

The NHS logo consists of the letters 'NHS' in a bold, white, sans-serif font, set against a blue rectangular background.

***National Institute for
Health and Clinical Excellence***

social care
institute for excellence



Issue date: November 2006

Dementia

**Supporting people with dementia and
their carers in health and social care**

NICE clinical guideline 42

Developed by the National Collaborating Centre for Mental Health

NICE clinical guideline 42

Dementia: supporting people with dementia and their carers in health and social care

Ordering information

You can download the following documents from www.nice.org.uk/CG042

- The NICE–SCIE guideline (this document) – all the recommendations.
- A quick reference guide – a summary of the recommendations for healthcare professionals.
- ‘Understanding NICE–SCIE guidance’ – information for patients and carers.
- The full guideline – all the recommendations, details of how they were developed, and summaries of the evidence they were based on.

For printed copies of the quick reference guide or ‘Understanding NICE–SCIE guidance’, phone the NHS Response Line on 0870 1555 455 and quote:

- N1144 (quick reference guide)
- N1145 (‘Understanding NICE–SCIE guidance’).

This guidance is written in the following context

This guidance represents the view of NICE and SCIE, which was arrived at after careful consideration of the evidence available. Health and social care staff are expected to take it fully into account when exercising their professional judgement. The guidance does not, however, override the individual responsibility of health and social care staff to make decisions appropriate to the circumstances of the individual person with dementia, in consultation with the person and/or guardian or carer.

National Institute for Health and Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk

Social Care Institute for Excellence

Goldings House
2 Hay’s Lane
London
SE1 2HB

www.scie.org.uk

Contents

| | |
|-----------------------------------------------------------------------------------------------------------|-----------|
| Introduction | 4 |
| Person-centred care | 6 |
| Key priorities for implementation | 9 |
| 1 Guidance | 12 |
| 1.1 <i>Principles of care for people with dementia</i> | 12 |
| 1.2 <i>Integrated health and social care</i> | 20 |
| 1.3 <i>Risk factors, prevention and early identification</i> | 21 |
| 1.4 <i>Diagnosis and assessment of dementia</i> | 22 |
| 1.5 <i>Promoting and maintaining independence of people with dementia</i> | 28 |
| 1.6 <i>Interventions for cognitive symptoms and maintenance of function for people with dementia</i> | 29 |
| 1.7 <i>Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia</i> | 33 |
| 1.8 <i>Interventions for comorbid emotional disorders in people with dementia</i> | 40 |
| 1.9 <i>Inpatient dementia services</i> | 41 |
| 1.10 <i>Palliative care, pain relief and care at the end of life for people with dementia</i> | 41 |
| 1.11 <i>Support and interventions for the carers of people with dementia</i> | 44 |
| 2 Notes on the scope of the guidance | 46 |
| 3 Implementation | 47 |
| 4 Research recommendations | 48 |
| 5 Other versions of this guideline | 50 |
| 5.1 <i>Full guideline</i> | 50 |
| 5.2 <i>Quick reference guide</i> | 50 |
| 5.3 <i>'Understanding NICE guidance'</i> | 51 |
| 6 Related NICE and SCIE guidance | 51 |
| 7 Updating the guideline | 52 |
| Appendix A: The Guideline Development Group | 53 |
| Appendix B: The Guideline Review Panel | 56 |

Introduction

Dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function. Although many people with dementia retain positive personality traits and personal attributes, as their condition progresses they can experience some or all of the following: memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, psychiatric symptoms (for example, apathy, depression or psychosis) and out-of-character behaviour (for example, aggression, sleep disturbance or disinhibited sexual behaviour, although the latter is not typically 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 services. As the condition progresses, people with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures. The impact of dementia on an individual may be compounded by personal circumstances such as changes in financial status and accommodation, or bereavement.

This guideline makes specific recommendations on Alzheimer's disease, dementia with Lewy bodies (DLB), frontotemporal dementia, vascular dementia and mixed dementias, as well as recommendations that apply to all types of dementia. Dementia in Parkinson's disease shares a number of similarities with DLB. Although the evidence base for dementia in Parkinson's disease was not examined specifically in the context of this guideline, the recommendations for DLB may be useful when considering treatments for dementia in Parkinson's disease.¹

This guideline makes recommendations for the identification, treatment and care of people with dementia and the support of carers. Settings relevant to

¹ For other recommendations regarding the physical treatments for Parkinson's disease see the NICE clinical guideline on Parkinson's disease (available from www.nice.org.uk/CG035).

these processes include primary and secondary healthcare, and social care. Wherever possible and appropriate, agencies should 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 and on support for their carers. There is broad consensus that the principles of person-centred care underpin good practice in the field of dementia care and they are reflected in many of the recommendations made in the guideline. The principles assert:²

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- the importance of the perspective of the person with dementia
- the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

The fourth principle emphasises the imperative in dementia care to consider the needs of carers, whether family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia. This is increasingly described as 'relationship-centred care'.

Capacity and dementia

People with dementia should have the opportunity to make informed decisions about their care and treatment in partnership with their health and social care professionals. If they do not have the capacity to make decisions, health and social care professionals should follow the Department of Health guidelines – 'Reference guide to consent for examination or treatment' (2001), 'Seeking consent: working with older people' (2001) and 'Seeking consent: working with people with learning disabilities' (2001) (all available from www.dh.gov.uk). From April 2007 health and social care professionals will need to follow a code of practice accompanying the Mental Capacity Act 2005 (summary

² Kitwood TM (1997) *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press; Brooker D (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13: 215–22.

available from www.dca.gov.uk/menincap/bill-summary.htm). The Act will have implications for all people with dementia, their carers and those who work with them. It has five key principles.

- Adults must be assumed to have capacity to make decisions for themselves unless proved otherwise.
- Individuals must be given all available support before it is concluded that they cannot make decisions for themselves.
- Individuals must retain the right to make what might be seen as eccentric or unwise decisions.
- Anything done for or on behalf of individuals without capacity must be in their best interests.
- Anything done for or on behalf of individuals without capacity must be the least restrictive alternative in terms of their rights and basic freedoms.

Involving others

The views of people with dementia concerning who should and should not be involved in their care are important 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 lacks the capacity to decide who should and should not be involved, health and social care professionals must act in his or her best interests, bearing in mind the provisions of the Mental Capacity Act 2005.

Health and social care staff should take account of the views of carers and relatives who describe behaviour that could be in keeping with dementia. This information, in conjunction with an assessment of the person concerned, will help with diagnosis and deciding on care. It will also help in the estimation of the person's capacity to make decisions. People with dementia should continue to have the opportunity to make informed decisions about those aspects of their care and personal lives for which they retain capacity.

Good communication between care providers and people with dementia and their families and carers is essential, so that people with dementia receive the information and support they require. Evidence-based information should be

offered in a form that is tailored to the needs of the individual. 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 physical, cognitive or sensory disabilities, or who do not speak or read English.

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

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 coexisting learning disabilities.

