

# Practice *Nursing*

PROMOTING EXCELLENCE IN EDUCATION AND CLINICAL PRACTICE

## Better recognition of dementia

A guide for general practice

# PracticeNursing

PROMOTING EXCELLENCE IN EDUCATION AND CLINICAL PRACTICE

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## The Authors

**Helen Dickens** is Communications Manager, Alzheimer's Society, Devon House, 58 St Katharine's Way, London E1W 1JX

**David Jolley** is Honorary Reader in Old Age Psychiatry (PSSRU), University of Manchester

**Bernadette McGuinness** is Beeson Scholar, Ireland, Queen's University Belfast

**Chris O'Connor** is Head of Nursing Practice and Development, Springfield University Hospital, London

**Peter Passmore** is Professor of Ageing and Geriatric Medicine, Queen's University Belfast, Northern Ireland

**Louise Robinson** is GP/Clinical Senior Lecturer, Institute of Health and Society, Newcastle University, 21 Claremont Place, Newcastle upon Tyne NE2 4AA

**Stephen Todd** is Beeson Scholar Ireland, Queen's University Belfast

**David Wilson** is Northern Ireland Clinician Scientist in Stroke, Queen's University Belfast

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Dementia is characterised by a loss of core abilities, complicated by abnormalities of mood, perception and behaviour. The epidemiology and pathophysiology of dementia are explained with specific attention paid to the risk factors, its increasing prevalence, and the disease trajectory.

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**Louise Robinson**

The early signs and symptoms of dementia are sometimes overlooked, ignored, misunderstood or misdiagnosed. The key signs and symptoms are highlighted and some of the key assessments used in diagnosis explained. Recommendations are made for improving the diagnosis of dementia in primary care.

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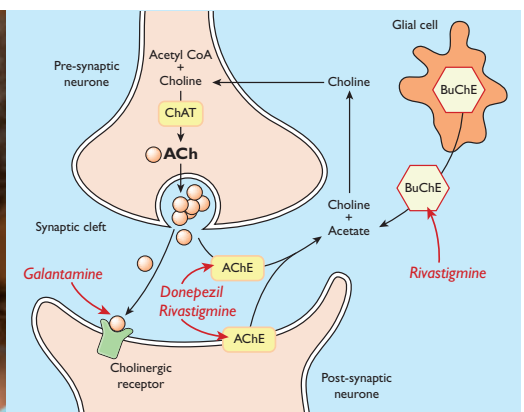
**Bernadette McGuinness, David Wilson, Stephen Todd and Peter Passmore**

The authors provide an introduction to the use of acetylcholinesterase inhibitors in Alzheimer's disease. They look at the potential benefits and limitations of the drugs, highlight the importance of regular review, and provide guidance on maximising the benefits of treatment and deciding when to discontinue or switch medications.

## S15 Better understanding makes diagnosis faster

**Helen Dickens**

It is important that people seek help and advice from a health professional if they have concerns about their memory. The aims of Alzheimer's Society's public awareness campaign, 'Worried about your memory?' are outlined and its impact considered.



# A glimmer of hope

**D**ementia has been making headline news this year. The Department of Health launched its National Dementia Strategy in February (2009); newsreader John Suchet spoke about his experiences of caring for his wife who has been diagnosed with dementia in her early 60s; and author Terry Pratchett explored his own dementia in a BBC documentary. Like many of my colleagues who have worked with underresourced services for people with dementia, I have read and watched with interest media reports of ‘our dementia crisis’, as though this is something that has just been discovered.

Many of those who have been working with patients with dementia across the health economy, from general practice to specialist services have said and felt the same thing: we lack the resources to provide adequate and appropriate care. When a group of senior nurses and I from across the southwest London area put together a guide to dementia and challenging behaviour (entitled *Not Mad Not Bad: A Guide to Dementia and Challenging Behaviour*), it became apparent that patients with dementia had an impact on all our services (O’Connor et al, 2006). We also found that staff were desperate for information, advice and guidance, and wanted to develop a better understanding of why people with dementia behaved in the ways they did.

The National Dementia Strategy is a 5-year plan, backed by £150 million for the first 2 years, which aims to improve public and professional understanding of dementia. It would appear that the government has woken up to the fact that 700 000 people in the UK have a diagnosis of dementia. This is predicted to rise to almost 1 million by 2025.

The strategy has 17 key objectives (*Box 1*) which include key reforms for care homes, where about two thirds of residents have dementia. As part of the strategy, each home will appoint a senior staff member to lead improvements in the quality of dementia care, while best-practice guidance will be issued to staff.

Another key strand of the strategy will be a national campaign to tackle stigma—the word ‘dementia’ alone conjures up negative images in people’s minds. Patients often talk about their sense of shame or guilt, as if they should or could have done something to prevent it. A patient I worked with referred jokingly to his ‘memoryitis’ as he felt that sounded less frightening. As Alan Johnson said before the launch of the strategy, ‘It’s a bit like

cancer was 20 years ago. It wasn’t the subject of polite conversation.’ The hope is that raising public and professional understanding of dementia will lead to people feeling more comfortable to talk about it and seek help and treatment earlier.

There has been some criticism of this strategy for failing to deliver on two important issues: first, research into the causes and potential treatments of dementia; and second, the use of psychiatric medication in care homes.

For many, however, the launch of this strategy injects a sense of hope and gives a clear focus for development in all care settings. Dementia is going to continue to affect increasing numbers of people for the foreseeable future, and for the staff, carers and people with dementia, this strategy is a real glimmer of hope that things will improve in the long term.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. 3 February. The Stationery Office  
O’Connor C, Isenman M, Hadland S (2006) People with dementia: Not mad and not bad. *Practice Nursing* 17(7): 324–7

*‘Patients often talk about their sense of shame or guilt, as if they should or could have done something to prevent it’*

**Chris O’Connor** is Head of Nursing Practice and Development, South West London & St Georges Mental Health Trust, London

## Box 1. Dementia strategy objectives

- 1 Improve public and professional understanding of dementia, and address stigma to encourage timely diagnosis and care
- 2 Provide earlier, more rapid diagnosis through better access to specialist assessment and ongoing care and support; memory clinics may form the core of new diagnostic services
- 3 Improve information available to those with dementia and their carers at diagnosis and throughout the course of care
- 4 Appoint a dementia adviser to facilitate easy access to appropriate care, support and advice
- 5 Develop structured peer support and learning networks for people with dementia and their carers, and enable people to take an active role in service development
- 6 Provide accessible, flexible and reliable services that are responsive to personal needs and preferences to support people with dementia living at home and their carers
- 7 Implement the Carers’ Strategy so that carers, particularly young carers, have access to assessment of their needs and can be supported through an agreed plan, including good-quality, personalised breaks
- 8 Improve the quality of care for people with dementia in general hospitals
- 9 Improve the intermediate care available for people with dementia
- 10 Consider the potential for housing-related services, assistive technology and telecare
- 11 Improve the quality of care for people with dementia living in care homes including the commissioning of specialist in-reach services from community mental health teams, and inspection
- 12 Improve end-of-life care by involving people with dementia and their carers in care planning according to the aims of the End of Life Care Strategy
- 13 Improve basic training in dementia and continuous professional development for health and social care professionals
- 14 Establish commissioning and planning mechanisms to determine service needs
- 15 Improve assessment and regulation of health and social care services
- 16 Provide evidence on the existing research base on dementia in the UK and identify gaps that need to be filled
- 17 Provide effective national and regional support for implementation of the strategy

From: Department of Health, 2009.

