

## Dementia

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Dementia is a clinical syndrome characterised by a cluster of symptoms and signs manifested by difficulties in memory, disturbances in language, psychological and psychiatric changes, and impairments in activities of daily living. Alzheimer's disease is a specific disease entity and is the commonest cause of dementia. In this, the first of two articles, we will review the clinical and service implications of dementia syndrome; the second will concentrate on Alzheimer's disease.

### What is the burden of disease?

About 12 million people worldwide have dementia, and this total is likely to increase to 25 million by 2040.<sup>1</sup> The *Dementia UK* report<sup>2</sup> estimated that about 637 000 people in the UK have dementia syndrome and the annual cost of their care is £17bn (€18.7bn; \$24.7bn), which is more than heart disease (£4bn), stroke (£3bn), and cancer (£2bn). Annual costs per patient have been estimated at \$57 000 in the United States and \$64 000 in Italy (including estimates for informal care) and \$24 000 in Sweden and \$14 000 in Canada (excluding informal care).<sup>w1</sup> Dementia is one of the main causes of disability in later life; in terms of global burden of disease, it contributes 11.2% of all years lived with disability—higher than stroke (9.5%), musculoskeletal disorders (8.9%), heart disease (5%), and cancer (2.4%).<sup>w2</sup> The scale of the problem of dementia, and the under-response to it that is evident world wide, has prompted governments to review their policies. One example of the political pressure facing industrial societies can be seen in the arguments of the UK's Alzheimer's Society (box 1), which has been influential in developing the dementia strategy for England.

### What are the barriers to making a diagnosis early?

The benefits of early investigation and diagnosis include identification of treatable physical and

### Box 1 Seven recommendations from the *Dementia UK* report<sup>2</sup>

- Make dementia a national priority
- Increase funding for dementia research
- Improve skills in dementia care
- Develop community support
- Guarantee support packages for carers
- Hold a national debate on who pays for care
- Develop comprehensive dementia care models

psychiatric causes, treatment of comorbid conditions, initiation of psychosocial support, and instigation of pharmacological symptomatic treatments. However, early recognition is not easy because of the insidious and variable onset of the syndrome, which emerges through the personality of the individual, sometimes without a clear demarcation until late in the disease process. Patients, families, and general practitioners may all be reluctant to diagnose dementia because it is such a serious and largely unmodifiable disease that still carries a huge burden of stigma. Physicians may unconsciously hesitate to label a patient as such,<sup>3</sup> and family members may gradually take over social roles from the patient, protecting him or her from difficulties in daily life, but also delaying the conscious recognition of the disorder by offsetting impairments.<sup>4</sup>

### How can clinicians recognise dementia?

Recognition of an emerging dementia syndrome depends on the triad of patient report, informant history, and assessment of cognitive function.

Awareness that memory problems in old age, particularly when deteriorating and interfering with daily activities, may be the harbinger of dementia is the most important factor in recognition. The most commonly used cognitive assessment tool is the mini-mental state examination,<sup>5</sup> which is scored out of 30: a score of <24 suggests dementia. However, performance requires intact language and is dependent on educational attainment and cultural background. It can take up to 20 minutes to complete and so may be practical for use only in secondary care. The general practitioner assessment of cognition test,<sup>6</sup> and two other cognitive screening tests (the mini-cog

### SOURCES AND SELECTION CRITERIA

We searched Medline and Pubmed from 2006 to September 2008, previous work having been summarised in the joint dementia guideline published by NICE and the Social Care Institute for Excellence in 2006. We searched the Cochrane database (2008 version) for randomised controlled trials for drug treatment and psychosocial interventions and used our own knowledge of the literature and selected authoritative reviews to supplement these sources.

**Box 2 The six item cognitive impairment test\***

**Six questions**

- What year is it?
- What month is it?
- Give the patient an address phrase to remember with five components (such as John, Smith, 42, High Street, Bedford)
- About what time is it (within one hour)
- Count backwards from 20-1
- Say the months of the year in reverse

**Repetition**

- Ask the patient to repeat the address phrase requested earlier

\*See Brooke et al<sup>6</sup> for the scoring system

assessment instrument<sup>w3</sup> and the memory impairment screen<sup>w4</sup>) are as clinically and psychometrically robust as and more appropriate for use in primary care than the mini-mental state examination.<sup>7</sup> The six item cognitive impairment test (box 2) was designed for use in general practice and produces more reliable results than the mini-mental state examination.<sup>8</sup>

**How is dementia usually diagnosed?**

Current UK guidance recommends that the general practitioner perform some routine investigations (standard blood screening and possibly chest radiography if the patient has a history of chest disease and

electrocardiography if heart disease is suspected) before referring the patient for a specialist secondary care assessment, preferably by an old age psychiatrist.<sup>9</sup> The second step comprises the exclusion of potentially reversible conditions (such as normal pressure hydrocephalus) and the confirmation of the dementia pathology via detailed neurocognitive assessment and, if available, computed tomography. This allows the subtyping of dementia that is important for prognosis and treatment, particularly given that some physicians are reluctant to diagnose Alzheimer's disease, the only one of the dementias in which symptom modification with drug treatment is possible. Box 3 summarises the investigations that should be considered.