Valid consent

- Health and social care professionals should always seek valid consent from people with dementia. This should entail informing the person of options, and checking that he or she understands, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.

Carers

- Health and social care managers should ensure that the rights of carers to receive an assessment of needs, as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004, are upheld.
- Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.

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, including jointly agreeing written policies and procedures. Joint planning should include local service users and carers in order to highlight and address problems specific to each locality.

- Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:
 - a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers
 - assignment of named health and/or social care staff to operate the care plan
 - endorsement of the care plan by the person with dementia and/or carers
 - formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes.³

Memory services

- Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia.

Structural imaging for diagnosis

- Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Specialist advice should be taken when interpreting scans in people with learning disabilities.

Behaviour that challenges

- People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish the likely

³ Time periods for review of care plans are stipulated by Care Programme Approach guidance and 'Fair access to care services – guidance on eligibility criteria for adult social care' (see www.dh.gov.uk).

factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include:

- the person's physical health
- depression
- possible undetected pain or discomfort
- side effects of medication
- individual biography, including religious beliefs and spiritual and cultural identity
- psychosocial factors
- physical environmental factors
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.

Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly. The frequency of the review should be agreed by the carers and staff involved and written in the notes.

Training

- Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training (skill development) that is consistent with their roles and responsibilities.

Mental health needs in acute hospitals

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

1 Guidance

The following guidance is based on the best available evidence for the treatment and care of people with dementia. However, there are limitations to the current evidence base. There are limited data on the differential responses of individuals to specific treatments, on the long-term benefits of both pharmacological and psychological interventions, and on quality of life and social functioning for all interventions. The [full guideline](#) gives details of the methods and the evidence used to develop the guidance (see section 5 for details).

The guideline makes evidence-based recommendations for the diagnosis of dementia, and the treatment and care of people with the condition. These approaches include psychological, pharmacological, service-level and self-help interventions.

1.1 Principles of care for 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 coexisting learning disabilities.
- 1.1.1.2 Health and social care staff should treat people with dementia and their carers with respect at all times.
- 1.1.1.3 Health and social care staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), religion and personal care. Care plans should record and address these needs.
- 1.1.1.4 Health and social care staff should identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities. Care plans should record and address these needs.

- 1.1.1.5 Health and social care staff, especially in residential settings, should identify and, wherever possible, accommodate the preferences of people with dementia and their carers, including diet, sexuality and religion. Care plans should record and address these preferences.
- 1.1.1.6 People who are suspected of having dementia because of evidence of functional and cognitive deterioration, but who do not have sufficient memory impairment to be diagnosed with the condition, should not be denied access to support services.
- 1.1.1.7 If language or acquired language impairment is a barrier to accessing or understanding services, treatment and care, health and social care professionals should provide the person with dementia and/or their carer with:
- information in the preferred language and/or in an accessible format
 - independent interpreters
 - psychological interventions in the preferred language.

1.1.2 Younger people with dementia

- 1.1.2.1 Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care.

1.1.3 People with a learning disability

- 1.1.3.1 Health and social care 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 advice and support regarding dementia.

1.1.4 Ethics, consent and advance decision making

- 1.1.4.1 Health and social care professionals should always seek valid consent from people with dementia. This should entail informing the person of options, and checking that he or she understands, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.
- 1.1.4.2 Health and social care professionals should inform people with dementia and their carers about advocacy services and voluntary support, and should encourage their use. If required, such 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 health and social care professionals involved in their care in a confidential manner. Professionals should discuss with the person any 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 should be made in the context of the Mental Capacity Act 2005 and its Code of Practice. If information is to be shared with others, this should be done only if it is in the best interests of the person with dementia.
- 1.1.4.4 Health and social care professionals should discuss with the person with dementia, while he or she still has capacity, and his or her carer the use of:
- advance statements (which allow people to state what is to be done if they should subsequently lose the capacity to decide or to communicate)

- advance decisions to refuse treatment⁴
- Lasting Power of Attorney (a legal document that allows people to state in writing who they want to make certain decisions for them if they cannot make them for themselves, including decisions about personal health and welfare)⁵
- a Preferred Place of Care Plan (which allows people to record decisions about future care choices and the place where the person would like to die).⁶

1.1.5 Impact of dementia on personal relationships

1.1.5.1 At the time of diagnosis and when indicated subsequently, the impact of dementia on relationships, including sexual relationships, should be assessed in a sensitive manner. When indicated, people with dementia and/or their partner and/or carers should be given information about local support services.

1.1.6 Risk of abuse and neglect

1.1.6.1 Because people with dementia are vulnerable to abuse and neglect, all health and social care staff supporting them should receive information and training about, and abide by the local multi-agency policy on, adult protection.

1.1.7 Management and coordination of care

1.1.7.1 Health and social care staff should ensure that care of people with dementia and support for their carers is planned and provided within the framework of care management/coordination.⁷

⁴ Under the provisions of the Mental Capacity Act 2005.

⁵ Under the provisions of the Mental Capacity Act 2005.

⁶ See www.cancerlancashire.org.uk/ppc.html

⁷ 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 needs within the framework of the single assessment process.

1.1.7.2 Care managers and care coordinators should ensure that care plans are based on an assessment of the person with dementia's life history, social and family circumstance, and preferences, as well as their physical and mental health needs and current level of functioning and abilities.

1.1.7.3 Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:

- a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers
- assignment of named health and/or social care staff to operate the care plan
- endorsement of the care plan by the person with dementia and/or carers
- formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes.⁸

1.1.8 Funding arrangements for health and social care

1.1.8.1 Care managers/care coordinators should explain to people with dementia and their carers that they have the right to receive direct payments and individual budgets (where available). If necessary, people with dementia and their carers should be offered additional support to obtain and manage these.

1.1.8.2 People with dementia and their carers should be informed about the statutory difference between NHS care and care provided by local authority social services (adult services) so that they can

⁸ Time periods for review of care plans are stipulated by Care Programme Approach guidance and 'Fair access to care services – guidance on eligibility criteria for adult social care' (see www.dh.gov.uk).

make informed decisions about their eligibility for NHS Continuing Care.

1.1.9 Training and development of health and social care staff

1.1.9.1 Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training (skill development) that is consistent with their roles and responsibilities.

1.1.9.2 When developing educational programmes for different health and social care staff, trainers should consider the following elements, combined according to the needs of the staff being trained (if staff care for people with learning disabilities, the training package should be adjusted accordingly).

- Early signs and symptoms suggestive of dementia and its major subtypes.
- The natural history of the different types of dementia, the main signs and symptoms, the progression and prognosis, and the consequences for the person with dementia and his or her carers, family and 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; particular attention should be paid to respect, dignity, learning about each person's life story, individualising activities, being sensitive to individuals' religious beliefs and spiritual and cultural identity, and understanding behaviour that challenges as a communication of unmet need.
- The importance of and use of communication skills for working with people with dementia and their carers; particular attention should be paid to pacing of communication, non-verbal

communication and the use of language that is non-discriminatory, positive, and tailored to an individual's ability.

