



**National Institute for
Health and Clinical Excellence**

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Quick reference guide

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Dementia

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

This quick reference guide has been revised to incorporate the updated NICE technology appraisal of drugs for Alzheimer's disease, published in March 2011 (www.nice.org.uk/TA217). See pages 14 and 15 for the updated information.

About this booklet

This booklet summarises the recommendations NICE and SCIE have made to the NHS and social care services in 'Dementia: supporting people with dementia and their carers in health and social care' (NICE clinical guideline 42).

Who should read this booklet?

The booklet is for health and social care staff who work with people with dementia and their carers, and those who work with older people and people with learning disabilities. This includes GPs, nurses, geriatricians, psychiatrists, social workers, care home managers and care staff. The booklet also includes recommendations relevant to commissioners, managers and coordinators of health and social care. It contains what you need to know to put the guideline's recommendations into practice.

Who wrote the guideline?

The guideline was developed by the National Collaborating Centre for Mental Health, which is a partnership of the Royal College of Psychiatrists and the British Psychological Society. The Collaborating Centre worked with a group of health and social care professionals (including consultants, GPs, nurses and social workers), representatives of the Royal Colleges and professional bodies, patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

For information on how NICE clinical guidelines are developed, go to www.nice.org.uk

Where can I get more information about the guideline on dementia?

The NICE and SCIE websites have the recommendations in full, summaries of the evidence they are based on, a summary of the guideline for patients and carers, and tools to support implementation (see inside back cover for more details).

National Institute for Health and Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk

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Social Care Institute for Excellence

Goldings House
2 Hay's Lane
London
SE1 2HB

www.scie.org.uk

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NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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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. NICE has also produced a clinical guideline on Parkinson's disease (available from www.nice.org.uk/CG35).

This guideline includes recommendations derived from NICE technology appraisal 111 on acetylcholinesterase inhibitors and memantine for Alzheimer's disease. They have been incorporated into the guideline in accordance with NICE processes. More details of the technology appraisal are available from www.nice.org.uk/TA111

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 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.

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.

Key priorities for implementation *continued*

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 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.

Principles of care

Person-centred care

Treatment and care should take into account each person's individual needs and preferences. Good communication is essential, supported by evidence-based information, to allow people to reach informed decisions about their care.

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 people 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). The Mental Capacity Act 2005 (available from www.dca.gov.uk/menincap/legis.htm) is due to be implemented in April 2007 and 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 the 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 should restrict their rights and basic freedoms as little as possible.

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. Carers and relatives should be provided with the information and support they need, and carers should be offered an assessment of their own needs.

Community-based care

Support people with dementia in the community as far as possible. If considering psychiatric inpatient admission see 'Accommodation and hospital care', page 23.

Diversity and equality

- Always treat people with dementia and their carers with respect.
- Ensure people with dementia are not excluded from services because of their diagnosis, age (whether regarded as too old or too young), or any learning disability.
- If there is a language barrier, offer:
 - written information in the preferred language and/or an accessible format
 - independent interpreters
 - psychological interventions in the preferred language.
- Ensure that people suspected of having dementia because of cognitive and functional deterioration, but who do not have sufficient memory impairment for diagnosis, are not denied access to support services.

Needs and preferences of people with dementia

- Identify specific needs, including those arising from:
 - diversity (such as sex, ethnicity, age, religion and personal care)
 - ill health, physical and learning disabilities, sensory impairment, communication difficulties, problems with nutrition and poor oral health.
- Identify and wherever possible accommodate preferences (such as diet, sexuality and religion), particularly in residential care.

Record and address needs and preferences in the care plan.

Younger people with dementia

Specialist multidisciplinary services, allied to existing dementia services, should be developed for the assessment, diagnosis and care of younger people with dementia.

People with learning disabilities

Health and social care staff working with people with learning disabilities and other younger people at risk of dementia should be trained in dementia awareness.

People with learning disabilities and those supporting them should have access to specialist advice and support for dementia.