# The epidemiology of dementia

**David Jolley** explains that dementia is a syndrome characterised by a loss of core abilities, often complicated by abnormalities of mood, perception and behaviour. He defines the different forms of dementia, provides an overview of its epidemiology, pathophysiology, risk factors and increasing prevalence, and explains the disease trajectory

**David Jolley** is Consultant Old Age Psychiatrist, Pennine Care NHS Foundation Trust, Tameside General Hospital, Ashton under Lyne OL6 9RW and Honorary Reader Manchester University, Personal Social Services Research Unit, Dover Street, M13 9PL

**D**ementia is a clinical concept characterised by loss of core abilities and often complicated by the presence of additional abnormalities of mood, perception and behaviour. The primary losses are described by Lishman (1978) as: 'a syndrome characterised by acquired global impairment of intellect, memory and personality without impairment of consciousness'. Most 'cases' of dementia arise in older people and some aspects of intellect, memory and even personality become altered when people enter their seventh and subsequent decades.

Symptoms of anxiety or depression may accompany loss of health, vigour and abilities.

Neither the normal changes of ageing, nor the symptoms of depression constitute evidence of dementia. But they must be acknowledged and considered within the spectrum of differential diagnosis alongside symptomatic confusional states, hearing impairment, learning disability or other long-standing mental disorders.

The clinical syndrome of dementia may be symptomatic of an underlying body or brain disorder such as anaemia, vitamin deficiency, endocrine abnormality or pressure from a tumour or other intracranial lesion. Sometimes it is due to chronic

toxicity from a prescribed or self-administered medicine. Thus careful assessment and investigation are essential once the possibility of dementia is being considered (Royal College of Psychiatrists, 2005).

## Who, when, where, why?

Dementia is a rare condition when looking at the population as a whole—it affects only 1 in 100 people. It becomes progressively more common in old age (*Table 1*). A further 15 000 people in the UK have dementia under the age of 65 years; two thirds of these are aged 55–64 years.

The Dementia UK study (Knapp and Prince, 2007) estimated that there were 683 597 people with dementia in the UK in 2006. This number will increase progressively over the next 45 years (*Table 2*). An even more spectacular increase is predicted for the wider world (Ferri et al, 2005).

Most of this increase will be in people aged 75 years and over, because more people are expected to survive to an age when the incidence and prevalence of dementia are greatest. Prevalence rises progressively from 1.3% in those aged 65–69 years, 5.9% between the ages of 75–79 years, 20.3% between the ages of 85–89 years, and to over 30% in those over the age of 95 years. Age is therefore an important determinant in an individual's chances of having dementia.

Genetic inheritance is another (Saunders et al, 1993), although its main influence is in dementia of early onset. These are factors which do not offer opportunity for prevention.

But risk factors for vascular disease in middle age—e.g. hypertension, diabetes, smoking, obesity and hyperlipidaemia—are all associated with the subsequent incidence of dementia, of both Alzheimer's and vascular type (Kivipelto et al, 2001). This seems to offer clues to a framework for early detection and possibly prevention. So does the relationship with head trauma (Mortimer et al, 1991) and excessive use of alcohol and other psychoactive substances (Oslin et al, 1998). It seems likely that stress or trauma of any sort predisposes a brain to the development of dementia and increases its rate of progression.

**Table 1. UK population with dementia by age and sex, 2005**

Age (years)	Male	Female	Total
65–69	19 593	14 058	33 651
70–74	33 599	30 096	63 695
75–79	42 795	72 026	114 821
80–84	57 573	121 682	179 255
85–89	42 796	117 624	160 420
90–94	21 586	67 942	89 528
≥95	4 983	22 213	27 196
Total	222 925	445 641	668 566

From: Knapp and Prince, 2007

## Changes in the brain and body

The common forms of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia and fronto-temporal dementia (Burns et al, 2005a).

### *Alzheimer's disease*

Many of the brain changes found in Alzheimer's disease are seen at postmortem in the brains of normal old people. In Alzheimer's they are more marked and more widespread (Mann et al, 1985). The brain shrinks; it weighs less and takes up less space. These changes were evident to Alois Alzheimer when investigating the brain of August D over 100 years ago (Maurer et al, 2006), as were characteristic intra-neuronal tangles and extra-neuronal plaques which stain with silver. August D was a woman in her forties when she developed the degenerative disease which is now recognised as a worldwide epidemic.

Early-onset Alzheimer's was deemed an interesting but rare disorder, awful for the patient and his/her family, but of limited global importance. But it has become apparent that these neuro-pathological characteristics are shared by the much more common disorder, previously accepted as an inevitable consequence of great age: 'senility' or 'senile dementia'.

The first changes in the brain of a person developing Alzheimer's occur in the cells of the hippocampus. Imaging shows the hippocampus to be shrunken and atrophied, its cells cluttered with plaques and tangles (Figure 1). The pathology spreads to include the cerebral cortex, particularly associated areas of the parietal lobes. The cortex becomes thinned and the convolutions of the cerebral gyri more deeply ridged.

Argyrophilic plaques and tangles include amyloid deposits: recent studies suggest that the production of aberrant proteins, which form this amyloid, is the basic error which underpins all subsequent pathological change (Esiri and Morris, 1997). Clinico-pathological studies in the 1960s demonstrated a quantitative relationship between the severity of cognitive impairment in the last weeks of life and the number and concentration of argyrophilic plaques identified at postmortem (Blessed et al, 1968). Advances in neurochemical techniques demonstrated loss of neuro-transmitters, particularly acetylcholine, in Alzheimer's disease (Perry et al, 1978). There are changes in blood vessels in Alzheimer's disease and it seems probable that an absolute differentiation between Alzheimer's and vascular dementia will prove naïve (Burns et al, 2005b). Dementia of mixed (Alzheimer and vascular) aetiology is recognised.

There may be abnormalities of function of the neuroglia which support neurones within the central nervous system themselves (Itagakai et al, 1989).

Brain scanning now allows the demonstration of structural changes that differ depending on the type of dementia; they can contribute to the differential diagnosis (Frisoni, 2001).