- Assertive outreach techniques to support people who may not be engaged with services.
- A clear description of the roles of the different health and social care professionals, staff 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 the reporting of concerns or malpractice and, in particular, who to contact.
- The palliative care approach.

1.1.9.3 Managers of 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.

1.1.9.4 Liaison teams from local mental health and learning disability services should offer regular consultation and training for healthcare professionals in acute hospitals who provide care for people with dementia. This should be planned by the acute hospital trust in conjunction with mental health, social care and learning disability services.

1.1.9.5 Evidence-based educational interventions, such as decision-support software and practice-based workshops,⁹ to improve the diagnosis and management of dementia should be made widely available and implemented in primary care.

⁹ See, for example, Downs M, Turner S, Bryans M et al. (2006) Effectiveness of educational interventions in improving detection and management of dementia in primary care: a cluster randomized controlled study. *British Medical Journal* 332: 692–6.

1.1.10 Environmental design for people with dementia

- 1.1.10.1 When organising and/or purchasing living arrangements or care home placements for people with dementia, health and social care managers should ensure that the design of built environments meets the needs of people with dementia¹⁰ and complies with the Disability Discrimination Acts 1995 and 2005, because dementia is defined as a disability within the meaning of the Acts.
- 1.1.10.2 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, assistive technology, signage, garden design, and the access to and safety of the external environment.
- 1.1.10.3 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.

1.1.11 Care for people with dementia in an acute hospital facility

- 1.1.11.1 Acute and general hospital trusts should plan and provide services that address the specific personal and social care needs and the mental and physical health of people with dementia who use acute hospital facilities for any reason.
- 1.1.11.2 Acute trusts should ensure that all people with suspected or known dementia using inpatient services are assessed by a liaison service that specialises in the treatment of dementia. Care for such people in acute trusts should be planned jointly by the trust's hospital staff,

¹⁰ See, for example, Judd S, Marshall M, Phippen P (editors) (1997) *Design for Dementia*. London: Hawker.

liaison teams, relevant social care professionals and the person with suspected or known dementia and his or her carers.

1.2 Integrated health and social care

1.2.1.1 Health and social care staff should use the Department of Health's publication 'Everybody's business. Integrated mental health services for older adults: a service development guide' (www.everybodysbusiness.org.uk) in conjunction with this guideline as a framework for the planning, implementation and delivery of:

- primary care
- home care
- mainstream and specialist day services
- sheltered and extra-care housing
- assistive technology and telecare
- mainstream and specialist residential care
- intermediate care and rehabilitation
- care in general hospitals
- 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, including jointly agreeing written policies and procedures. Joint planning should include local service users and carers in order to highlight and address problems specific to each locality.

1.2.1.3 Health and social care professionals should ensure that people with dementia and their carers are given up-to-date information on local arrangements (including inter-agency working) for health and social care, including the independent and voluntary sectors, and on how to access such services.

1.3 *Risk factors, prevention and early identification*

1.3.1 Risk factors, screening and genetic counselling

- 1.3.1.1 General population screening for dementia should not be undertaken.
- 1.3.1.2 In middle-aged and older people, vascular and other modifiable risk factors for dementia (for example, smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol) should be reviewed and, if appropriate, treated.
- 1.3.1.3 Healthcare professionals working with people likely to have a genetic cause for their dementia (for example, familial autosomal dominant Alzheimer's disease or frontotemporal dementia, cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy [CADASIL], or Huntington's disease) should offer to refer them and their unaffected relatives for genetic counselling.
- 1.3.1.4 Regional genetic services should provide genetic counselling to people who are likely to have a genetic cause for their dementia and their unaffected relatives.
- 1.3.1.5 If a genetic cause for dementia is not suspected, including late-onset dementia, genotyping should not be undertaken for clinical purposes.

1.3.2 Preventive measures

- 1.3.2.1 The following interventions should not be prescribed as specific treatments for the primary prevention of dementia:
- statins
 - hormone replacement therapy
 - vitamin E
 - non-steroidal anti-inflammatory drugs.

- 1.3.2.2 For the secondary prevention of dementia, vascular and other modifiable risk factors (for example, smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol) should be reviewed in people with dementia, and if appropriate, treated.

1.3.3 Early identification of dementia

- 1.3.3.1 Primary healthcare staff should consider referring people who show signs of mild cognitive impairment (MCI)¹¹ for assessment by memory assessment services to aid early identification of dementia, because more than 50% of people with MCI later develop dementia.
- 1.3.3.2 Those undertaking health checks as part of health facilitation for people with learning disabilities should be aware of the increased risk of dementia in this group. Those undertaking health checks for other high-risk groups, for example those who have had a stroke and those with neurological conditions such as Parkinson's disease, should also be aware of the possibility of dementia.
- 1.3.3.3 Memory assessment services that identify people with MCI (including those without memory impairment, which may be absent in the earlier stages of non-Alzheimer's dementias) should offer follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage.

1.4 *Diagnosis and assessment of dementia*

1.4.1 Recognition

- 1.4.1.1 A diagnosis of dementia should be made only after a comprehensive assessment, which should include:

¹¹ 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 living. It is not a diagnosis of dementia of any type, although it may lead to dementia in some cases.

- history taking
- cognitive and mental state examination
- physical examination and other appropriate investigations
- a review of medication in order to identify and minimise use of drugs, including over-the-counter products, that may adversely affect cognitive functioning.

1.4.1.2 People who are assessed for the possibility of dementia should be asked if they wish to know the diagnosis and with whom this should be shared.

1.4.1.3 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 for this purpose, but a number of alternatives are now available, such as the 6-item Cognitive Impairment Test (6-CIT), the General Practitioner Assessment of Cognition (GPCOG) and the 7-Minute Screen. Those interpreting the scores of such tests should take full account of other factors known to affect performance, including educational level, skills, prior level of functioning and attainment, language, and any sensory impairments, psychiatric illness or physical/neurological problems.

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

1.4.1.5 At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions.

1.4.2 Investigation

- 1.4.2.1 A basic dementia screen should be performed at the time of presentation, usually within primary care. It should include:
- routine haematology
 - biochemistry tests (including electrolytes, calcium, glucose, and 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 investigation of people with suspected dementia. These tests should be considered only in those with histories suggesting they are at risk or if the clinical picture dictates.
- 1.4.2.3 A midstream urine test should always be carried out if delirium is a possibility.
- 1.4.2.4 Clinical presentation should determine whether investigations such as chest X-ray or electrocardiogram are needed.
- 1.4.2.5 Cerebrospinal fluid examination should not be performed as a routine investigation for dementia.

1.4.3 Diagnosis of subtypes

- 1.4.3.1 A diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria (see table 1).