The diagnostic process may be iterative and extended.<sup>w5</sup> From first symptom to presentation to the general practitioner takes about 18 months, with a similar time to diagnosis thereafter. This time period can be shortened by using a structured educational intervention based on adult learning principles and conducted as a workshop in general practice. This educational package can improve diagnostic rates of dementia syndromes, as can decision support software designed to help diagnostic and management thinking.<sup>10</sup> The curriculum for the educational intervention has been distributed as an electronic tutorial on CD to all practices in England by the Alzheimer's Society, and the decision support software has been incorporated into the EMIS clinical software system for general practice.

**How can clinicians distinguish dementia and depression?**

To diagnose someone with dementia when in fact they are depressed is traditionally taught as one of the great errors of clinical practice. This rule was based largely on the fact that depression is potentially treatable and dementia largely untreatable. What is now known is that the comorbidity of depressive dementia symptoms is high. People with dementia syndrome have high rates of depression and people with depression often have prominent complaints of memory loss, neuropsychological deficits, and often organic brain changes.

In addition, the fear of triggering a depressive response, denial, or withdrawal from contact with services is one factor that inhibits practitioners from discussing dementia as a diagnosis.<sup>11</sup> As treatments for specific causes of dementia emerge, the traditional dichotomy of a treatable versus a non-treatable condition is less relevant to clinical practice, but nevertheless awareness of the overlap between these disorders is clinically important because clinical trials have shown that antidepressant treatment can be beneficial.<sup>9</sup>

**Why is it important to determine the cause of dementia?**

Box 4 outlines the different causes (sometimes referred to as subtyping) of dementia syndrome. The causes are important because different types of dementia can have different courses, with different patterns of symptoms, and can respond differently to treatment. For example, the symptoms of Alzheimer's disease can be modified

**Box 3 Investigations for dementia\***

**In primary care**

- Blood tests: full blood count, erythrocyte sedimentation rate, urea and electrolytes, thyroid function tests (to detect comorbid conditions such as anaemia resulting from vitamin B-12 deficiency or renal disease and to exclude reversible causes such as hypothyroidism).
- Syphilis serology is not recommended as a routine test but can be justified if the apparent course of the syndrome or the presentation is atypical.

**In secondary care**

- Computed tomography (to exclude intracranial lesions; cerebral infarction and haemorrhage; extradural and subdural haematomas; normal pressure hydrocephalus)
- Magnetic resonance imaging (sensitive indicator of cerebrovascular disease, higher resolution to detect focal atrophy—for example, in hippocampal area)
- Single photon emission tomography (to assess regional blood flow and dopamine scan to detect Lewy body disease)
- Carotid ultrasonography (if large vessel atherosclerosis is suspected)
- Electroencephalography is not part of routine investigations but can be useful if epilepsy or an encephalopathy is suspected

**General medical investigations**

- Chest radiography
- Mid-stream specimen urine if clinical symptoms indicate
- Lumbar puncture (but not to be carried out routinely)
- Electrocardiography (especially if treatment with a cholinesterase drug is being considered)

\*Informed by the guideline of the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence<sup>7</sup>

**Box 4 Causes of dementia**

- Alzheimer's disease (about 50% of cases)
- Vascular dementia (about 25%)
- Mixed Alzheimer's disease and vascular dementia (included in the above, 25%)
- Lewy body dementia (15%)
- All others (about 5% combined) including frontotemporal dementia, focal dementias (such as progressive aphasia), subcortical dementias (such as Parkinson's disease dementia), and secondary causes of dementia syndrome (such as intracranial lesions)

with cholinesterase inhibitors (discussed in detail in our second article). Lewy body dementia differs from the other types because of the dominance of motor symptoms (like Parkinson's disease) and the salience of visual hallucinations. People with Lewy body dementia who take antipsychotic drugs may have adverse effects.<sup>9</sup> The identification of vascular disease means that comorbidities can be treated.

