The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological means. Non-pharmacological therapies should be used with the person's history and preferences in mind.

1.10 Support and interventions for the carers of people with dementia

1.10.1 Carer assessment

1.10.1.1 Health and social care managers should ensure that the rights of carers to an assessment of needs as set out in the Carers (Equal Opportunities) Act 200423 are upheld.

1.10.2 Interventions for carers of people with dementia

1.10.2.1 People carrying out carers’ assessment should recognise and identify psychological distress and the psychosocial impact on the carer. This should be an ongoing process and should include any period after the person with dementia has entered residential care.

1.10.2.2 For carers of people with dementia, care plans for carers should include a range of tailored interventions. This should include multi-component interventions for individuals as well as group-based and telecommunications-based work. Interventions may include:

- individual or group psychoeducation,
- peer support groups with other carers, tailored to the needs of individual carers depending on the stage of dementia of the person being cared for or other characteristics
- support and information through telephone and internet links
- structured training courses about dementia, available services and benefits, and skill development in problem solving in relation to the care of the person with dementia
- involvement of other family members as well as the primary carer in family meetings.

1.10.2.3 Consideration should be given to involving people with dementia in psychoeducation, support, and other meetings for carers.

1.10.2.4 Health and social care practitioners should ensure that support is provided to overcome any obstacles to participation in interventions for carers, such as transport provision, or provision of sitting services for the person with dementia.

1.10.2.5 Health and social care practitioners who identify psychological distress and negative psychological impact in a carer of a person with dementia should arrange for the carer to be offered psychological therapy, including cognitive behavioural therapy, by a specialist practitioner.

1.10.3 Practical support for the caring role and services for carers

1.10.3.1 Health and social care managers should ensure access to a comprehensive range of respite/short break services to meet the needs of carers of people with dementia, in terms of location,
flexibility, timeliness and also the needs of the person with dementia. Such services can be delivered in a variety of ways including: day care, day- and night-sitting, adult placement and short-term and/or overnight care in residential settings. Flexible transport should be provided to enable full access to these services.

1.10.3.2 Respite or short break care of any sort should be characterised by meaningful and therapeutic activity tailored to meet the varying needs of the person with dementia and also be provided in an environment that meets their needs.
2 Notes on the scope of the guidance

All NICE guidelines are developed in accordance with a scope document that defines what the guideline will and will not cover. The scope of this guideline was established, after a period of consultation, at the start of the guideline development process; it is available from www.nice.org.uk/page.aspx?o=225369.

This guideline is relevant to people with Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, subcortical dementia, frontotemporal dementias, and mixed cortical and subcortical dementia, as well as their families or carers, and all health and social care practitioners involved in the help, treatment and care of people with dementia and their families and carers. These include:

- social care and healthcare staff who have direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings
- health and social care staff operating in the NHS, integrated health and social care services, statutory social services, and the voluntary and independent sectors.

The guideline does not specifically address:

- the treatment and management of Creutzfeldt–Jakob Disease (CJD)
- the physical treatments of organic disease sometimes associated with different forms of dementia, such as the treatment of convulsions or motor disorders
- the treatment of physical ill-health that is commonly encountered amongst elderly people, especially those with dementia, such as cardiovascular and neurological disease/disorders, except where the treatment of such conditions may alter the progress of dementia.
3 Implementation

The Healthcare Commission assesses the performance of NHS organisations in meeting core and developmental standards set by the Department of Health in ‘Standards for better health’ issued in July 2004. Implementation of clinical guidelines forms part of the developmental standard D2. Core standard C5 says that national agreed guidance should be taken into account when NHS organisations are planning and delivering care.

The Commission for Social Care Inspection (CSCI) uses SCIE practice guides to underpin and develop inspection standards.

NICE has developed tools to help organisations implement this guidance (listed below). These are available on our website (www.nice.org.uk/CG0XX).

[Tools will be available at time of publication]

4 Research recommendations

The Guideline Development Group has made the following recommendations for research, on the basis of its review of the evidence. The Group regards these recommendations as the most important research areas to improve NICE guidance and patient care in the future. The Guideline Development Group’s full set of research recommendations is detailed in the full guideline (see section 5).

[To be inserted]

5 Other versions of this guideline

How this guideline was developed

NICE commissioned the National Collaborating Centre for Mental Health, in partnership with the Social Care Institute for Excellence (SCIE), to develop this guideline. The Centre, with SCIE, established a Guideline Development Group (see appendix A), which reviewed the evidence and developed the recommendations. An independent Guideline Review Panel oversaw the development of the guideline (see appendix B).
5.1 Full guideline

The full guideline, ‘Dementia: supporting people with dementia and their carers’ is published by the National Collaborating Centre for Mental Health; it is available from [website details to be added], the NICE website (www.nice.org.uk/CGXXXfullguideline) and the website of the National Library for Health (www.nlh.nhs.uk). [Note: these details will apply to the published full guideline.]

5.2 Quick reference guide

A quick reference guide for health professionals is also available from the NICE website (www.nice.org.uk/CGXXXquickrefguide) or from the NHS Response Line (telephone 0870 1555 455; quote reference number N0XXX). [Note: these details will apply when the guideline is published.]

5.3 Understanding NICE guidance: information for patients and carers

A version of this guideline for people with dementia and their carers, and for the public, is available from the NICE website (www.nice.org.uk/CGXXXpublicinfo) or from the NHS Response Line (0870 1555 455); quote reference number N0xxx). [Note: these details will apply when the guideline is published.]

6 Related NICE and SCIE guidance

- Violence: the short-term management of disturbed/violent behaviour in psychiatric inpatient settings and emergency


NICE is in the process of developing the following guidance (details available from www.nice.org.uk):

- Donepezil, rivastigmine, galantamine and memantine for the treatment of Alzheimer's disease (including a review of existing guidance no. 19). *NICE technology appraisal*. (Publication expected July 2006.)

## 7 Updating the guideline

NICE clinical guidelines are updated as needed so that the results of new research can be put into practice. We check for new evidence 2 and 4 years after publication, to decide whether all or part of the guideline should be updated. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. The process of reviewing the evidence is expected to begin 4 years after the date of issue of this guideline. Reviewing may begin before this if significant evidence that affects the guideline recommendations is identified. The updated guideline will be available within 2 years of the start of the review process.
Appendix A: The Guideline Development Group

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Special appreciation for advice and contributions on palliative care and medical ethics

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Appendix B: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring its quality. The Panel includes experts on guideline methodology, health professionals and people with experience of the issues affecting patients and carers. The members of the Guideline Review Panel were as follows.

[NICE to add]