Ethics and consent

- Always seek valid consent from people with dementia.
 - Explain options and check that the person understands, has not been coerced and continues to consent over time.
 - Use the Mental Capacity Act 2005 if the person lacks capacity.
- Encourage the use of advocacy services and voluntary support. These services should be available to people with dementia and carers separately if required.
- Allow people with dementia to convey information in confidence.
 - Discuss with the person any need to share information with colleagues or other agencies.
 - Only disclose confidential material without consent in exceptional circumstances.
 - As the dementia worsens, any decisions about sharing information should be made in the context of the Mental Capacity Act 2005.
- Discuss with the person with dementia, while he or she still has capacity, and his or her carer the use of:
 - advance statements (stating what is to be done if the person loses the capacity to communicate or make decisions)
 - advance decisions to refuse treatment
 - Lasting Power of Attorney
 - a Preferred Place of Care Plan.

Other principles of care

Impact of dementia on relationships

- Assess the impact of dementia on personal (including sexual) relationships at the time of diagnosis and when indicated subsequently. Provide information about local support services if required.

Because people with dementia are vulnerable to abuse and neglect, health and social care staff should have access to information and training about adult protection and abide by the local multi-agency policy.

Financial support and NHS Continuing Care

- Explain to people with dementia and their carers:
 - that they have the right to receive direct payments and individual budgets (where available); offer support to obtain and manage these if needed
 - the statutory difference between NHS care and care provided by local authority social services to help them decide whether they are eligible for NHS continuing care.

Diagnosis and assessment

Except where indicated, recommendations in this section are mainly relevant to healthcare professionals.

Risk factors and prevention

Risk factors

- Do not conduct general population screening.
- In middle-aged and older people, review and treat vascular and other risk factors for dementia, such as smoking, excessive alcohol use, obesity, diabetes, hypertension and raised cholesterol levels.

Genetic counselling

- Offer referral to genetic counselling to those thought to have a genetic cause of dementia¹ and to their unaffected relatives.
 - Genetic counselling should be provided by regional genetic services.
 - Do not use clinical genotyping if a genetic cause for dementia is not suspected, including late-onset dementia.

Prevention

- Do not use the following as specific treatments for the primary prevention of dementia:
 - statins
 - hormone replacement therapy
 - vitamin E
 - non-steroidal anti-inflammatory drugs.
- For the secondary prevention of dementia, review and treat vascular and other risk factors in people with the condition.

Early identification

- In primary care, consider referring people with signs of mild cognitive impairment (MCI)² for assessment at memory assessment services.
- If undertaking health checks, including those conducted as part of health facilitation, be aware of:
 - the increased risk of dementia in people with learning disabilities and
 - the possibility of dementia in other high-risk groups (for example people who have had a stroke or have a neurological condition such as Parkinson's disease).

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 signs of possible dementia.

¹ Examples include familial autosomal dominant Alzheimer's disease or frontotemporal dementia, cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL) and Huntington's disease.

² MCI is a syndrome defined as cognitive decline greater than expected for an individual's age and education level that 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.

Diagnosis and assessment

- Make a diagnosis of dementia only after a comprehensive assessment, including:
 - history taking
 - cognitive and mental state examination
 - physical examination
 - review of medication to identify any drugs that may impair cognitive functioning.
- Ask people who are assessed for possible dementia whether they wish to know the diagnosis and with whom it should be shared.
- If dementia is mild or questionable, conduct formal neuropsychological testing.
- At the time of diagnosis, and regularly afterwards, assess medical and psychiatric comorbidities, including depression and psychosis.

Clinical cognitive assessment

- Examine:
 - attention and concentration
 - orientation
 - short- and long-term memory
 - praxis
 - language
 - executive function.
- Conduct formal cognitive testing using a standardised instrument, such as:
 - Mini Mental State Examination (MMSE)
 - 6-Item Cognitive Impairment Test (6-CIT)
 - General Practitioner Assessment of Cognition (GPCOG)
 - 7-Minute Screen.

Take into account other factors that may affect performance, including educational level, skills, prior level of functioning and attainment, language, sensory impairment, psychiatric illness and physical or neurological problems.

Investigation of suspected dementia

- Conduct a basic dementia screen at the time of presentation, usually in primary care. Include:
 - routine haematology
 - biochemistry tests (electrolytes, calcium, glucose, and renal and liver function)
 - thyroid function tests
 - serum vitamin B₁₂ and folate levels.
- Perform a midstream urine test if delirium is a possibility.
- Conduct investigations such as chest X-ray or electrocardiogram (ECG) as determined by clinical presentation.
- Do not routinely:
 - test for syphilis serology or HIV unless there are risk factors or the clinical picture dictates
 - examine cerebrospinal fluid.