**Table 2. Projected increase in the incidence of dementia 2006–2051**

Year	People with dementia	Increase from 2006
2006	683 597	
2021	940 110	38%
2051	1 735 087	154%

From: Knapp and Prince, 2007

### *Vascular dementia*

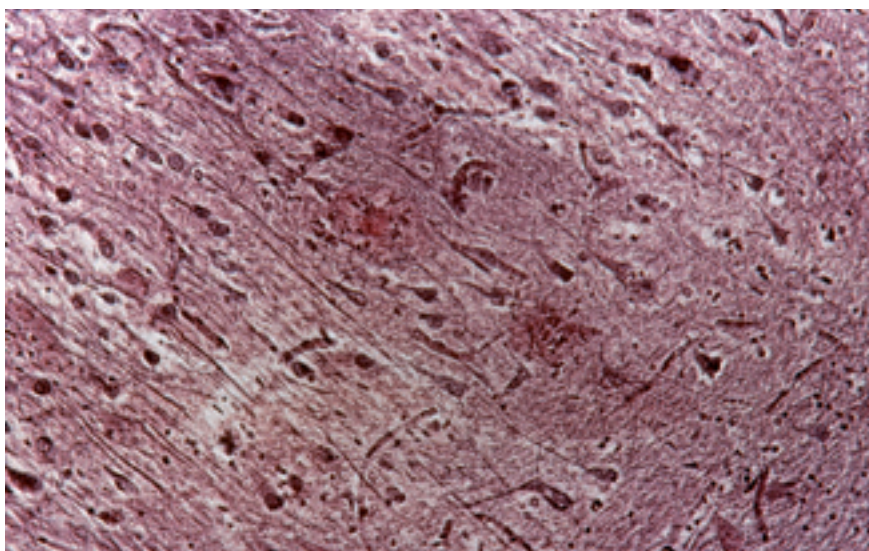
Cerebral function needs a generous and competent blood supply. Atherosclerotic obstruction to large or small vessels results in a range of neurological syndromes according to the site of obstruction and consequent infarction (Desmond, 1996). In addition periods of hypo-perfusion of the brain may follow a heart attack, asystole or systemic hypotension, with infarction in watershed areas. A smaller number (10%) of people whose dementia arises directly from circulation failure are survivors of intra-cerebral bleeds.

The clinical picture in vascular dementia is described as 'patchy' with a mixture of preserved and lost functions. The volume of cortex lost to infarction correlates with the severity of cognitive loss. Neurotransmitter changes occur in vascular dementia but are less predictable and characteristic than in Alzheimer's disease.

### *Lewy body dementia*

Lewy bodies are inclusion bodies found with in the basal ganglia neurones of people who have Parkinson's disease and more widely in the cerebral cortex of a subset of people with dementia identified for the first time in the 1980s (McKeith et al, 1996). Lewy bodies stain with ubiquitin. The clinical picture includes periods of altered consciousness, vivid visual illusions

*Figure 1. Light micrograph of a section through the brain of a patient with Alzheimer's disease. An amyloid plaque (centre) is shown. Neurofibrillary tangles (insoluble twisted fibres) are also present (black lines).*



## Key Points

- ▶ Dementia is characterised by impairment of intellect, memory and personality
- ▶ Dementia usually arises in older people but normal changes of ageing alone do not constitute dementia
- ▶ Alzheimer's begins in the hippocampus where cells become cluttered with plaques and tangles
- ▶ Vascular risk factors in middle age—e.g. hypertension, diabetes, smoking, obesity and hyperlipidaemia—are associated with later Alzheimer's and vascular dementia

and hallucinations without (in the early stages) severe cognitive impairment. There is almost always some evidence of Parkinsonism and falls are common.

### Frontal lobe dementia

Malfunction of the frontal lobes, producing altered mood, disinhibition or reduction of initiative, can occur in dementia of any aetiology. David Neary and others have characterised a condition which is based on atrophy of the frontal and temporal lobes and relative preservation of the rest of the brain (Neary et al, 1998). The neuropathology is different from that seen in Alzheimer's and frontal lobe dementia is probably a modern understanding of Pick's disease.

### What is life with dementia like?

It is difficult to be sure when insidious changes herald a departure from the normal course of ageing. This is the situation for most people with Alzheimer's or fronto-temporal pathologies. Sudden change associated with neurological symptoms make the onset of vascular dementia more easily recognised. The florid, fascinating perceptual changes of Lewy body dementia come early to attention.

Progress over time in all the dementias is variable (Fitzpatrick et al, 2005). What happens to an individual is a function of the underlying pathology, but is also influenced by the person's constitution, his/her general health, and the way he/she responds to the progressive undermining of competence and independence which it produces.

Environmental factors are also important. The presence of sympathetic, informed support is the best of therapies (Marshall, 2005). People and places have an influence. Most people prefer to live in the private household which has been 'home' for years, but this becomes hazardous if the person is alone and muddled. Living with a long-term partner (spouse) or other relative is a stronger scenario.

The health and wellbeing of carers requires as much respect and attention as those of the individual with dementia. If both remain well and supported, a full and rewarding life may be sustained for months or years. At any one time 40% of people with dementia in the UK are living in a residential home or nursing home. Their quality of life and maintenance of wellbeing and abilities are acutely sensitive to the characteristics of the professional care environment.

Progression of cognitive impairment averages two points on the Mini-Mental State Examination (MMSE) scale annually (Folstein et al, 1975; Clark et al, 1999) but there is wide variation. Physical frailty, loss of weight, loss of sphincter control and vulnerability to recurrent falls and infections may eventually supervene as dementia shows itself as a terminal illness. Life expectation in dementia is reduced. Survival from diagnosis ranges from a few months to more than ten years. Many will die of

intercurrent illness before experiencing the most debilitating dependency of end-state dementia (Hughes et al, 2007).

*Conflict of interest: none declared*

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# How to recognise the early signs of dementia

**Louise Robinson** explores the reasons why the early signs and symptoms of dementia are sometimes overlooked, ignored, misunderstood or misdiagnosed. She explains the key signs and symptoms of the different types of dementia and provides an overview of the key assessments used in diagnosis. The importance of referral for specialist assessment and issues about communicating a diagnosis are considered.

**D**ementia is an age-related illness, although in rare cases it presents in people under 60 years of age. Approximately 1 in 14 people aged 65 years and over have some form of dementia; this rises to 1 in 5 of those aged 80 years and over. As the UK population is rapidly ageing, with life expectancy increasing by 2 years every decade, the numbers of people with dementia will consequently increase. In the UK, there are currently around 700 000 people with dementia; however, this is predicted to rise to 1.5 million by 2050. The direct and indirect costs of caring for people with dementia have been estimated at £17 billion (Knapp and Prince, 2007). It is therefore vitally important that we diagnose dementia as early as possible in order to ensure the best possible care for both patients and carers. This is particularly relevant for primary and community care professionals as the vast majority of older people with health concerns will present to their general practice first. The aim of this article is to review the early signs and symptoms of dementia, discuss practical tests to confirm the diagnosis and discuss how current practice can be improved on.

## Dementia: signs and symptoms

The term dementia relates to a number of different dementia syndromes (*Table 1*). However, a common range of symptoms can be observed in the different stages of the illness (*Table 2*). In the early stages of dementia, there may be obvious memory difficulties, usually related to impairment of short-term rather than long-term memory, e.g. forgetting the name of common objects, times and places, and also the ability to perform activities of daily living correctly.