It is important to differentiate between different types of dementia because patients (and with their permission their carers) have the right to a definitive diagnosis (for example, saying someone has jaundice is not a diagnosis in itself) and specific treatments are available for Alzheimer's disease. None the less, the different subtypes have much in common, and there are some generic approaches to dementia that should inform clinical practice.

**What is the evidence for managing patients with dementia?**

The most comprehensive review of the evidence for different approaches to long term care for people with dementia was carried out jointly by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence in 2006.<sup>9</sup> This review identified key priorities for service development and the implementation of the guidelines (box 5).

**Box 5 Key priorities for implementation of the guideline on dementia produced jointly by NICE and the Social Care Institute for Excellence<sup>9</sup>**

- Memory services need further development
- Structural imaging is essential for diagnosis
- No discrimination should exist in provision of medical and surgical services for people with dementia
- Capacity to make decisions must be assessed according to the rules of the Mental Capacity Act 2005
- Carers' needs must be recognised and met
- Coordination and integration of health and social care are likely to improve the quality of life of people with dementia
- Challenging behaviour can be managed without necessarily using drug treatment
- Training for professionals should have high priority
- The needs of people with dementia in acute hospitals requires attention

**How can clinicians judge mental capacity?**

The Mental Capacity Act 2005<sup>12</sup> is complex, and all those working with older people need to be aware of its principles, which include the following propositions:

- Adults are assumed to have capacity unless proved otherwise
- Individuals must be given all available support before concluding that they cannot make decisions for themselves
- People must retain the right to make what may be seen as eccentric and unwise decisions
- Anything done for a person without capacity must be in their best interests and should restrict their rights and basic freedoms as little as possible.

Doctors are increasingly being asked to assess capacity in people with cognitive impairment. The medical assessment is based on a person's ability to understand what is being asked, retain the information long enough to make a judgment, and be able to express that judgment. The important issues of capacity are that they may vary over time and are specific to a decision—for example, giving consent to a medical procedure, to a move to a nursing home, or to making a will.

**What psychosocial interventions are helpful in dementia?**

Cognitive behavioural therapy in patients with mild to moderate dementia seems useful for overcoming "catastrophic thinking" (experiencing all adversity as a disaster) and depressive withdrawal.<sup>13</sup> "Cognitive reframing" (see box 6) can play a role in developing positive coping strategies in carers and may be more effective than problem solving approaches or support group interventions for carers.<sup>16</sup> Case studies of cognitive behavioural therapy involving people with dementia<sup>14</sup> have shown how a person centred approach can help to alleviate fears of other people "finding out" the diagnosis, to reduce rapid deterioration in abilities, to avoid socially embarrassing behaviour, and to avoid losing any influence over care planning. The techniques used include combinations of reality orientation, memory strategies, and reframing (box 6). Psychotherapeutic approaches to dementia are successful.<sup>15</sup>

**Box 6 Psychosocial interventions**

- Reality orientation focuses on the likely slow progression in early dementia and offsets "catastrophic" fears that may be triggered by mild memory lapses
- Memory enhancement strategies include setting shorter term goals and maintaining a social circle and useful family roles that reinforce memory
- Reframing dementia means presenting dementia to the patient as a disability that can be accommodated and emphasising the persistent abilities

**Box 7 Drug treatments (daily doses) for behavioural problems in dementia**

**For mild agitation**

- Trazodone 50-300 mg
- Benzodiazepines, such as lorazepam 0.5-4 mg
- Clomethiazole up to three capsules (5-15 ml liquid)
- Selective serotonin reuptake inhibitors, such as citalopram 10-20 mg, sertraline 50-100 mg
- Also consider sodium valproate 250 mg to 1 g, carbamazepine (50-300 mg), cholinesterase inhibitors (particularly rivastigmine 1.5-6 mg in Lewy body dementia), promazine 25-100 mg

**For severe agitation or if psychosis is present**

- Quetiapine 25-200 mg
- Risperidone 0.5-2 mg
- Olanzapine 2.5-10 mg
- Aripiprazole 5-15 mg

**If depressive symptoms are present**

- Selective serotonin reuptake inhibitors such as citalopram 10-20 mg, sertraline 50-100 mg
- Mirtazapine 15-45 mg

**If severe behavioural problems are present**

- Consider haloperidol in small doses (0.5-4 mg) and time limited

**What information do people with dementia and their families need?**

For people with newly diagnosed dementia and members of their family accurate information about local support should be available in primary and secondary care, social care, and voluntary and community settings.<sup>16</sup> Information for patients with dementia is most useful if people with dementia have been involved in its compilation and presentation, and examples of good practice should be adapted for local circumstances and services.<sup>17,7</sup> Family members may have concerns that differ from those anticipated by clinicians and so should have access to information and advice from sources that are able to resolve these differences.<sup>18</sup>