Table 1: Diagnostic criteria for dementia

| Type of dementia | Diagnostic criteria |
|---------------------------|--------------------------------------------------------------------------|
| Alzheimer's disease | Preferred criteria: NINCDS/ADRDA. Alternatives include ICD-10 and DSM-IV |
| Vascular dementia | Preferred criteria: NINDS-AIREN. Alternatives include ICD-10 and DSM-IV |
| Dementia with Lewy bodies | International Consensus criteria for dementia with Lewy bodies |
| Frontotemporal dementia | Lund-Manchester criteria, NINDS criteria for frontotemporal dementia |

DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, fourth edition; ICD-10, International Classification of Diseases, 10th revision; 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.

- 1.4.3.2 Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Specialist advice should be taken when interpreting scans in people with learning disabilities.
- 1.4.3.3 Perfusion hexamethylpropyleneamine oxime (HMPAO) single-photon emission computed tomography (SPECT) should be used to help differentiate Alzheimer's disease, vascular dementia and frontotemporal dementia if the diagnosis is in doubt. People with Down's syndrome may show SPECT abnormalities throughout life that resemble those in Alzheimer's disease, so this test is not helpful in this group.

- 1.4.3.4 If HMPAO SPECT is unavailable, 2-[¹⁸F]fluoro-2-deoxy-D-glucose positron emission tomography (FDG PET) should be considered to help differentiate between Alzheimer's disease, vascular dementia and frontotemporal dementia if the diagnosis is in doubt.
- 1.4.3.5 Dopaminergic iodine-123-radiolabelled 2β-carbomethoxy-3β-(4-iodophenyl)-N-(3-fluoropropyl) nortropane (FP-CIT) SPECT should be used to help establish the diagnosis in those with suspected dementia with Lewy bodies (DLB) if the diagnosis is in doubt.
- 1.4.3.6 Cerebrospinal fluid examination should be used if Creutzfeldt–Jakob disease or other forms of rapidly progressive dementia are suspected.
- 1.4.3.7 Electroencephalography should not be used as a routine investigation in people with dementia.
- 1.4.3.8 Electroencephalography should be considered if 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 be considered only in highly selected people whose dementia is thought to be due to a potentially reversible condition that cannot be diagnosed in any other way.

1.4.4 Mixed dementias

- 1.4.4.1 Many cases of dementia may have mixed pathology (for example, Alzheimer's disease and vascular dementia or Alzheimer's disease and DLB). Unless otherwise stated in this guideline, such cases should be managed according to the condition that is thought to be the predominant cause of dementia.

1.4.5 Specialist services for dementia assessment

1.4.5.1 Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia.

1.4.5.2 Memory assessment services should offer a responsive service to aid early identification and should include a full range of assessment, diagnostic, therapeutic, and rehabilitation services to accommodate the needs of people with different types and all severities of dementia and the needs of their carers and family.

1.4.5.3 Memory assessment services should ensure an integrated approach to the care of people with dementia and the support of their carers, in partnership with local health, social care, and voluntary organisations.

1.4.6 Addressing needs that arise from the diagnosis of dementia

1.4.6.1 The experience of the diagnosis of dementia is challenging both for people with dementia and family members and for healthcare professionals, so healthcare professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members (usually only with the consent of the person with dementia). Healthcare professionals should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis.

1.4.6.2 Following a diagnosis of dementia, health and social care professionals 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 of the condition
- treatments
- local care and support services
- support groups
- sources of financial and legal advice, and advocacy
- medico-legal issues, including driving
- local information sources, including libraries and voluntary organisations.

Any advice and information given should be recorded in the notes.

- 1.4.6.3 Healthcare professionals who regularly diagnose dementia and discuss this with people with the condition and carers should consider mentoring or providing clinical supervision to less experienced colleagues.

1.5 *Promoting and maintaining independence of people with dementia*

- 1.5.1.1 Health and social care staff should aim to promote and maintain the independence, including mobility, of people with dementia. Care plans should address activities of daily living (ADLs) that maximise independent activity, enhance function, adapt and develop skills, and minimise the need for support. When writing care plans, the varying needs of people with different types of dementia should be addressed. Care plans should always include:

- consistent and stable staffing
- retaining a familiar environment
- minimising relocations
- flexibility to accommodate fluctuating abilities
- assessment and care-planning advice regarding ADLs, and ADL skill training from an occupational therapist
- assessment and care-planning advice about independent toileting skills; if incontinence occurs all possible causes should

be assessed and relevant treatments tried before concluding that it is permanent

- environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist and/or clinical psychologist
- physical exercise, with assessment and advice from a physiotherapist when needed
- support for people to go at their own pace and participate in activities they enjoy.

1.5.1.2 When developing a care plan for a person with a learning disability newly diagnosed with dementia, an assessment using the Assessment of Motor and Process Skills (AMPS)¹² should be considered. The Dementia Questionnaire for Mentally Retarded Persons (DMR)¹³ and Dalton's Brief Praxis Test (BPT)¹⁴ should be considered for monitoring change in function over time.

1.6 *Interventions for cognitive symptoms and maintenance of function for people with dementia*

1.6.1 Non-pharmacological interventions for cognitive symptoms and maintaining function

1.6.1.1 People with mild-to-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 staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia.

¹² The AMPS should be carried out by someone with formal training in its use.

¹³ Evenhuis HM, Kengen MMF, Eurlings HAL (1990) *Dementia Questionnaire for Persons with Mental Retardation (DMR)*. Zwammerdam, The Netherlands: Hooge Burch.

¹⁴ Dalton AJ, Fedor BL (1998) Onset of dyspraxia in aging persons with Down syndrome: longitudinal studies. *Journal of Intellectual and Developmental Disability* 23: 13–24.

1.6.2 Pharmacological interventions for the cognitive symptoms of Alzheimer's disease¹⁵

1.6.2.1 The three acetylcholinesterase inhibitors donepezil, galantamine and rivastigmine¹⁶ are recommended as options in the management of people with Alzheimer's disease of moderate severity only (that is, those with a Mini Mental State Examination [MMSE] score of between 10 and 20 points), and under the following conditions. **[NICE TA 2006]**

- Only specialists in the care of people with dementia (that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of the elderly) should initiate treatment. Carers' views on the patient's condition at baseline should be sought.
- Patients who continue on the drug should be reviewed every 6 months by MMSE score and global, functional and behavioural assessment. Carers' views on the patient's condition at follow-up should be sought. The drug should only be continued while the patient's MMSE score remains at or above 10 points and their global, functional and behavioural condition remains at a level where the drug is considered to be having a worthwhile effect. Any review involving MMSE assessment should be undertaken by an appropriate specialist team, unless there are locally agreed protocols for shared care.

1.6.2.2 Although it is recommended that acetylcholinesterase inhibitors should be prescribed only to people with Alzheimer's disease of

¹⁵ This section includes recommendations from the NICE technology appraisal on the clinical and cost-effectiveness of donepezil, galantamine and rivastigmine for mild-to-moderate Alzheimer's disease and memantine for moderate-to-severe Alzheimer's disease (see www.nice.org.uk/TA111). Following NICE protocol, the recommendations have been incorporated verbatim into this guideline (where one of these recommendations appears, it is indicated as NICE TA 2006).