Diagnosis of subtype

- Diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria.

Type	Recommended diagnostic criteria*
Alzheimer's disease	Prefer NINCDS/ADRDA criteria. Alternatives include ICD-10 and DSM-IV.
Vascular dementia	Prefer NINDS-AIREN criteria. Alternatives include ICD-10 and DSM-IV.
Dementia with Lewy bodies (DLB)	International Consensus criteria for DLB.
Frontotemporal dementia (FTD)	Lund–Manchester criteria, NINDS criteria for FTD.

*See NICE–SCIE guideline for further details (available from www.nice.org.uk/CG042).

- Use cerebrospinal fluid examination if Creutzfeldt–Jakob disease (CJD) or other forms of rapidly progressive dementia are suspected.
- Do not routinely use electroencephalography (EEG). Consider in:
 - suspected delirium, frontotemporal dementia or CJD
 - associated seizure disorder in those with dementia.
- Consider brain biopsy only if a potentially reversible cause is suspected that cannot be diagnosed in any other way.

Imaging

- Use structural imaging to exclude other cerebral pathologies and help establish the subtype.
 - Prefer MRI to assist with early diagnosis and detect subcortical vascular changes. However, CT scanning could be used.
 - Take specialist advice when interpreting scans in people with learning disabilities.
- Use perfusion hexamethylpropyleneamine oxime (HMPAO) single-photon emission computed tomography (SPECT) to help differentiate Alzheimer's disease, vascular dementia and frontotemporal dementia.
 - The test is not useful in people with Down's syndrome, who may have SPECT abnormalities resembling Alzheimer's disease throughout life.
 - If HMPAO SPECT is unavailable, consider 2-[¹⁸F]fluoro-2-deoxy-D-glucose positron emission tomography (FDG PET) as an alternative.
- Use dopaminergic iodine-123-radiolabelled 2β-carbomethoxy-3β-(4-iodophenyl)-N-(3-fluoropropyl) nortropane (FP-CIT) SPECT to confirm suspected DLB.

- Usually manage dementia with mixed pathology according to the likely dominant condition.

Specialist assessment services

Memory assessment services (provided by a memory assessment clinic or community mental health teams) should be the single point of referral for people with possible dementia. They should provide:

- a responsive service with a full range of assessment, diagnostic, therapeutic and rehabilitation services to accommodate different types and all severities of dementia and the needs of families and carers
- integrated care in partnership with local health, social care, and voluntary organisations.

Needs arising from diagnosis

Following a diagnosis of dementia:

- make time available to discuss the diagnosis with the person with dementia and, if the person consents, with their family. Both may need ongoing support.
- offer the person with dementia and their family written information about:³
 - signs and symptoms
 - course and prognosis
 - 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.

Record any advice and information given in the notes.

Consider mentoring or supervising less experienced colleagues if you regularly diagnose dementia and discuss this with people with the condition and carers.

³ This recommendation is also relevant to social care staff.

Promoting independence and maintaining function

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 (ADL) that maximise independent activity, enhance function, adapt and develop skills, and minimise need for support. They should also address the varying needs of people with different types of dementia. Essential components are:
 - consistent and stable staffing
 - retaining a familiar environment
 - minimising relocations
 - flexibility to accommodate fluctuating abilities
 - ADL advice and skill training from an occupational therapist
 - advice about independent toileting skills (if incontinence occurs, all possible causes should be assessed and treatment options tried before concluding it is permanent)
 - environmental modifications to aid independence, 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 take part in activities they enjoy.
- In people with a learning disability newly diagnosed with dementia, consider using:
 - the Assessment of Motor and Process Skills (AMPS)⁴ at the time of diagnosis to help develop the care plan
 - Dementia Questionnaire for Mentally Retarded Persons (DMR) and Dalton's Brief Praxis Test (BPT) for monitoring change in functioning.

⁴ The AMPS should be carried out by someone with formal training in its use.

Interventions for cognitive symptoms and maintenance of function

Non-pharmacological interventions

- Offer people with mild-to-moderate dementia the opportunity to participate in a structured group cognitive stimulation programme irrespective of drug treatment for cognitive symptoms.