Communication difficulties and changes in personality and mood may also ensue, leading GPs to make an initial inaccurate diagnosis of depression, although depression may coexist alongside dementia. Other possible illnesses which may present in this way include hypothyroidism, vitamin B<sub>12</sub> deficiency, and alcohol problems, and more, rarely a brain tumour. Family carers often present their concerns to a health

professional before the person attends him/herself or asks for help (Bamford et al, 2007a).

As the illness progresses, the person with dementia may gradually experience difficulties with independent living. This can lead to financial problems and an inability to take care of personal hygiene and preparing meals. People may also endanger their personal safety by leaving gas burners, electric appliances or bath taps on.

Non-cognitive symptoms are particularly distressing for families. These are usually referred to as behavioural and psychological symptoms in dementia (BPSD). Between 20–60% of people with dementia will experience BPSD at some time, particularly in the middle and later stages of the illness. The term BPSD encompasses a range of symptoms from agitation and pacing through to wandering and getting lost. However, the risks from such behaviour are often not as high as might be expected but BPSD can lead relatives or nursing home staff to curtail the activities of a person with dementia for fear that he/she may come to harm (Robinson et al, 2007).

## Dr Louise Robinson

is GP/Clinical Senior Lecturer, Institute of Health and Society, Newcastle University, 21 Claremont Place, Newcastle upon Tyne NE2 4AA

**Table 1. Types of dementia**

<b>Alzheimer's disease</b>	<ul style="list-style-type: none"> <li>▶ Most common form (about 60% of all dementias)</li> <li>▶ Gradual onset</li> <li>▶ Early symptoms: memory loss</li> <li>▶ Late symptoms: language difficulties, behavioural problems such as aggression, wandering</li> </ul>
<b>Vascular dementia</b>	<ul style="list-style-type: none"> <li>▶ Mixed dementia (Alzheimer's and vascular) accounts for about 27% of all dementias</li> <li>▶ Often abrupt onset; may be related to stroke or brain haemorrhage</li> <li>▶ Fluctuating course with stepwise deterioration</li> </ul>
<b>Dementia with Lewy bodies</b>	<ul style="list-style-type: none"> <li>▶ Characteristic picture: fluctuating cognitive impairment, visual hallucinations, spontaneous Parkinsonism</li> <li>▶ Memory relatively spared: cognitive loss related to attention and visuospatial problems</li> </ul>
<b>Rare dementias</b>	<ul style="list-style-type: none"> <li>▶ Include frontal-lobe dementia and Huntington's disease</li> </ul>

In the later stages of dementia, communication can be lost entirely and the person will no longer recognise loved ones or may mistake them for someone else, a particularly distressing symptom for families. Swallowing difficulties are common and poor nutrition can lead to recurrent infections such as pneumonia or urinary tract infections, which may eventually be fatal.

### Diagnosis of dementia

The diagnosis of dementia can take up to 4 years from initial presentation of symptoms, but on average takes around 18–30 months (Bamford et al, 2007a).

A report from the National Audit Office (2007) considered such a delay to be unacceptable, and called for greater public awareness of the illness and improved training of both medical students and GPs to reduce diagnostic delays. Although in some cases such delays may be the result of a reluctance of the patient and family to accept symptoms and acknowledge difficulties, primary and community care staff need to be more aware and refer patients for an expert opinion from an old age psychiatrist as soon as dementia is suspected (National Collaborating Centre for Mental Health (NCC-MH), 2006).

An early diagnosis allows patients and their families more time to adjust both emotionally and practically to the diagnosis, even though they may find the initial process of disclosure distressing. Also people in the earlier stages of dementia are more able to discuss their management preferences and wishes for future care, allowing a person-centred approach to care as recommended in the *National Service Framework for Older People* (Department of Health, 2001).

### Assessment of cognitive function

Simple tests are available for use in the community to make an initial assessment of a person's cognitive function. Currently routine screening for dementia is not considered effective clinically or financially (NCC-MH, 2006).

The most commonly used tool for assessment of cognitive function in dementia is the Mini-Mental State Examination (MMSE) (Folstein et al, 1975). The MMSE is scored out of 30: a score of <25 is suggestive of dementia. It can take between 12–20 minutes to complete, however, so that in general practice, an abbreviated MMSE is often used to save time (Table 3).

The clock drawing test may be used in addition to the MMSE or abbreviated MMSE. A patient is asked to draw a clock, number it and add a specified time correctly (Shulman et al, 1986). Clock drawing tests are rarely used alone in clinical practice as there are a plethora of different forms and scoring methods. One common scoring method comprises a range from 5–1:

- 5 Represents a perfect clock
- 4 A clock with minor visuo-spatial numbering errors
- 3 Inaccurate representation of the time
- 2 Moderate visuo-spatial numbering errors
- 1 Severe visuo-spatial numbering errors
- 0 Inability to make any representation of a clock.

Other brief cognitive tests available include the General Practitioner Assessment of Cognition (GPCOG) (Brodsky et al, 2002) and the Six-Item Cognitive Impairment Test (6-CIT). The GPCOG is estimated to take 6–7 minutes to complete (4 minutes for the patient and 3 minutes for the carer) and thus it may be more relevant and convenient for use in general practice.

Table 2. Symptoms of dementia by progressive stages	
Early stage (MMSE >21)	<ul style="list-style-type: none"> <li>➤ Loss of memory</li> <li>➤ Poor judgment and reasoning</li> <li>➤ Confusion</li> <li>➤ Personality changes</li> <li>➤ Mood disturbance</li> </ul>
Middle stage (MMSE 20 or less)	<ul style="list-style-type: none"> <li>➤ Worsening memory</li> <li>➤ Difficulties with activities of normal daily living</li> <li>➤ Behavioural and psychological symptoms</li> <li>➤ Speech and communication difficulties</li> <li>➤ Safety hazards</li> </ul>
Late stage	<ul style="list-style-type: none"> <li>➤ Swallowing difficulties</li> <li>➤ Malnutrition</li> <li>➤ Physical frailty and immobility</li> <li>➤ Recurrent infections</li> <li>➤ Incontinence</li> </ul>

Table 3. The abbreviated mental test score	
The 10-point test	<ol style="list-style-type: none"> <li>1. Age: must be correct</li> <li>2. Time: correct to nearest hour without looking at time</li> <li>3. 42 West St: give this address and check registration: check memory at end of test</li> <li>4. Month: exact</li> <li>5. Year: exact; previous year fine in January or February</li> <li>6. Location name: if not in hospital, type of place or area of town</li> <li>7. Date of birth: exact</li> <li>8. Start of World War I: exact</li> <li>9. Name of present monarch: exact</li> <li>10. Count backwards down from 20 to 1: patient can hesitate and self-correct; can give prompts for 20, 19, 18</li> </ol>
What it means	<ul style="list-style-type: none"> <li>☐ Score 8–10: normal</li> <li>☐ Score 7: probably abnormal</li> <li>☐ Score &lt;7: abnormal</li> </ul>
From: Qureshi and Hodkinson, 1974	

## Clinical assessment

Cognitive assessment tests alone are insufficient to diagnose dementia; a detailed history and examination by the GP is required, including a comprehensive assessment of the patient's social functioning using information from family carers. The GP should perform some routine blood tests (fasting blood glucose, biochemistry, glucose, thyroid function, vitamin B<sub>12</sub> and liver function), and perhaps a chest X-ray and electrocardiogram (ECG) to exclude other causes, before referring the patient for a specialist assessment in secondary care. This should preferably be undertaken by an old age psychiatrist (NCC-MH, 2006), who can confirm the diagnosis from a detailed neurocognitive assessment and possibly a brain scan.