¹⁶ The guidance applies to the marketing authorisation held for each drug at the time of the appraisal.

moderate severity, healthcare professionals should not rely on the MMSE score in certain circumstances. These are:

- in those with an MMSE score greater than 20, who have moderate dementia as judged by significant impairments in functional ability and personal and social function compared with premorbid ability
- in those with an MMSE score less than 10 because of a low premorbid attainment or ability or linguistic difficulties, who have moderate dementia as judged by an assessment tool sensitive to their level of competence
- in people with learning disabilities
- in people who are not fluent in spoken English or in the language in which the MMSE is applied.

1.6.2.3 For people with learning disabilities, tools used to assess the severity of dementia should be sensitive to their level of competence. Options include:

- Cambridge Cognitive Examination (CAMCOG)¹⁷
- Modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)¹⁸
- DMR
- Dementia Scale for Down Syndrome (DSDS)¹⁹, which can be useful in diagnosis of dementia in people with learning disabilities who do not have Down's syndrome.

¹⁷ Hon J, Huppert FA, Holland AJ et al. (1999) Neuropsychological assessment of older adults with Down's syndrome: an epidemiological study using the Cambridge Cognitive Examination (CAMCOG). *British Journal of Clinical Psychology* 38: 155–65.

¹⁸ Ball SL, Holland AJ, Huppert FA et al. (2004) The modified CAMDEX informant interview is a valid and reliable tool for use in the diagnosis of dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research* 48: 611–20.

¹⁹ Gedye A (1995) Dementia Scale for Down Syndrome Manual. Vancouver, BC: Gedye Research and Consulting.

- 1.6.2.4 When the decision has been made to prescribe an acetylcholinesterase inhibitor, it is recommended that therapy should be initiated with a drug with the lowest acquisition cost (taking into account required daily dose and the price per dose once shared care has started). However, an alternative acetylcholinesterase inhibitor could be prescribed where it is considered appropriate having regard to adverse event profile, expectations around concordance, medical comorbidity, possibility of drug interactions, and dosing profiles. **[NICE TA 2006]**
- 1.6.2.5 Memantine is not recommended as a treatment option for people with moderately severe to severe Alzheimer's disease except as part of well-designed clinical studies. **[NICE TA 2006]**
- 1.6.2.6 People with mild Alzheimer's disease who are currently receiving donepezil, galantamine or rivastigmine, and people with moderately severe to severe Alzheimer's disease currently receiving memantine, whether as routine therapy or as part of a clinical trial, may be continued on therapy (including after the conclusion of a clinical trial) until they, their carers and/or specialist consider it appropriate to stop. **[NICE TA 2006]**
- 1.6.3 Pharmacological interventions for the cognitive symptoms of non-Alzheimer dementias and MCI**
- 1.6.3.1 For people with vascular dementia, acetylcholinesterase inhibitors and memantine should not be prescribed for the treatment of cognitive decline, except as part of properly constructed clinical studies.
- 1.6.3.2 For people with MCI, acetylcholinesterase inhibitors should not be prescribed, except as part of properly constructed clinical studies.

1.7 *Interventions for non-cognitive symptoms and behaviour that challenges in people with dementia*

Non-cognitive symptoms include hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviour. 'Behaviour that challenges' encompasses a wide range of difficulties that are often experienced by people with dementia and that may have an effect on those who provide care. It may include aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting.

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

1.7.1.1 People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish likely factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include:

- the person's physical health
- depression
- possible undetected pain or discomfort
- side effects of medication
- individual biography, including religious beliefs and spiritual and cultural identity
- psychosocial factors
- physical environmental factors
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.

Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly. The frequency of the review should be agreed by the carers and staff involved and written in the notes.

1.7.1.2 For people with all types and severities of dementia who have comorbid agitation, consideration should be given to providing access to interventions tailored to the person's preferences, skills and abilities. Because people may respond better to one treatment than another, the response to each modality should be monitored and the care plan adapted accordingly. Approaches that may be considered, depending on availability, include:

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

These interventions may be delivered by a range of health and social care staff and volunteers, with appropriate training and supervision. The voluntary sector has a particular role to play in delivering these approaches. Health and social care staff in the NHS and social care, including care homes, should work together to ensure that some of these options are available, because there is some evidence of their clinical effectiveness. More research is needed into their cost effectiveness.

1.7.2 Pharmacological interventions for non-cognitive symptoms and behaviour that challenges

1.7.2.1 People with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others. The assessment and care-planning approach, which includes behavioural management, should be followed as soon as possible (see recommendation 1.7.1.1). If distress and/or agitation are less severe, the interventions described in recommendations 1.7.1.2,

1.8.1.2 and 1.8.1.3 should be followed before a pharmacological intervention is considered.

- 1.7.2.2 People with Alzheimer's disease, vascular dementia or mixed dementias with mild-to-moderate non-cognitive symptoms should not be prescribed antipsychotic drugs because of the possible increased risk of cerebrovascular adverse events and death.²⁰
- 1.7.2.3 People with DLB with mild-to-moderate non-cognitive symptoms, should not be prescribed antipsychotic drugs, because those with DLB are at particular risk of severe adverse reactions.
- 1.7.2.4 People with Alzheimer's disease, vascular dementia, mixed dementias or DLB with severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) may be offered treatment with an antipsychotic drug after the following conditions have been met.
- There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
 - Changes in cognition should be assessed and recorded at regular intervals. Alternative medication should be considered if necessary.
 - Target symptoms should be identified, quantified and documented.
 - Changes in target symptoms should be assessed and recorded at regular intervals.

²⁰ In March 2004, the Medicines and Healthcare products Regulatory Agency's Committee on Safety of Medicines issued a safety warning about the atypical antipsychotic drugs risperidone and olanzapine, advising that these drugs should not be used for the treatment of behavioural symptoms of dementia. Further information is available from www.mhra.gov.uk

- The effect of comorbid conditions, such as depression, should be considered.
- The choice of antipsychotic should be made after an individual risk–benefit analysis.
- The dose should be low initially and then titrated upwards.
- Treatment should be time limited and regularly reviewed (every 3 months or according to clinical need).

For people with DLB, healthcare professionals should monitor carefully for the emergence of severe untoward reactions, particularly neuroleptic sensitivity reactions (which manifest as the development or worsening of severe extrapyramidal features after treatment in the accepted dose range or acute and severe physical deterioration following prescription of antipsychotic drugs for which there is no other apparent cause).

1.7.2.5 People with mild, moderate, or severe Alzheimer’s disease who have non-cognitive symptoms and/or behaviour that challenges, causing significant distress or potential harm to the individual, may be offered an acetylcholinesterase inhibitor if:

- a non-pharmacological approach is inappropriate or has been ineffective, and
- antipsychotic drugs are inappropriate or have been ineffective.

1.7.2.6 People with DLB who have non-cognitive symptoms causing significant distress to the individual, or leading to behaviour that challenges, should be offered an acetylcholinesterase inhibitor.

1.7.2.7 People with vascular dementia who develop non-cognitive symptoms or behaviour that challenges should not be prescribed acetylcholinesterase inhibitors, except as part of properly constructed clinical studies.

