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Dementia

Definition^[1]

Dementia is a syndrome caused by a number of brain disorders which cause memory loss, decline in some other aspect of cognition, and difficulties with activities of daily living.

The symptoms fall into three groups:

- Cognitive impairment: causing difficulties with memory, language, attention, thinking, orientation, calculation, and problem-solving.
- Psychiatric or behavioural disturbances: changes in personality, emotional control, and social behaviour; depression, agitation, hallucinations, and delusions.
- Difficulties with activities of daily living, such as driving, shopping, eating, and dressing.

Deterioration must represent a progressive decline from a previous higher level of functioning, and consciousness should not be clouded (compare with [acute confusional state or delirium](#)). Memory loss is typically for recent events and long-term memory can be remarkably intact.

Mild cognitive impairment (MCI) is a decline in cognitive function greater than expected, taking account of the subject's age and education, which is not interfering with activities of daily living. This is often clinically a pre-dementia state.

Epidemiology

- According to figures provided by the Alzheimer's Society, there are currently 800,000 people with dementia in the UK. ^[2] There are estimated to be over a million by 2021.
- Prevalence rises with age: ^[1]
 - 1.5% in people aged 65-69 years
 - 2.4% in people aged 70-74 years
 - 6% in people aged 75-79 years
 - 13.3% in people aged 80-84 years
 - 20% in people aged 85-89 years
 - 25%+ in people aged 95 or older
- Overall prevalence is similar in men and women, but Alzheimer's disease is more common in women (67% vs 55%), whereas vascular and mixed dementias are more common in men (31% vs 25%). ^[1]
- 60,000 deaths a year in the UK are directly attributable to dementia, and the financial cost to the UK is estimated to be over £23 billion per year. ^[2]

Aetiology^[1]

Some of the more common causes of dementia are:

- **Alzheimer's disease** (about 50%). Degeneration of the cerebral cortex, with cortical atrophy, neurofibrillary tangles, amyloid plaque formation and reduction in acetylcholine production from affected neurons.
- **Vascular dementia** (about 25%). Brain damage due to cerebrovascular disease: either major stroke, multiple smaller unrecognised strokes (multi-infarct) or chronic changes in smaller vessels (subcortical dementia).
- **Dementia with Lewy bodies (DLB)** (about 15%). Deposition of abnormal protein within neurons in the brain stem and neocortex.

- **Frontotemporal dementia** (less than 5%). Specific degeneration/atrophy of the frontal and temporal lobes of the brain. One type of frontotemporal dementia is Pick's disease, where protein tangles (Pick's bodies) are seen histologically.
- Mixed dementia.
- **Parkinson's disease**.
- Potentially treatable dementias (fewer than 5%):
 - Substance abuse
 - **Hypothyroidism**
 - **Space-occupying intracranial lesions**
 - **Normal pressure hydrocephalus**
 - Syphilis
 - **Vitamin B12 deficiency**
 - **Folate deficiency**
 - Pellagra
- Genetic causes of dementia such as familial autosomal dominant Alzheimer's disease.

Presentation

There are subtle differences in the presentation of different types of dementia. These are covered in detail in their specific articles. Alzheimer's disease tends to have an insidious onset, whereas vascular dementia typically has a series of stepwise increases in symptom severity. DLB may present with fluctuating levels of consciousness, hallucinations, sleep disorders, falls and Parkinsonian features. In Parkinson's disease dementia, the Parkinsonian features predate the dementia by a significant amount of time. In frontotemporal dementia, behavioural changes (such as disinhibition or apathy) and language disturbances are often presenting features. It may be important to determine the type of dementia - in DLB, for example, making this diagnosis will have important implications for treatment (use of neuroleptics is avoided, as motor and mental impairment is worsened and mortality may be increased).^[3] Treatment guidelines vary slightly for some of the different types of dementia.

Dementia presents in contrast to acute confusional state, which is usually of recent onset and may have a reversible cause; the history should go back at least several months and usually several years.

For objective evidence, carry out a test of cognitive functioning (see 'Diagnosis', below).

Diagnosis^[3]

The diagnosis of dementia should only be made after:

- Comprehensive history and physical examination. The key to diagnosis is a good history of progressive impairment of memory and other cognitive functioning (usually requiring the help of a spouse, relative or friend).