Memory clinics are increasingly being established to provide specialist centres for such an assessment, as recommended by the National Institute for Health and Clinical Excellence (NICE) (NCC-MH, 2006) and by the National Dementia Strategy (Department of Health, 2009). Such clinics also encourage the referral of people with mild memory loss which may not yet be interfering with their daily lives, usually termed mild cognitive impairment (*Box 1*).

Mild cognitive impairment refers to memory loss greater than would be expected with increasing age but which is not yet disabling to the patient (usually an MMSE >26). Only between 15–20% of people with mild cognitive impairment progress to full dementia each year.

## Best practice in diagnosis

The NICE guidelines on dementia for health and social care professionals (NCC-MH, 2006) provide a clear pathway for the detection and referral of people with a suspected dementia. Notwithstanding such clarity, the National Audit Office's report on dementia (2007) highlighted poor performance in this area, with the reported time to diagnosis in the UK twice that of some other European countries and a deteriorating confidence in the ability of GPs to diagnose dementia.

So why is the UK performing so poorly in this area? Unfortunately, there would appear to be multiple contributing factors. A wide variation in GPs' abilities and confidence in diagnosing dementia has been reported consistently, and would appear to have improved little in the last 20 years (O'Connor et al, 1988). Currently UK medical students receive little training in dementia and the National Audit Office (2007) has called for urgent attention to this area by the royal colleges of psychiatry and general practice at both undergraduate and postgraduate levels.

Research has revealed that GPs appear to carry out a 'watchful waiting' process on people presenting with suspicious symptoms, rather than referring them at an early stage (Bamford et al, 2007a). This is probably the result of a tendency to assume that such cognitive changes are merely the result of 'old age', limited

## Box 1. RICE memory clinics

The RICE Centre in Bath carries out research into Alzheimer's disease and other dementias and related cognitive disorders. It also runs a weekly memory clinic and a nurse-led community memory screening clinic for people concerned about their own or a loved one's memory loss.

### Aims of the memory clinic

- ▶ To give an in-depth assessment of a person's memory function and cognition
- ▶ To make a diagnosis and exclude and treat any reversible causes
- ▶ To provide support and counselling to sufferers, relatives and carers and, where necessary, put them in touch with the appropriate services
- ▶ To offer treatment with therapeutic agents to suitable patients and, if appropriate, participation in a clinical trial.

### Tests conducted

- ▶ Full medical history
- ▶ Neuropsychological assessment
- ▶ Physical examination
- ▶ Screening blood and urine tests

### Who conducts assessments?

At the first appointment, routine assessments are made by a doctor, a nurse and sometimes a psychologist. Results are discussed at a multidisciplinary meeting, and a report is sent to the patient's GP.

### Referral

Referrals can be made by GPs and other health professionals including practice nurses. Patients already with a diagnosis of Alzheimer's disease or vascular dementia are also accepted.

### Benefits

- ▶ Early expert assessment, diagnosis and possible treatment.
- ▶ Coordinated multidisciplinary assessment
- ▶ Treatment with therapeutic agents if appropriate
- ▶ Entry if appropriate into a clinical trial
- ▶ Referral to other health professionals, social services and voluntary agencies
- ▶ Advice and support to patients and carers on coping with memory problems, such as attendance at a carers' course.

### Nurse-led memory screening clinics

Memory screening is offered to local residents aged over 50 years to distinguish between early dementing illness and memory or concentration problems due to other causes such as stress and bereavement. A general health questionnaire, a brief history of memory problems, and neuro-psychological tests are conducted. Results are discussed with patients and sent to their GPs if they wish. Practical advice about memory loss, help for carers is also offered.

### Further information

[www.rice.org.uk](http://www.rice.org.uk)

access in some areas of the country to specialist mental health services (Audit Commission, 2002), and restrictions on the prescribing of anti-dementia drugs (acetylcholinesterase inhibitors) in the early stages of the illness (NICE, 2006). However, following a judicial review in 2007, this NICE guidance has been amended and the prescribing of such drugs is not now solely dependent on MMSE scores but on a more holistic assessment of the person's functioning.

However, another important area of concern is the apparent difficulty many health professionals have in openly saying the 'D word'. A systematic review of the process of disclosure of a diagnosis of dementia found that disclosure was rated by GPs as one of the five most difficult areas in dementia management (Bamford et al, 2004). It was also found that GPs were less likely to use the correct terminology than psychiatrists, and that carers were more likely to be told the diagnosis than patients (Bamford et al, 2004). Although disclosure has been reported as having negative consequences including effects on self-esteem and anxiety about the future, reported benefits include an 'end to uncertainty', access to support, and better understanding of the symptoms and effects of dementia (Bamford et al, 2004).

## Key Points

- ▶ Confirmation of a diagnosis of dementia can take up to 4 years from initial presentation to a GP
- ▶ GPs appear to carry out a 'watchful waiting' process on people with symptoms indicative of dementia, rather than referring early for specialist assessment
- ▶ Dementia screening is not considered clinically or cost-effective
- ▶ The detection of dementia could be improved by better training of health professionals
- ▶ The National Dementia Strategy recommends raising public awareness of dementia to improve detection

## Improving the detection of dementia in primary care

How can current performance be improved? As previously highlighted, the National Audit Office (2007) has made some extremely useful and practical recommendations. In addition to the need for better training of health and social care professionals, it suggested that primary care trusts (PCTs) should set dementia prevalence benchmarks for general practice (i.e. the number of people with dementia that an individual practice should theoretically have on its dementia register). These figures would then be compared to the actual register to identify possible 'missed diagnoses'.

In addition, PCTs should develop their own best practice local care pathway for detection and diagnosis and ensure implementation. Research has already confirmed that evidence-based practice protocols can enhance detection rates in primary care (Downs et al, 2006); research, however, needs to be translated into practice and not left on an academic journal shelf. It may also help to add a short cognitive assessment (i.e. using the GPCOG or Abbreviated MMSE) into the routine care of older people who may be at greater risk of developing dementia, such as those with high blood pressure and heart disease. This has been successfully achieved with depression screening, which has been introduced into the Quality and Outcomes Framework (QOF) for certain chronic illnesses (British Medical Association and NHS Employers, 2006).

A major issue for us all, whether potential patient, family carer, or health professional, is to ensure that dementia is no longer to medicine what Voldemort is to Harry Potter, i.e. that which should not be named. A major national campaign is required to improve public and professional awareness and understanding about the illness. The National Dementia Strategy for England has now been published following a long process of consultation (DH, 2009). A national awareness programme is now in development and a long awaited change in service provision will hopefully be the result in time.