Drugs for Alzheimer's disease

1. The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine are recommended as options for managing mild to moderate Alzheimer's disease under all of the conditions specified in paragraphs 3 and 4 below.
2. Memantine is recommended as an option for managing Alzheimer's disease for people with:
 - moderate Alzheimer's disease who are intolerant of or have a contraindication to AChE inhibitors or
 - severe Alzheimer's disease.Treatment should be under the conditions specified in paragraph 3.
3. Treatment should be under the following conditions:
 - Only specialists in the care of patients with dementia (that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of older people) should initiate treatment. Carers' views on the patient's condition at baseline should be sought.
 - Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms.
 - Patients who continue on treatment should be reviewed regularly using cognitive, global, functional and behavioural assessment. Treatment should be reviewed by an appropriate specialist team, unless there are locally agreed protocols for shared care. Carers' views on the patient's condition at follow-up should be sought.
4. If prescribing an AChE inhibitor (donepezil, galantamine or rivastigmine), treatment should normally be started with the 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 AChE inhibitor could be prescribed if it is considered appropriate when taking into account adverse event profile, expectations about adherence, medical comorbidity, possibility of drug interactions and dosing profiles.
5. When using assessment scales to determine the severity of Alzheimer's disease, healthcare professionals should take into account any physical, sensory or learning disabilities, or communication difficulties that could affect the results and make any adjustments they consider appropriate. Healthcare professionals should also be mindful of the need to secure equality of access to treatment for patients from different ethnic groups, in particular those from different cultural backgrounds.

continued

6. When assessing the severity of Alzheimer's disease and the need for treatment, healthcare professionals should not rely solely on cognition scores in circumstances in which it would be inappropriate to do so. These include:
- if the cognition score is not, or is not by itself, a clinically appropriate tool for assessing the severity of that patient's dementia because of the patient's learning difficulties or other disabilities (for example, sensory impairments), linguistic or other communication difficulties or level of education or
 - if it is not possible to apply the tool in a language in which the patient is sufficiently fluent for it to be appropriate for assessing the severity of dementia or
 - if there are other similar reasons why using a cognition score, or the score alone, would be inappropriate for assessing the severity of dementia.

In such cases healthcare professionals should determine the need for initiation or continuation of treatment by using another appropriate method of assessment. (Note: also see the box below.)

These are the recommendations in the NICE technology appraisal 217, published in March 2011. Technology appraisal 217 updates and replaces Technology appraisal 111 and the recommendations on drug treatment for the cognitive symptoms of Alzheimer's disease in NICE clinical guideline 42.

Assessing severity of Alzheimer's disease in people with learning disabilities

According to the level of competence, consider alternative tests:

- Cambridge Cognitive Examination (CAMCOG)
- Modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)
- Dementia Questionnaire for Mentally Retarded Persons (DMR)
- Dementia Scale for Down Syndrome (DSDS) (also useful in people without Down's syndrome)

Drugs for non-Alzheimer dementias and MCI

- Except as part of properly constructed clinical studies, do not use:
 - acetylcholinesterase inhibitors or memantine for cognitive decline in vascular dementia
 - acetylcholinesterase inhibitors in MCI.

Interventions for non-cognitive symptoms and behaviour that challenges

Non-cognitive symptoms of dementia include hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviour. Behaviour that challenges may include aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting.

Consider medication for non-cognitive symptoms or behaviour that challenges in the first instance only if there is severe distress or an immediate risk of harm to the person with dementia or others.

- Use the assessment and care-planning approach (see below) as soon as possible.
- For less severe distress and/or agitation, initially use a non-drug option (see below and page 19).

Non-pharmacological interventions

- If a person with dementia develops distressing non-cognitive symptoms or behaviour that challenges, offer an early assessment to identify factors that may influence the behaviour. Include:
 - physical health
 - depression
 - possible undetected pain or discomfort
 - side effects of medication
 - individual biography
 - psychosocial factors
 - physical environmental factors
 - behavioural and functional analysis in conjunction with carers and care workers.

Develop individual care plans, record in the notes and review regularly at a frequency agreed with carers and staff.