Make specific notes on the following:

- Attention and concentration ability.
 - Orientation - time, place, person.
 - Memory - both short- and long-term.
 - Praxis - whether they can get dressed, lay a table, etc.
 - Language function (usually evident during questioning).
 - Executive function - problem-solving, etc.
 - Psychiatric features - depression, anxiety, psychotic symptoms.
- Medication review to exclude a cause which may be contributing to symptoms.
 - A formal screen for cognitive impairment - see separate article **Screening for Cognitive Impairment**. Tools include the Mini Mental State Examination (MMSE), the Six Item Cognitive Impairment Test (6CIT), the General Practitioner Assessment of Cognition (GPCOG) and the 7 Minute Screen (7MS).
 - Other reversible organic causes have been excluded.

NB: it is important to identify **depression** and treat it appropriately. Sometimes it is difficult to distinguish between depression and dementia and depression is quite common in dementia. If in doubt, treat.

Diagnostic criteria for all types of dementia^[4]

There are cognitive or behavioural symptoms which:

- Affect ability to function in normal activities.
- Represent a decline from a previous level of function.
- Cannot be explained by delirium or other major psychiatric disorder.
- Have been established by history-taking from patient and informant, and formal cognitive assessment.
- Involve impairment of at least two of the following domains:
 - Ability to acquire and remember new information
 - Judgement, ability to reason or handle complex tasks
 - Visuospatial ability
 - Language functions
 - Personality and behaviour

Investigations^[1, 3]

- Ensure no treatable cause has been missed, by arranging FBC, ESR or CRP, MSU, U&E, LFT, glucose, Ca^{2+} , TFT, B12 and folate (red cell folate). Don't always believe normal B12s: assays are known often to be inaccurate and methylmalonic acid or homocysteine levels may be more helpful.^[5] If in doubt, one should treat.
- VDRL/TPHA should not be performed routinely - only if risk factors are present.
- Consider blood cultures, CXR and MRI scan, and psychometric testing as appropriate to confirm diagnosis.
- Specialist assessment is required to determine the subtype of dementia. If this cannot be done on clinical grounds, perfusion hexamethylpropyleneamine oxime (HMPAO) single-photon emission computed tomography (SPECT) may be used to distinguish between Alzheimer's disease, vascular dementia and frontotemporal dementia. This is not useful in the presence of Down's syndrome.
- CSF examination may occasionally be helpful if Creutzfeldt-Jakob disease or other forms of rapidly progressive dementia are suspected.^[6]
- Genetic clinical genotype analysis should only be requested where an inherited cause is suspected.

Management: general principles^[3]

- People with dementia benefit from person-centred care. This means not only respecting the person and their carer, and taking account of their perspective and interactions, but tailoring the management to them as an individual.
- People with dementia should not be discriminated against when considering treatment options for other conditions. They should benefit from support appropriate to their needs, and should not be discriminated against in terms of race, language, religion or sexuality.
- Early discussions should take place to allow advance planning. This involves discussion about advance statements or decisions, lasting power of attorney and preferred place of care plans. This is one of the most important reasons for early diagnosis and referral.
- A memory assessment service should act as the single point of referral for all patients with a suspected diagnosis of dementia. 50% of those diagnosed with mild cognitive impairment go on to develop dementia, according to National Institute for Health and Care Excellence (NICE) guidelines; so primary care professionals should consider referring at this stage.
- Valid consent should be sought for treatment, wherever possible. This may mean making information available to them in an appropriate form. The use by patients and carers of advocacy services and voluntary organisations should be encouraged. If patients are not competent to make a decision, the requirements of the [Mental Capacity Act 2005](#) should be followed (see 'Mental capacity to make decisions', below).
- Carers should receive an assessment of needs as required by the Carers and Disabled Children Act 2004 and the Carers (Equal Opportunities) Act 2004. Carers should be offered individual or group psycho-education and psychological therapy, peer-support groups, information in a variety of media, and training courses. Issues such as transport, night-sitting, and respite care should also be considered. See the separate article [Supporting the Family of People with Dementia](#).