Health professionals need to overcome their own personal demons and learn to be able to say the word 'dementia' openly and sensitively to patients without whispering it to their relatives behind their backs. A course developed from research carried out at Newcastle University videoing medical consultations between people with dementia, their carers and their doctors, affords great potential to improve skills in talking to people with dementia about dementia (Bamford et al, 2007b).

## Conclusions

Currently, the confirmation of a diagnosis of dementia can take up to 4 years from a patient's initial presentation to a GP (and averages 18–30 months).

This may be explained by lack of understanding of the signs and symptoms of dementia among health professionals and the general public, so that many GPs carry out a watchful waiting process rather than refer patients with possible symptoms early for specialist assessment.

The detection of dementia could be improved through a range of local and national strategies such as diagnostic care pathways, enhanced training for health professionals at both undergraduate and postgraduate levels, better communication skills training, and public awareness raising as recommended by the National Dementia Strategy (DH, 2009).

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# Effective use of drugs in Alzheimer's disease

**Bernadette McGuinness, David Wilson, Stephen Todd and Peter Passmore** provide an introduction to the use of acetylcholinesterase inhibitors in Alzheimer's disease. They look at the potential benefits and limitations of the drugs, highlight the importance of regular review, and provide guidance about maximising the benefits of treatment, and deciding when to discontinue or switch medications.

Three main drugs, acetylcholinesterase inhibitors (AChEIs), are licensed for the pharmacological management of Alzheimer's disease: donepezil, rivastigmine and galantamine. Questions about what can be expected from these drugs often arise during treatment, and may lead to premature discontinuation of medications. Another difficult area for doctors and nurses is what to do when treatment appears to be losing efficacy, i.e. when patients decline more rapidly in phases of their disease.

## Action of acetylcholinesterase inhibitors on the brain

The development of AChEIs followed the finding that cholinergic pathways in the cerebral cortex and basal forebrain are compromised in Alzheimer's (Richter et al, 1980). AChEIs boost the brain's levels of acetylcholine (ACh), a neurotransmitter important in the formation of memory. AChEIs target the process by which the enzyme acetylcholinesterase breaks down ACh into its constituents, acetate and choline, following its release into the synaptic cleft. This leaves more ACh in the synaptic cleft for communication between the neurones (Figure 1).

AChEIs act more specifically in the brain than the medications initially developed. Their selectivity for the brain is highlighted by their lack of activity in peripheral tissue such as cardiac tissue or gut smooth muscle (Rogers et al, 1991; Enz et al, 1993; Anand et al, 1996). This means that therapy is more targeted and there is potential reduction of adverse events.

Donepezil is a reversible AChEI (i.e. the effects can be reversed) with a high specificity for acetylcholinesterase. Rivastigmine is a 'pseudo-irreversible' inhibitor, because it mimics ACh by binding with acetylcholinesterase to form a carbamylated complex. This prevents further enzyme-catalysed hydrolysis of ACh. Rivastigmine also inhibits the activity of butyrylcholinesterase, another enzyme that can break down ACh. Animal studies show that rivastigmine targets the cortex and

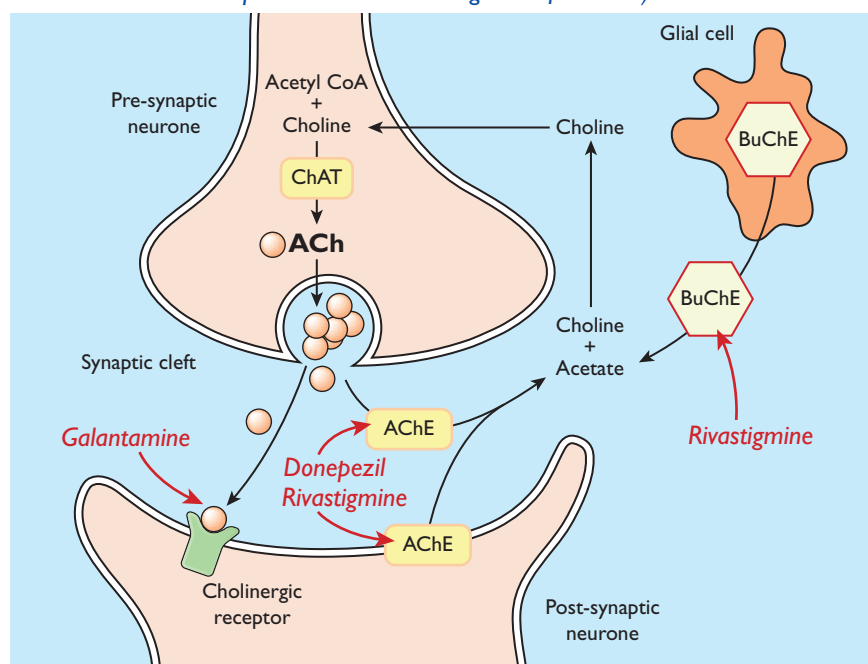
hippocampus (Enz et al, 1993). Galantamine is a reversible inhibitor of acetylcholinesterase and enhances the intrinsic action of ACh on the cholinergic receptors, increasing neurotransmission (Razay and Wilcock, 2008).

## Potential benefits

Double-blind, placebo-controlled trials have shown that AChEIs produce small but significant changes in cognition, function and neuropsychiatric symptoms, accompanied by significant improvements in global clinical assessments in patients with mild-to-moderate Alzheimer's disease (Birks, 2006). Despite variations in their modes of action, the efficacy of these drugs is similar (Birks, 2006). The evidence is for up to 1 year in the double-blind trials. The AD2000 study

**Bernadette McGuinness** is Beeson Scholar Ireland, **David Wilson** is Northern Ireland Clinician Scientist in Stroke, **Stephen Todd** is Beeson Scholar Ireland and **Peter Passmore** is Professor of Ageing and Geriatric Medicine, Queen's University Belfast

*Figure 1. Normal cholinergic function showing the sites where anti-Alzheimer's drugs inhibit acetylcholinesterase (AChE) or butyrylcholinesterase (BuChE) or improve transmission at the cholinergic (nicotinic) receptor. (Glial cells modulate neurotransmission and provide nutrition among other functions.)*



indicated that donepezil improves cognition and function for up to 2 years (Courtney et al, 2004), although the placebo-controlled arm of this study is difficult to interpret. In a 2-year double-blind placebo-controlled comparison study, donepezil and rivastigmine were equipotent but more adverse events were seen with rivastigmine (Bullock et al, 2005). Available evidence indicates that all AChEIs appear to reduce the projected rate of cognitive decline for up to 3 years (Burns et al, 2007; Wallin et al, 2007), although the data beyond 1 year are mostly open label and should be interpreted with caution. Over 48 months' use of galantamine, about one third of patients showed little decline, while one third showed important decline (Rockwood et al, 2008). There is some evidence that nursing home placement is reduced (Lopez et al, 2002; Feldman et al, 2009).