1.7.3 Behaviour that challenges requiring urgent treatment

The control of behaviour that challenges becomes a priority if violence, aggression and extreme agitation threaten the safety of the person with dementia or others.

Managing risk

1.7.3.1 Health and social care staff who care for people with dementia should identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of behaviour that challenges, especially violence and aggression, and the risk of harm to self or others. These factors include:

- overcrowding
- lack of privacy
- lack of activities
- inadequate staff attention
- poor communication between the person with dementia and staff
- conflicts between staff and carers
- weak clinical leadership.

1.7.3.2 Health and social care staff should be trained to anticipate behaviour that challenges and how to manage violence, aggression and extreme agitation, including de-escalation techniques and methods of physical restraint.

1.7.3.3 Healthcare professionals who use medication in the management of violence, aggression and extreme agitation in people with dementia should:

- be trained in the correct use of drugs for behavioural control, specifically benzodiazepines and antipsychotics
- be able to assess the risks associated with pharmacological control of violence, aggression and extreme agitation, particularly in people who may be dehydrated or physically ill

- understand the cardiorespiratory effects of the acute administration of benzodiazepines and antipsychotics and the need to titrate dosage to effect
- recognise the importance of nursing people who have received these drugs in the recovery position and of monitoring pulse, blood pressure and respiration
- be familiar with and trained in the use of resuscitation equipment
- undertake annual retraining in resuscitation techniques
- understand the importance of maintaining an unobstructed airway.

Principles of pharmacological control of violence, aggression and extreme agitation

- 1.7.3.4 For people with dementia who are at significant risk to themselves or others because of violence, aggression and extreme agitation, immediate management should take place in a safe, low-stimulation environment, separate from other service users.
- 1.7.3.5 Drug treatments for the control of violence, aggression and extreme agitation should be used to calm the person with dementia and reduce the risk of violence and harm, rather than treat any underlying psychiatric condition. Healthcare professionals should aim for an optimal response in which agitation or aggression is reduced without sedation.
- 1.7.3.6 Violent behaviour should be managed without the prescription of high doses or combinations of drugs, especially if the person with dementia is elderly or frail. The lowest effective dose should be used.
- 1.7.3.7 Drugs for behavioural control should be used with caution, particularly if the person with dementia has been restrained, because of the following risks:
- loss of consciousness instead of sedation

- over-sedation with loss of alertness
- damage to the relationship between the person with dementia, their carers and the health and social care team
- specific issues related to age and physical and mental health.

1.7.3.8 People with dementia who have received involuntary sedation and their carers should be offered the opportunity to discuss their experiences and be provided with a clear explanation of the decision to use urgent sedation. This should be documented in their notes.

Route of drug administration

1.7.3.9 If drugs are necessary for the control of violence, aggression and extreme agitation, oral medication should be offered before parenteral medication.

1.7.3.10 If parenteral treatment is necessary for the control of violence, aggression and extreme agitation, the intramuscular (IM) route should be preferred because it is safer than intravenous administration. Intravenous administration should be used only in exceptional circumstances.

1.7.3.11 Vital signs should be monitored after parenteral treatment for the control of violence, aggression and extreme agitation. Blood pressure, pulse, temperature and respiratory rate should be recorded at regular intervals agreed by the multidisciplinary team until the person with dementia becomes active again. If the person appears to be or is asleep, more intensive monitoring is required.

Intramuscular agents for behavioural control

1.7.3.12 If IM preparations are needed for behavioural control, lorazepam, haloperidol or olanzapine should be used. Wherever possible, a single agent should be used in preference to a combination.

- 1.7.3.13 If rapid tranquillisation is needed, a combination of IM haloperidol and IM lorazepam should be considered.
- 1.7.3.14 IM diazepam and IM chlorpromazine are not recommended for the management of behaviour that challenges in people with dementia.
- 1.7.3.15 If using IM haloperidol (or any other IM conventional antipsychotic) for behavioural control, healthcare professionals should monitor closely for dystonia and other extrapyramidal side effects. If side effects become distressing, especially in acute dystonic reactions, the use of anticholinergic agents should be considered. If using anticholinergic agents, healthcare professionals should monitor for deteriorating cognitive function.

1.8 *Interventions for comorbid emotional disorders in people with dementia*

1.8.1 Psychological interventions for people with dementia with depression and/or anxiety

- 1.8.1.1 Care packages for people with dementia should include assessment and monitoring for depression and/or anxiety.
- 1.8.1.2 For people with dementia who have depression and/or anxiety, cognitive behavioural therapy, which may involve the active participation of their carers, may be considered as part of treatment.
- 1.8.1.3 A range of tailored interventions, such as reminiscence therapy, multisensory stimulation, animal-assisted therapy and exercise, should be available for people with dementia who have depression and/or anxiety.

1.8.2 Pharmacological interventions for people with dementia with depression

1.8.2.1 People with dementia who also have major depressive disorder should be offered antidepressant medication. Treatment should be started by staff with specialist training, who should follow the NICE clinical guideline 'Depression: management of depression in primary and secondary care'²¹ after a careful risk–benefit assessment. Antidepressant drugs with anticholinergic effects should be avoided because they may adversely affect cognition. The need for adherence, time to onset of action and risk of withdrawal effects should be explained at the start of treatment.

1.9 *Inpatient dementia services*

1.9.1.1 As far as possible, dementia care services should be community-based, but psychiatric inpatient admission may be considered in certain circumstances, including if:

- the person with dementia is severely disturbed and needs to be contained for his or her own health and safety and/or the safety of others (in some cases, this might include those liable to be detained under the Mental Health Act 1983)
- assessment in a community setting is not possible, for example if a person with dementia has complex physical and psychiatric problems.

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

1.10.1 Palliative care and end of life issues

Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their

²¹ Available from www.nice.org.uk/CG023

choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.²²

- 1.10.1.1 Health and social care professionals working with people with dementia and their carers should adopt a palliative care approach. They should consider physical, psychological, social and spiritual needs to maximise the quality of life of the person with dementia and their family.
- 1.10.1.2 Palliative care professionals, other health and social care professionals, and commissioners should ensure that people with dementia who are dying have the same access to palliative care services as those without dementia.
- 1.10.1.3 Primary care teams should ensure that the palliative care needs of people with dementia who are close to death are assessed and that the resulting information is communicated within the team and with other health and social care staff.
- 1.10.1.4 Health and social care staff 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. Dietary advice may also be beneficial. Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity. Ethical²³ and legal²⁴ principles should be applied when making decisions about withholding or withdrawing nutritional support.

²² Information on good practice, resources, and tools to support end of life care are available at www.endoflifecare.nhs.uk

²³ See General Medical Council (2002) 'Withholding and withdrawing life-prolonging treatments: good practice and decision-making', available at www.gmc-uk.org

²⁴ See the Mental Capacity Act 2005.