- Health and social care managers should take a joint approach to management, and this should include joint written policies and procedures, and joint planning of services which take on board the views of local service users and carers. Care managers and co-ordinators should ensure that a combined care plan, which takes account of the changing needs of the patient and the carers, is reviewed regularly, and receives the endorsement of the patient and carers. Named health and/or social care staff should be assigned to operate the plan.
- Following diagnosis the patient and carers should be given written information about:
 - The symptoms and signs of dementia
 - 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
- Health and social care staff should aim to promote independence where possible, including mobility. Strategies to cope with disabilities should be promoted, such as modifications to the living environment and simplification of daily activities.
- Young people with dementia and those with learning disabilities have special needs, and require specialist advice and focused support.

NICE Quality Statements

NICE has produced Quality Standards for dementia, and supporting people to live well with dementia.^[7, 8] These link into the NICE pathway on dementia, and provide a number of quality statements, advising on principles of care and good standards of care.

Mental capacity to make decisions

If the patient does not have capacity to make decisions, the Department of Health guidance should all be followed.^[9] The Mental Capacity Act 2005 has the following principles:

- Adults must be assumed to have capacity to make decisions about their care unless proved otherwise.
- Individuals should be given all available support to help them come to a decision.
- Individuals should retain the right to make what others might consider eccentric or unwise decisions.
- Anything done on behalf of an individual without capacity must be in that person's best interests.
- The rights and basic freedoms of an individual without capacity should be restricted as little as possible.
- With the patient's consent, relatives and carers should be involved in management decisions. Relatives and carers should also have their own needs assessed.

Driving

People who have been diagnosed with dementia are legally obliged to inform the Driver and Vehicle Licensing Agency (DVLA). For HGV or passenger carrying vehicles, a licence would be revoked at this point, but some people may be able to continue driving an ordinary car, subject to medical reports or assessment, and annual review.

Management: non-pharmacological^[3]

Non-pharmacological interventions should be tailored to the individual person's preferences and abilities as well as to local resources, and adapted depending on response. These include:

- Cognitive stimulation programmes
- Multisensory stimulation
- Music therapy
- Art therapy
- Dancing
- Massage
- Aromatherapy
- Structured exercise programmes

- Animal-assisted therapy

Community and hospital care

Patients should be cared for in the community as much as possible. However, if they become severely disturbed and need to be contained for their own safety or the safety of others, inpatient care should be considered (this might include those liable to be detained under the [Mental Health Act 1983](#)). Inpatient admission would also be justified for patients with complex physical and psychiatric problems who could not be properly assessed in the community.

Non-pharmacological management of behaviour that challenges^[3, 7]

People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, should have an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan. Factors which may exacerbate violent or aggressive behaviour, or increase the risk of harm to self or others include:

- Overcrowding
- Lack of privacy
- Boredom or lack of activity
- Poor communication
- Conflict
- Weak clinical leadership in care home settings

Staff should identify, monitor and address factors such as these, and be trained in managing aggression or agitation.

Management: pharmacological treatment of dementia^[3]

Acetylcholinesterase (AChE) inhibitors

In 2011, NICE reviewed its guidance on the use of these drugs (donepezil, galantamine or rivastigmine) in mild and moderate Alzheimer's disease, and updated the 2006 dementia guidance in the relevant sections to incorporate it.^[10] This brought it in line with the Scottish Intercollegiate Guidelines Network (SIGN).^[6]

- AChE inhibitor treatment (donepezil, galantamine or rivastigmine) should be considered in patients with mild or moderate Alzheimer's disease. It should only be started by dementia specialists (psychiatrists, neurologists, and physicians specialising in the care of older people), after appropriate discussion with family and carers. These drugs have cholinergic side-effects and should be started at a low dose, and then be titrated according to response.
- The drug with the lowest cost should be used as first choice. They should not be prescribed for mild cognitive impairment.
- It should be continued for only as long as it is having a worthwhile effect on cognitive, global, functional or behavioural symptoms.
- Patients on treatment should be reviewed regularly by an appropriate specialist team, or by shared care with GPs where such an agreement exists. This should include cognitive, global, functional and behavioural assessments and discussion with carers.
- The MMSE should be part of a full assessment of a patient, including quality of life changes and social interaction. Clinicians should be free to treat patients after this assessment, and should not be precluded from doing so on the basis of the MMSE score. The MMSE is not sensitive enough to differentiate between patients who would benefit from treatment and those who would not, and was not designed for this use.
- Evidence from clinical studies and Cochrane reviews suggests that there is benefit from AChE inhibitors in mild-to-moderate Alzheimer's disease, but that the benefits are small.^[11, 12] There is some evidence that continuing use in moderate-to-severe disease confers some benefit.^[13]
- AChE inhibitors should not be prescribed for non-Alzheimer's dementia according to NICE guidelines.
- The latest Cochrane review suggests there is some evidence to support the use of AChE inhibitors for Parkinson's disease dementia, but this is not yet clear for DLB.^[14]