- For comorbid agitation, consider interventions tailored to the person's preferences, skills and abilities.
 - Monitor response and adapt the care plan as needed.
 - Depending on availability, consider options including:⁵
 - ◆ aromatherapy
 - ◆ multisensory stimulation
 - ◆ therapeutic use of music and/or dancing
 - ◆ animal-assisted therapy
 - ◆ massage.

⁵ These can be delivered by a range of health and social care staff and volunteers. Health and social care staff should ensure that some options are available.

Pharmacological interventions

Consider medication for non-cognitive symptoms or behaviour that challenges in the first instance only if there is severe distress or an immediate risk of harm to the person with dementia or others.

Antipsychotics

- Do not use antipsychotic drugs for mild-to-moderate non-cognitive symptoms in:
 - DLB, because of the risk of severe adverse reactions
 - Alzheimer's disease, vascular dementia or mixed dementias, because of the increased risk of cerebrovascular adverse events and death.
- Consider antipsychotics for severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) only if:
 - risks and benefits have been fully discussed; assess cerebrovascular risk factors and discuss possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition
 - changes in cognition are regularly assessed and recorded; consider alternative medication if necessary
 - target symptoms have been identified, quantified and documented, and changes are regularly assessed and recorded
 - comorbid conditions, such as depression, have been considered
 - the drug is chosen after an individual risk–benefit analysis
 - the dose is started low and titrated upwards
 - treatment is time limited and regularly reviewed (every 3 months or according to clinical need). In DLB, monitor for severe untoward reactions, particularly neuroleptic sensitivity reactions (development or worsening of extrapyramidal features or acute, severe physical deterioration).

Acetylcholinesterase inhibitors

- Consider an acetylcholinesterase inhibitor for:
 - people with DLB who have non-cognitive symptoms causing significant distress or leading to behaviour that challenges
 - 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 if:
 - ◆ a non-pharmacological approach is inappropriate or has been ineffective, and
 - ◆ antipsychotic drugs are inappropriate or have been ineffective.
- Do not use acetylcholinesterase inhibitors for non-cognitive symptoms or behaviour that challenges in vascular dementia except as part of properly constructed clinical studies.

Behaviour that challenges requiring urgent treatment

Managing risk

- Address environmental, physical health and psychosocial factors that may increase the likelihood of behaviour that challenges. These 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.

Principles of pharmacological control of violence, aggression and extreme agitation

- Conduct immediate management in a safe, low-stimulation environment, away from others.
- Use drugs to calm the person and reduce the risk of violence and harm, rather than to treat any underlying psychiatric condition. Aim to reduce agitation or aggression without sedation.
- Use the lowest effective dose. Avoid high doses and drug combinations, especially in elderly or frail people.
- Use drugs for control of behaviour with caution, particularly if the person 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 care team
 - specific issues related to age and physical and mental health.
- Offer people with dementia and their carers the opportunity to discuss their experiences, and explain the decision to use urgent sedation. Record in the notes.

Route of drug administration

- Offer oral medication before parenteral medication.
 - If parenteral treatment is necessary, prefer intramuscular to intravenous injection. Give drugs intravenously only in exceptional circumstances.
 - Monitor vital signs after parenteral administration. Record blood pressure, pulse, temperature and respiratory rates at regular intervals until the person with dementia becomes active again.
 - Monitor more intensively if the person appears to be or is asleep.

Behaviour that challenges requiring urgent treatment *continued*

Intramuscular agents for behavioural control

- Use lorazepam, haloperidol or olanzapine. If possible, use a single agent.
- For rapid tranquillisation, consider haloperidol and lorazepam in combination.
- Do not use diazepam or chlorpromazine.
- When using haloperidol (or any other conventional antipsychotic), monitor closely for dystonia and other extrapyramidal side effects.
- If side effects become distressing, consider an anticholinergic agent; monitor for deteriorating cognitive function if used.

Interventions for comorbid emotional disorders

- Assess and monitor people with dementia for depression and/or anxiety.

Psychosocial interventions for comorbid depression and/or anxiety

- Consider cognitive behavioural therapy (possibly involving carers).
- A range of tailored interventions, such as reminiscence therapy, multisensory stimulation, animal-assisted therapy and exercise, should be available.

Pharmacological interventions for comorbid depression

- Offer antidepressant medication.
 - Specialist staff should start treatment after risk–benefit analysis.
 - Treatment should follow the NICE guideline on depression.
 - 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.