A key aim of the National Dementia Strategy for England (Department of Health (DH), 2009) is early diagnosis of Alzheimer's. European and US consensus statements recommend use of AChEIs as soon as diagnosis is made (Farlow and Cummings, 2007; Waldemar et al, 2007). However, guidance from the National Institute for Health and Clinical Excellence (NICE) (2007) restricts use of AChEIs to moderate Alzheimer's disease as defined by a Mini-Mental State Examination (MMSE) score <20. The available evidence suggests that effects of AChEIs are the same in all stages of Alzheimer's (Seltzer et al, 2004; Birks, 2006) but a delayed start to treatment is detrimental for patients (Winblad et al, 2006).

The data appear to suggest that patients, caregivers and physicians will still observe some decline in patients on AChEIs after a period of stabilisation, but this may be slower and later than expected if the patients were left untreated. This applies across all domains of Alzheimer's—not simply cognition—and

activities of daily living can be relatively preserved, even if cognitive scores are falling (Bullock and Dengiz, 2005).

On average, patients may return to their pre-treatment status between 9 and 12 months after starting treatment. However, a return to pre-treatment level does not mean that the treatment effect has disappeared. At this point, the patient may still function better than he/she would have without treatment. Setting a fixed measurement such as an MMSE score as a 'when to stop treatment limit' is not clinically rational. The length of treatment should depend on several individual patient factors, such as the stage of disease, the rate of decline, and whether improvement has occurred on initial treatment. The earlier the diagnosis is made and the slower the rate of disease progression, the longer the treatment period tends to be. Treatment duration must therefore be evaluated on an individual basis, and the patient's status compared with what would have been expected without treatment. If a clinical evaluation is conducted with a view to stopping or switching treatment, it is crucial that all domains are evaluated and that the patient is evaluated at more than one point in time before the decision is made.

### Limitations

There is a clear dose-response relationship for AChEIs and each drug should be increased to the maximum tolerated dose using four weekly titration steps. While not a major problem there are potential difficulties with patients not reaching the maximum dose and thus not achieving optimum benefit. Only donepezil is effective at the initial dose of 5 mg but the dose should still be increased to 10 mg (Table 1).

AChEIs are well tolerated and safe. Contraindications are the presence of significant electrocardiographic (ECG) abnormalities, peptic ulcer disease and significant chronic obstructive pulmonary disease.

Adverse events are more common when treatment is started or the dose increased, and are mostly gastrointestinal: nausea, vomiting or diarrhoea, which often respond to symptomatic treatment. Syncope can occur but is rare. In one study the five most common side effects were, in order of frequency: nausea, agitation, vomiting, headache and fainting. In the long term, the most frequent side effects from AChEIs, generally speaking, are muscle cramps, tremors, nightmares, nausea, vomiting, fatigue, vertigo and loss of weight (López-Pousa et al, 2007).

It is difficult to make the decision about when to withdraw therapy. AChEIs' effectiveness eventually wears off and this needs to be discussed with patients and carers when treatment is started and at intervals thereafter. The evidence on withdrawal is mainly on donepezil. Studies show that cognitive decline and emergence of adverse behaviours can occur when the

**Table 1. Anticholinesterase inhibitors for treatment of Alzheimer's disease**

Ingredient	Trade name	Dose
Donepezil	Aricept (tablets) Aricept Evess (orodispersible tablets)	Start: 5 mg once daily at bedtime Titrate to 10 mg once daily after 4 weeks
Galantamine	Reminyl  Reminyl XL (modified release)	Start: 4 mg twice daily for 4 weeks. Titrate to 8 mg twice daily for 4 weeks then 12 mg twice daily  Start: 8 mg once daily for 4 weeks. Titrate to 16 mg daily for 4 weeks then 16–24 mg daily
Rivastigmine	Exelon (capsules, oral solution)  Patches	Start: 1.5 mg twice daily for 2 weeks. Increase by 1.5 mg steps every 2 weeks to max. 6 mg twice daily  4.6 mg/24 hours. Increase to 9.5 mg/24 hour patch after 4 weeks

From: Joint Formulary Committee, 2009

drug is still having an effect (Rogers et al, 1998; Holmes et al, 2004). If a trial withdrawal is indicated, patients, carers and primary care physicians must be advised of these possibilities and the need to reintroduce medication as quickly as possible. A trial withdrawal of treatment is usually considered when the patient reaches the more advanced stages of disease, based on a clinical assessment which may show greatly impaired cognitive and functional abilities.

### Regular follow-up and reassessment

Because there is currently no cure for Alzheimer's, an initial cognitive improvement observed in the first few months of therapy cannot be sustained indefinitely. However, a patient who is treated early and persistently with AChEIs can be expected to show less evidence of behavioural, functional, and cognitive deterioration over a period than a patient who is not treated with AChEIs. Treatment success is measured not only by short-term improvement of symptoms but also by less decline in the long term. Determination of treatment success therefore also requires awareness of the typical progression of untreated Alzheimer's (Geldmacher et al, 2006). It is therefore important that patients are regularly reviewed by specialist services to advise on management particularly as Alzheimer's disease is a progressive disorder. In addition, NICE recommends regular follow-up (National Collaborating Centre for Mental Health, 2006; NICE, 2007).

### Importance of continuing treatment to maximise benefits

Persistence with treatment is crucial to delay impairment in patients' function and cognitive abilities. In the initial few weeks of treatment if significant adverse events occur then patients will need to stop that particular medication. However, adverse events are not seen to the same extent with different AChEIs so a trial of an alternative AChEI is recommended. In one naturalistic study, 14.5% of the patients showed intolerance to AChEIs during the first 15 days. Of those patients who initially tolerated the treatment, 18.5% gave it up after a mean duration of 13.36 months and a mean dose of 7.5 mg/day of donepezil or 14.3 mg/day of galantamine. The mean duration of the treatment in patients who did not abandon the treatment was 25.4 months and the mean dose was donepezil 8.1 mg/day or galantamine 20 mg/day (López-Pousa et al, 2007).

Another study showed significant differences in the global treatment persistence among AChEIs, with higher persistence in patients treated with donepezil compared to those who received rivastigmine, galantamine or memantine (Sicras-Mainar et al, 2006). It is important to note that those staying on treatment appear to show some degree of stabilisation

(Persson et al, 2009). In a study designed to address the possible benefits of continuing treatment with donepezil, patients who had declined or were unchanged after 12–24 weeks were randomised to placebo or donepezil. Among patients for whom clinical benefit was uncertain, improvements in cognition and behaviour were observed for those who continued donepezil treatment compared with the group switched to placebo.

Initial decline or stabilisation does not necessarily indicate a lack of efficacy in Alzheimer's disease, and the decision to discontinue treatment should be based on an evaluation of all domains (cognition, behaviour and activities of daily living) and performed at several timepoints (Johannsen et al, 2006).

### Switching of medication

The difficulty in clinical practice concerns those patients who deteriorate rapidly despite treatment. The options are to continue with existing treatment or switch to an alternative AChEI, to add memantine to the existing AChEI or to switch to memantine. There are few well designed switching studies to guide decision-making. All are open label and most refer to switching from donepezil. There are fewer studies on switching from galantamine, while rivastigmine is the most common agent patients are switched to. The data suggest that about 50% of patients will respond when switched to another AChEI (Bartorelli et al, 2005; Gauthier et al, 2006; Dantoine et al, 2006).