- 1.10.1.5 If a person with severe dementia has a fever, especially in the terminal stages, a clinical assessment should be undertaken. Simple analgesics, antipyretics and mechanical means of cooling the person may suffice. Antibiotics may be considered as a palliative measure in the terminal stages of dementia, but this needs an individual assessment.
- 1.10.1.6 Policies in hospitals and long-stay residential, nursing or continuing care units should reflect the fact that cardiopulmonary resuscitation is unlikely to succeed in cases of cardiopulmonary arrest in people with severe dementia.
- 1.10.1.7 In the absence of a valid and applicable advance decision to refuse resuscitation, the decision to resuscitate should take account of any expressed wishes or beliefs of the person with dementia, together with the views of the carers and the multidisciplinary team. The decision should be made in accordance with the guidance developed by the Resuscitation Council UK²⁵ and, if the person lacks capacity, the provisions of the Mental Capacity Act 2005. It should be recorded in the medical notes and care plans.

1.10.2 Pain relief

- 1.10.2.1 If a person with dementia has unexplained changes in behaviour and/or shows signs of distress, health and social care professionals should assess whether the person is in pain, using an observational pain assessment tool if helpful. However, the possibility of other causes should be considered.
- 1.10.2.2 The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological measures. Non-pharmacological therapies should be used with the person's history and preferences in mind.

²⁵ See 'Decisions relating to cardiopulmonary resuscitation: a joint statement', available from www.resus.org.uk/pages/dnar.htm

1.11 Support and interventions for the carers of people with dementia

1.11.1 Assessment of carers' needs

1.11.1.1 Health and social care managers should ensure that the rights of carers to receive an assessment of needs, as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004,²⁶ are upheld.

1.11.2 Interventions

1.11.2.1 Those carrying out carers' assessment should seek to identify any 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.

1.11.2.2 Care plans for carers of people with dementia should involve a range of tailored interventions. These may consist of multiple components including:

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

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

²⁶ See 'Implementing the Carers (Equal Opportunities) Act 2004.' *SCIE practice guide* no. 5 (2005).

1.11.2.4 Health and social care professionals should ensure that support, such as transport or short-break services, is provided for carers to enable them to participate in interventions.

1.11.2.5 Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.

1.11.3 Practical support and services

1.11.3.1 Health and social care managers should ensure that carers of people with dementia have access to a comprehensive range of respite/short-break services. These should meet the needs of both the carer (in terms of location, flexibility and timeliness) and the person with dementia and should include, for example, day care, day- and night-sitting, adult placement and short-term and/or overnight residential care. Transport should be offered to enable access to these services if they are not provided in the person's own home.

1.11.3.2 Respite/short-break care of any sort should be characterised by meaningful and therapeutic activity tailored to the person with dementia and provided in an environment that meets their needs. Providing this in the person's own home should be considered whenever possible.

2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available from www.nice.org.uk/CG042.

This guideline is relevant to people with Alzheimer's disease, vascular dementia, DLB, dementia with Parkinson's disease, subcortical dementia, frontotemporal dementias, and mixed cortical and subcortical dementia, as well as their families or carers, and all health and social care staff involved in the help, treatment and care of people with dementia and their families and carers including:

- health and social care 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 working 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
- 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 commonly encountered in elderly people, especially those with dementia, such as cardiovascular and neurological disorders, except where the treatment of such conditions may alter the progress of dementia.

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).

There is more information in the booklet 'The guideline development process: an overview for stakeholders, the public and the NHS' (second edition, published 2006), which is available from www.nice.org.uk/guidelinesprocess or by telephoning 0870 1555 455 (quote reference N1113).

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 and SCIE have developed tools to help organisations implement this guidance (listed below). These are available on our websites

(www.nice.org.uk/CG042 and www.scie.org.uk/publications/misc/dementiaguidelines.asp).

- Slides highlighting key messages for local discussion
- Costing tools
 - Costing report to estimate the national savings and costs associated with implementation

- Costing template to estimate the local costs and savings involved.
- Implementation advice on how to put the guidance into practice and national initiatives that support this locally.
- Audit criteria to monitor local practice.

4 Research recommendations

The Guideline Development Group has made the following recommendations for research, on the basis of its review of the evidence, to improve NICE and SCIE guidance and the care of people with dementia in the future. The effective care of people with dementia (included in standard 7 of the National Service Framework for older people) is of great importance, especially because the proportion of people with dementia will rise in line with the aging population. Therefore, further research is urgently needed to generate a better evidence base for the update of this guideline.

4.1 *Acetylcholinesterase inhibitors and memantine for the treatment of psychotic symptoms in dementia*

For people with dementia who develop severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress), is an acetylcholinesterase inhibitor (donepezil, galantamine or rivastigmine) and/or memantine effective in improving quality of life and reducing non-cognitive symptoms/behaviour that challenges when compared with placebo over 6 months, and is treatment cost effective in dementia and/or its subtypes?

Why this is important

Up to 75% of people with dementia may be affected by non-cognitive symptoms/behaviour that challenges. They are a leading cause of distress to carers and often lead to the institutionalisation of the person with dementia. Several studies have shown that acetylcholinesterase inhibitors may improve non-cognitive symptoms of dementia; however, the cost-effectiveness of these drugs in the treatment of people with dementia with severe non-cognitive symptoms has not been established.

4.2 Cognitive stimulation and/or acetylcholinesterase inhibitors in Alzheimer's disease

For people with Alzheimer's disease, are cognitive stimulation (activities involving cognitive processing; usually in a social context and often group-based, with an emphasis on enjoyment of activities), acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) or combined treatment clinically and cost effective in terms of cognition, global functioning, ADLs and quality of life when compared with placebo over 6 months?

Why this is important

No randomised studies have directly compared cognitive stimulation with an acetylcholinesterase inhibitor, and few randomised studies have compared the combination with an acetylcholinesterase inhibitor alone in people with mild-to-moderate Alzheimer's disease. Evidence suggests that cognitive stimulation is effective in people with dementia, but it is difficult to compare the magnitude of the effect with that of acetylcholinesterase inhibitors.

4.3 Psychological interventions for carers of people with dementia

For carers of people with dementia, is a psychological intervention cost effective when compared with usual care?

Why this is important

Those providing care for people with dementia are one of the most vulnerable groups of carers and often have high levels of stress, feelings of guilt, depression and other psychological problems. They often ignore their own health needs in favour of those of the person for whom they care. They may become exhausted, have poor physical health and feel isolated. Current research suggests that psychological interventions may be effective, but there is insufficient evidence to establish cost effectiveness. The promotion of good mental health in older people (many carers are the spouses of people with dementia) – included in standard 7 of the National Service Framework for older people – is vital, especially because the proportion of people with

dementia will rise in line with our aging population. Support for carers in general has been given priority in England and Wales through Carers' Strategy documents. Further research is urgently needed to generate a better evidence base for the update of this guideline.

4.4 *The effect of staff training on behaviour that challenges*

Does training of care staff in dementia-specific person-centred care lead to improvement in behaviour that challenges and reduced prescription of medication to control such behaviour in people with dementia requiring 24-hour care when compared with current practice?