Palliative and end-of-life care

A palliative care approach

Adopt a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing. Information on end-of-life care is available from www.endoflifecare.nhs.uk

- Consider physical, psychological, social and spiritual needs.
- Ensure people with dementia have the same access to palliative care services as others.
- Primary care teams should assess the palliative care needs of people close to death. Communicate the result within the team and to other health and social care staff.
- Encourage people with dementia to eat and drink by mouth for as long as possible.
 - Specialist assessment and advice about swallowing and feeding should be available.
 - Dietary advice may be useful.
 - Do not generally use tube feeding in severe dementia if dysphagia or disinclination to eat is a manifestation of disease severity.
 - ◆ Consider nutritional support, including tube feeding, if dysphagia is thought to be transient.
 - ◆ Apply ethical and legal principles to decisions to withhold or withdraw nutritional support.
- Clinically assess fever in severe dementia (especially in the terminal stages).
 - Treatment with simple analgesics, antipyretics and mechanical cooling may suffice.
 - Consider palliative use of antibiotics after an individual assessment.

Resuscitation

Institutional policies should reflect the fact that cardiopulmonary resuscitation is unlikely to succeed in people with severe dementia.

- If the person with dementia has not made an advance decision to refuse resuscitation:
 - take into account any expressed wishes of the person with dementia and the views of the carers and the multidisciplinary team
 - follow the Resuscitation Council UK's guidance (available from www.resus.org.uk/pages/dnar.htm)
 - follow the Mental Capacity Act 2005 if the person lacks capacity
 - record decisions in the notes and care plan.

Pain relief

- If there are unexplained changes in behaviour or signs of distress, assess for undetected pain, using an observational pain assessment tool if helpful. However, do not rule out other causes.
- In severe dementia, treat pain both pharmacologically and non-pharmacologically. Consider the person's history and preferences when choosing non-pharmacological therapies.

Support for carers

Assessment

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

Carers' assessments should seek to identify any psychological distress and the psychosocial impact on the carer, including after the person with dementia has entered residential care.

Interventions

- Care plans for carers should include tailored interventions, such as:
 - individual or group psychoeducation
 - peer-support groups tailored to the needs of the individual (for example, the stage of dementia of the person being cared for)
 - telephone and internet information and support
 - training courses about dementia, services and benefits, and dementia-care problem solving. Consider involving the person with dementia and other family members as well as the primary carer.
- Ensure support (such as transport or short-break services) is provided to enable carer participation in interventions.
- Offer psychological therapy (including cognitive behavioural therapy) with a specialist practitioner to carers who experience psychological distress and negative psychological impact.

Practical support

- Health and social care managers should ensure that carers of people with dementia have access to a range of respite or short-break services.
 - Services should meet the needs of both the carer (in terms of location, flexibility, and timeliness) and the person with dementia.
 - Services should include, for example, day care, day- and night-sitting, adult placement and short-term and/or overnight residential care.
 - Transport to these services should be offered.
- Respite/short-break care should include therapeutic activities tailored to the person with dementia provided in an environment that meets their needs (the person's own home wherever possible).

Integrated and coordinated care

Integrated health and social care

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.

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.

Health and social care managers should coordinate and integrate the work of agencies involved in the care of people with dementia, including:

- jointly agreeing written policies and procedures
- involving service users and carers in joint planning to help identify local problems.

Management and coordination of care

Plan and provide care of people with dementia and support for their carers within the framework of care management/coordination.

Care managers/coordinators should ensure that:

- there is coordinated delivery of health and social care services, including:
 - a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and carers
 - named health and social care staff to operate the care plan
 - endorsement of the plan by the person and/or carers
 - formal reviews of the plan at a frequency agreed with the person and carers and recorded in the notes
- care plans are based on the person with dementia's:
 - life history, social and family circumstances, and preferences
 - physical and mental health needs and current level of functioning.

Accommodation and hospital care

Living arrangements and care home placements

When organising or purchasing living arrangements or care home placements, health and social care managers should ensure that the design meets the needs of people with dementia and complies with the Disability Discrimination Acts 1995 and 2005.