N-methyl-D-aspartate (NMDA) antagonists

Memantine (an NMDA antagonist) is recommended by NICE as a second-line option for managing patients with moderate Alzheimer's disease where AChE inhibitors are not tolerated or are contra-indicated, or in the treatment of severe Alzheimer's disease. It is not recommended for non-Alzheimer's dementia.

Pharmacological treatment of associated non-cognitive problems

- Where antidepressants are needed, avoid tricyclic antidepressants and other anticholinergics, as they may have an adverse effect on cognition.
- Antipsychotics should be avoided where possible in Alzheimer's disease, vascular dementia or mixed dementias. Where needed for psychotic features or agitation:
 - Discuss the risks (sedation, risk of stroke, worsening cognition) and consider other cerebrovascular risk factors
 - Ideally treat under specialist advice
 - Monitor effects regularly
 - Use the lowest possible dose and titrate up slowly where necessary
 - Treatment should be time-limited
 - Consider risperidone as first choice.^[1]
- In those with Parkinson's dementia or DLB, antipsychotics are more likely to cause severe sensitivity reactions, and should be avoided where possible.
- Occasionally aggression, violence or agitation pose a threat to safety, and where non-pharmacological measures have failed, benzodiazepines or antipsychotics may be required urgently.
 - Oral medication should be used where possible; intramuscular (IM) route is safer than intravenous (IV) where it is not possible.
 - Lorazepam, haloperidol or olanzapine should be used where IM administration is required. IM diazepam and chlorpromazine are not recommended.
 - Effects should be closely monitored.

Management: palliative and end-of-life care

Physical, psychological, social and spiritual support should be offered, and dementia patients should have the same access to palliative care services as any other patient. Oral nutrition should be encouraged for as long as possible. Percutaneous endoscopic gastrostomy (PEG) feeding may be appropriate in patients with transient dysphagia but is not recommended in patients with severe dementia, as there is no evidence of increased survival or reduced complications.^[15, 16, 17] Decisions to withhold nutritional support should be taken within a legal and ethical framework.^[18] Fever may be managed with antipyretics and mechanical cooling. Palliative antibiotics should be given after an individual assessment of the patient. Resuscitation is unlikely to succeed in patients with severe dementia. If no advanced decision has been taken by the patient, the decision to resuscitate should take into account the views of the carers and the multidisciplinary team, the Resuscitation Council UK's guidance, and the Mental Capacity Act 2005.^[19] The decisions should be recorded in the notes and care plan.

Screening and prevention

Patients and relatives with a suspected genetic cause for dementia should be offered genetic counselling by the regional genetic services.

The focus for prevention should be the modification of behaviour in middle-aged and older people (reducing smoking, alcohol consumption, and obesity, and treating other cerebrovascular disease risk factors such as hypertension and hypercholesterolaemia).^[3]

Prognosis

The outlook for most types of dementia is poor. Dementia usually continues to worsen over time. The condition usually progresses over years until the person's death.

Further reading & references

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 - [Mental wellbeing and older people - guidance for occupational therapy and physical activity interventions to promote the mental wellbeing of older people in primary care and residential care](#); NICE Public Health Intervention Guidance (October 2008)
 - [Mental wellbeing of older people in care homes](#); NICE Quality Standard (Dec 2013)
 - [The dementia guide: Planning ahead](#); Alzheimer's Society
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 18. [Nutritional Advice in Common Clinical Situations](#); British Geriatrics Society, 2009
 19. [Do Not Attempt CPR \(DNACPR\)](#); Resuscitation Council (UK)

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