Why this is important

According to prescribing advice published by the Royal College of Psychiatrists, there is a history of inappropriate use of antipsychotic drugs in people with dementia. The proportion of people with dementia with behaviour that challenges tends to rise as the dementia progresses; therefore this issue is of particular importance for people requiring 24-hour care.

5 Other versions of this guideline

5.1 *Full guideline*

The full guideline, 'Dementia: supporting people with dementia and their carers in health and social care' contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Mental Health, and it is available from www.nccmh.org.uk, the NICE and SCIE websites (www.nice.org.uk/CG042fullguideline and www.scie.org.uk/publications/misc/dementiaguidelines.asp) and the website of the National Library for Health (www.nlh.nhs.uk).

5.2 *Quick reference guide*

A quick reference guide for health and social care staff is available from www.nice.org/CG042quickrefguide and www.scie.org.uk/publications/misc/dementiaguidelines.asp

For printed copies phone the NHS Response Line on 0870 1555 455 (quote reference number N1144).

5.3 'Understanding NICE guidance'

Information for people with dementia and their carers ('Understanding NICE–SCIE guidance') is available from www.nice.org.uk/CG042publicinfo

For printed copies, phone the NHS Response Line on 0870 1555 455 (quote reference number N1145).

6 Related NICE and SCIE guidance

NICE clinical guidelines

- Parkinson's disease: diagnosis and management in primary and secondary care. *NICE clinical guideline* no. 35 (2006). Available from www.nice.org.uk/CG035
- Depression: management of depression in primary and secondary care. *NICE clinical guideline* no. 23 (2004). Available from www.nice.org.uk/CG023
- Falls: the assessment and prevention of falls in older people. *NICE clinical guideline* no. 21 (2002). Available from: www.nice.org.uk/CG021

NICE technology appraisal

- Donepezil, galantamine, rivastigmine (review) and memantine for the treatment of Alzheimer's disease. *NICE technology appraisal* no. 111 (2006). Available from www.nice.org.uk/TA111

SCIE practice guides

- Assessing the mental health needs of older people. *SCIE practice guide* no. 2 (2006). Available from www.scie.org.uk/publications/practiceguides/practiceguide02
- Implementing the Carers (Equal Opportunities) Act 2004. *SCIE practice guide* no. 5 (2005). Available from www.scie.org.uk/publications/practiceguides/carersguidance

SCIE research briefing

- Aiding communication with people with dementia. *SCIE research briefing* no. 3 (2005). Available from www.scie.org.uk/publications/briefings/briefing03

7 Updating the guideline

NICE clinical guidelines are updated as needed so that recommendations take into account important new information. 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.

Appendix A: The Guideline Development Group

Dr Andrew Fairbairn (Chair)

Consultant in Old Age Psychiatry, Newcastle General Hospital,
Northumberland, Tyne and Wear NHS Trust

Professor Nick Gould (Deputy Chair)

Professor of Social Work, University of Bath, representing the Social Care
Institute for Excellence

Dr Tim Kendall (Lead Director and Guideline Facilitator)

Joint Director, National Collaborating Centre for Mental Health; Deputy
Director, Royal College of Psychiatrists Research and Training Unit;
Consultant Psychiatrist and Medical Director, Sheffield Care Trust

Mr Peter Ashley

Service user, Alzheimer's Society; former non-executive director, Warrington
Primary Care Trust

Mr Ian Bainbridge

Deputy Director, Commission for Social Care Inspection, London

Ms Lizzy Bower

Health Economist, National Collaborating Centre for Mental Health

Professor Stephen Brown

Consultant Psychiatrist in Learning Disability, Cornwall Partnership NHS
Trust; Honorary Professor of Developmental Neuropsychiatry, Peninsula
Medical School Developmental Disabilities Research and Education Group,
Bodmin

Mr Alan Duncan

Systematic Reviewer, National Collaborating Centre for Mental Health

Ms Gillian Garner

Lead Occupational Therapist, Mental Health for Older Adults, South London and Maudsley NHS Trust

Professor Jane Gilliard

Change Agent, Care Services Improvement Partnership, London

Ms Karen Harrison

Senior Nurse, Mental Health Services for Older People, Leicestershire Partnership NHS Trust

Ms Sarah Hopkins

Research Assistant, National Collaborating Centre for Mental Health

Dr Steve Iliffe

Reader in General Practice, University College London

Professor Roy Jones

Director, Research Institute for the Care of the Elderly, Bath; Professor of Clinical Gerontology, School for Health, University of Bath; Honorary Consultant Geriatrician, Avon and Wiltshire Mental Health Partnership NHS Trust/ Bath and North East Somerset PCT

Professor Jill Manthorpe

Professor of Social Work, Social Care Workforce Research Unit, King's College London

Dr Ifigeneia Mavranouzouli

Health Economist, National Collaborating Centre for Mental Health

Dr Nick Meader

Systematic Reviewer, National Collaborating Centre for Mental Health

Ms Mary Murrell

Carer representative; Alzheimer's Society volunteer

Professor John O'Brien

Professor of Old Age Psychiatry, Wolfson Research Centre, Institute for Ageing and Health, Newcastle University

Dr Catherine Pettinari

Senior Centre Project Manager, National Collaborating Centre for Mental Health

Ms Sara Stockton

Information Scientist, National Collaborating Centre for Mental Health

Dr Clare Taylor

Editor, National Collaborating Centre for Mental Health

Ms Sophie Weithaler

Service Development Manager, Hillingdon Primary Care Trust

Dr Craig Whittington

Senior Systematic Reviewer, National Collaborating Centre for Mental Health

Ms Jacqui Wood

Carer representative; Alzheimer's Society volunteer

Professor Bob Woods

Professor of Clinical Psychology of Older People, University of Wales, Bangor

Dr Claire Young

Consultant in Old Age Psychiatry, Older Adult Mental Health Care Group, Sheffield

Advice on palliative care and medical ethics

Dr Julian Hughes

North Tyneside General Hospital, Northumbria Healthcare NHS Trust

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 adherence to NICE guidance development processes. In particular, the Panel ensures that stakeholder comments have been adequately considered and responded to. The Panel includes members from the following perspectives; primary care, secondary care, social care, lay, public health and industry.

Mr Peter Robb (Chair)

Consultant ENT Surgeon, Epsom & St Helier University Hospitals and The Royal Surrey County NHS Trusts

Mr Mike Baldwin

Head of Health Technology Appraisals, Sanofi-Aventis

Mrs Jill Freer

Acting Director of Provider Services, Rugby Primary Care Trust

Dr Patricia Le Riche

Senior Lecturer in Social Care and Social Work, University of Sussex

Dr Roger Paxton

Director of Research and Development, Research and Clinical Effectiveness Department, Northumberland, Tyne and Wear NHS Trust

Dr Paul Rowlands

Consultant Psychiatrist, Derbyshire Mental Health Services Mental Health Care Trust

Mr John Seddon

Patent representative