- Built environments should be enabling and aid orientation. Attention should be paid to lighting, colour schemes, floor coverings, assistive technology, signage, garden design, and access to and safety of the external environment.
- Consideration should be given to size of units, mix of residents, and skills of staff to ensure that the environment is supportive and therapeutic.

Inpatient care

Support people with dementia in the community as far as possible. However, consider psychiatric inpatient admission if necessary, including if:

- the person is severely disturbed and needs to be contained for his or her own health and safety and/or the safety of others (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 there are complex physical and psychiatric problems.

Care in an acute hospital

Acute and general hospital trusts should:

- 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
- ensure that people with suspected or known dementia using inpatient services are assessed by a liaison service that specialises in the treatment of dementia. Care should be planned jointly by:
 - the trust's hospital staff
 - liaison teams
 - relevant social care staff
 - the person with suspected or known dementia and carers.

Staff training

Training in dementia care

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

- According to the needs of the staff being trained, trainers should consider the following when developing educational programmes:
 - early signs and symptoms suggestive of dementia and its major subtypes
 - natural history, signs and symptoms, and prognosis
 - impact of the condition on the person with dementia and carers, family and social network
 - assessment and treatment, including administration of medication and monitoring side effects
 - person-centred care in dementia
 - communication skills
 - assertive outreach techniques for people not engaged with services
 - roles of staff and agencies involved in care and basic advice on how they should work together
 - introduction to local adult protection policy and procedures, including the reporting of concerns or malpractice and who to contact
 - palliative care approach.

Training programmes should be adjusted for staff caring for people with learning disabilities.

In local mental health and learning disability services:

- managers should set up consultation and communication channels for care homes and other services
- liaison teams 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.

In primary care, there should be an evidence-based educational intervention, such as decision-support software and practice-based workshops, to improve the diagnosis and management of dementia.

Training in behaviour that challenges

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.

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

- be trained in the use of drugs for behavioural control (benzodiazepines and antipsychotics)
- be able to assess the risks of pharmacological control of violence, aggression and extreme agitation, particularly in dehydrated and physically ill people
- understand the cardiorespiratory effects of the acute administration of benzodiazepines and antipsychotics and the need to titrate dose to effect
- recognise the importance of nursing people who have received these drugs in the recovery position and monitoring pulse, blood pressure and respiration
- be trained in the use of resuscitation equipment and undertake annual retraining in resuscitation techniques
- understand the importance of maintaining an unobstructed airway.

See also 'Interventions for non-cognitive symptoms and behaviour that challenges' (page 16).

Further information

Ordering information

You can download the following versions of this guideline from www.nice.org.uk/CG42 and www.scie.org.uk/publications/misc/dementiaguidelines.asp

- The quick reference guide (this document) – a summary of the recommendations for health and social care staff.
- ‘Understanding NICE–SCIE guidance’ – information for people with dementia and their carers.
- The NICE–SCIE guideline – all the recommendations.
- The full guideline – all the recommendations, details of how they were developed and summaries of the evidence they are 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’).

Implementation tools

NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/guidance/CG42).

Related guidance

For information about NICE and SCIE guidance that has been issued or is in development, see www.nice.org.uk and www.scie.org.uk

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/CG35
- Depression: management of depression in primary and secondary care. NICE clinical guideline no. 23 (2004). Replaced by www.nice.org.uk/CG90
- Falls: the assessment and prevention of falls in older people. NICE clinical guideline no. 21 (2002). Available from: www.nice.org.uk/CG21

NICE technology appraisal

- Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer’s disease (review). NICE technology appraisal no. 217 (2011). Available from www.nice.org.uk/TA217

SCIE practice guides

- Assessing the mental health needs of older people. SCIE practice guide no. 3 (2006). Available from www.scie.org.uk/publications/guides/guide03/index.asp

- Implementing the Carers (Equal Opportunities) Act 2004. SCIE practice guide no. 9 (2005). Available from www.scie.org.uk/publications/guides/guide09/index.asp

SCIE research briefing

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

Updating the guideline

This guideline will be updated as needed, and information about the progress of any update will be posted on the NICE website (www.nice.org.uk/CG42).

**National Institute for
Health and Clinical Excellence**

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk

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**Social Care Institute
for Excellence**

Goldings House
2 Hay's Lane
London
SE1 2HB

www.scie.org.uk