### Polypharmacy

Major considerations in older people include comorbidity and polypharmacy. It is important to consider kidney and liver function. There are few important drug interactions with AChEIs. There is an increasing recognition that medications with anticholinergic properties—such as tricyclic antidepressants (e.g. amitriptyline) and preparations for urinary incontinence—can affect the efficacy of AChEIs. Concomitant use of anticholinergic medication is seen in about 35% patients (Carnahan et al, 2004; Herrmann et al, 2007). Patients with Alzheimer's disease deserve to receive the optimum benefit from cholinesterase inhibitor treatment, which can only be achieved through diligent and appropriate use of concurrent pharmacotherapy.

### Conclusions

AChEIs are a generally considered a standard of care in Alzheimer's, with consensus statements recommending their introduction after diagnosis. Three agents are available, with broadly similar efficacy and involving slightly different total titration

*'Decline may be slower and later than expected if patients were left untreated. ... Activities of daily living can be relatively preserved, even if cognitive scores are falling'*

## Key Points

- ▶ Acetylcholinesterase inhibitors (AChEIs) raise levels of acetylcholine in the brain to overcome the effects of Alzheimer's disease
- ▶ Level I evidence shows AChEIs produce small but significant changes in cognition, function and neuropsychiatric symptoms to slow the rate of decline
- ▶ Regular review and assessment of patients on AChEIs is important
- ▶ It is important to persist with therapy to gain optimal benefits—the earlier the diagnosis and the slower the rate of disease progression, the longer the drugs will be effective

times (4–8 weeks). Recognition of the need to achieve the maximum tolerated dose owing to the dose-response effects is important, as are realistic treatment expectations which include the important benefit of stabilisation at different stages of the disease.

Regular reassessment is needed and maximum benefit over time is seen with persistence of treatment. Treatment withdrawal remains an issue for consideration due to the possibility of clinical deterioration. There are few limiting contraindications and adverse events in the use of AChEIs. There should be an increasing focus on concomitant diseases and therapy, particularly the role of medications with anticholinergic properties which could negate some of the benefits of AChEIs.

*Conflict of interest: Peter Passmore has received payment for consultancy work on behalf of Eisai Ltd, and has received honoraria and educational grants from makers of all drugs discussed in this article. Bernadette McGuinness has received honoraria from Pfizer/Eisai and Novartis and educational grants from Shire. David Wilson has received educational grants from Shire. Stephen Todd has received honoraria from Novartis and educational grants from Shire.*

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# Better understanding makes diagnosis faster

Helen Dickens explains why it is so important for people to seek advice if concerned about their memory.

Getting a timely diagnosis of dementia is vital to enable people to access treatment and support, but there are many barriers to receiving one. Stigma and lack of understanding about the symptoms of dementia often prevent people from seeking help, despite fears about dementia. People may assume that forgetfulness or confusion is just a part of getting old. They may not realise that dementia is caused by diseases of the brain. Others may believe nothing can be done to help relieve their symptoms, or they may be scared to admit there is a problem. Challenging these perceptions is vital to ensure that more people seek help when they need it.

## Campaign

Alzheimer's Society's 'Worried about your memory?' public awareness raising campaign aims to challenge the stigma and misunderstanding that prevents people from seeking help if they are concerned about memory problems. It has been running in England, Wales and Northern Ireland since May 2008. Leaflets have been distributed to general practices which explain the difference between memory loss and symptoms that require assessment. While aiming to reassure the 'worried well' that memory loss can have many different causes, it encourages people who have noticed significant changes in their memory, concentration or behaviour to seek help from general practice. The leaflets include a response mechanism for people to return to the Alzheimer's Society if they require further information about dementia.

## Further information

### 'Worried about your memory?'

To find out more about the campaign, log on to [alzheimers.org.uk/memoryworry](http://alzheimers.org.uk/memoryworry)

To request copies of the campaign materials free of charge, including leaflets for your practice or a copy of the dementia CD-Rom, email: [waym@alzheimers.org.uk](mailto:waym@alzheimers.org.uk)

### Alzheimer's Society

For more information about Alzheimer's disease and other forms of dementia, visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Email [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

Tel +44 (0) 20 7423 3500

Helpline: 0845 300 0336 (8.30 am to 6.30 pm Mon–Fri)

To support the campaign, general practices have also been sent a resource pack, including an information CD-Rom outlining the key role of general practice in treating dementia. GPs, practice nurses and other primary care services are the first and best point of call for people who are worried about their own memory or the memory of someone they know.

## Impact

Since the launch of the campaign, more than 12 000 people have requested further information about dementia. While many have been reassured by the information, some have acted on it and sought help.

A survey of those who responded to the campaign suggests that nearly half visited their GP and up to one in five went on to receive a diagnosis of dementia. More than half had been worried for more than a year before picking up the leaflet. In addition, one in seven of over 1500 GPs surveyed noticed a rise in the number of patients visiting with memory problems since the beginning of the campaign.

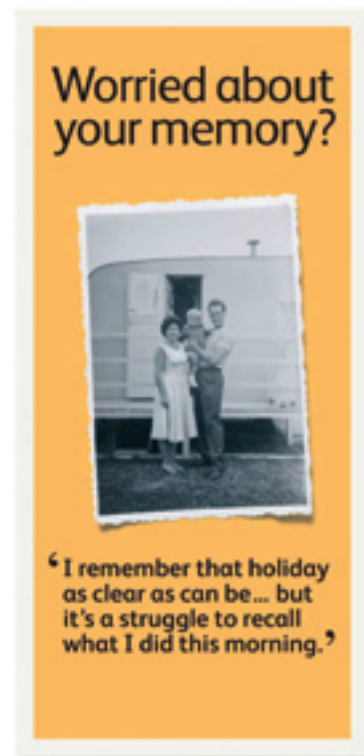
The National Dementia Strategy for England has highlighted the need to improve access to memory services and improve the diagnostic process for dementia. Over 90% of GPs surveyed for the 'Worried about your memory?' campaign agreed that an early diagnosis is important, but more than half thought a lack of access to services was a barrier to early diagnosis.

Increased access to memory clinics and specialists may ensure people with dementia receive a swift and accurate diagnosis. However, this needs to be accompanied by local support and information services to prevent people being left to come to terms with their diagnosis alone. More than half of the GPs surveyed reported that they required more information about local support services for people with dementia and their carers.

The GPs surveyed also highlighted that fear, stigma and misunderstanding prevent people from presenting with memory problems. The 'Worried about your memory?' campaign has started to break down some of the barriers that stop people approaching a health professional, but this is just the tip of the iceberg if every person with dementia is to receive the swift and timely diagnosis they deserve.

Leading the fight  
against dementia  
**Alzheimer's  
Society**

**Helen Dickens** is  
Communications Manager,  
Worried about your  
memory? campaign,  
Alzheimer's Society, Devon  
House, 58 St Katharine's  
Way, London E1W 1JX





# PracticeNursing

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