**How should carers be supported?**

Carers of people with dementia are more likely to experience depressed mood, report a higher burden, and have worse general health than carers of patients

with other chronic diseases,<sup>6,19</sup> but some evidence also exists that carers feel reluctant to ask for professional help.<sup>18 w8</sup> Depressed mood in the carer is one of the factors that determine transfer of the person with dementia to residential care.<sup>3</sup>

The experience of burden is related to the type of coping strategies used by the carer, the experience of loneliness, and the lack of accessible support rather than to “objective” measures of tasks and responsibilities.<sup>w9</sup> Supporting positive coping strategies and promoting problem solving behaviour seem effective in reducing depression,<sup>20</sup> but interventions for people with dementia living at home do not reduce perceived burden.<sup>21</sup>

**How should behavioural and psychological symptoms in dementia be managed?**

Non-cognitive symptoms (also called “behavioural and psychological symptoms in dementia” or “challenging behaviour”) are particularly distressing for families. Non-cognitive symptoms encompass a range of symptoms from agitation and pacing around through to wandering and getting lost, and up to 90% of people with dementia will experience such symptoms to some degree at some time, particularly in the middle and later stages of the illness.<sup>22</sup> While the risks of the behaviours may not be high, they can lead to high levels of stress in carers and may be one of the crucial factors leading to care home admission.<sup>23</sup>

Little high quality evidence exists for the clinical and cost effectiveness of non-drug treatments,<sup>22</sup> although research findings are starting to show the potential of exercise, aromatherapy, and behavioural interventions such as the ABC (antecedents, behaviour, consequences) approach.<sup>9</sup> Management of non-cognitive symptoms in dementia requires a thorough clinical assessment to exclude treatable causes such as infection or pain. Non-drug approaches should be used where possible and specialist advice sought. In the current situation of limited resources it is all too easy to

**TIPS FOR NON-SPECIALIST**

- Occasional lapses of memory are common, especially in the presence of physical illness or stress—if in doubt, offer to see someone again in three months
- If you ask a patient a simple question and they immediately turn their head to the spouse, suspect dementia
- If you suspect dementia, take a history from an informant
- Have a low threshold for referring someone to a memory clinic if you suspect he or she may have dementia
- Always consider dementia when seeing a patient, especially an older patient, who complains of memory problems
- Generally, memory problems developing over days are due to vascular disease, over weeks are due to depression, and over months are due to dementia

**Box 8 Current priorities in dementia\***

- Raise the national profile of dementia (both in professionals and the public)
- Gain wider acceptance of the need for early diagnosis and investigation
- Improve care for people with dementia in general hospitals (for example, by raising awareness among medical and nursing staff)
- Improve care for people with dementia in institutional settings (such as in the management of behavioural problems)
- Focus on the benefits of non-drug interventions (alone and in combination with drug treatment)
- Develop a research agenda to investigate the potential for preventive strategies

\*Based on the Department of Health’s proposed national dementia strategy<sup>24</sup>; the joint guideline from NICE and the Social Care Institute for Excellence<sup>25</sup>; and the Dementia UK report<sup>26</sup>

## SUMMARY POINTS

Dementia is a global health and social care crisis

In the United Kingdom 700 000 people have dementia, and the annual cost of care is £17bn a year; these values are set to rise

People with mild cognitive impairment are up to 15 times more likely to develop Alzheimer's disease than those with normal cognition

Complaints of memory loss often indicate the presence of depression

Trazodone, clomethiazole, and selective serotonin reuptake inhibitors are suitable alternatives to antipsychotic drugs in people with dementia who are agitated

Interventions by carers can be as powerful as drug treatment in terms of outcome

Apathy and withdrawal in people with dementia can be as distressing to carers as agitation and aggression

prescribe drug treatment for such symptoms, and 20-50% of people with dementia in institutional care receive antipsychotic drugs,<sup>24</sup> despite widespread concerns over the hazards of these drugs in people with dementia.<sup>25</sup> Box 7 outlines potential alternative drugs.

## Conclusion

The ageing of populations in industrialised and developing countries makes dementia syndrome everybody's business. It requires all practitioners working with older patients to understand the insidious onset, main features, and impact of dementia and to be aware of the range of responses available. Box 8 outlines a wider agenda for professional and service development that is likely to have an impact on most primary and secondary care clinicians.

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## ADDITIONAL EDUCATIONAL RESOURCES

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