

# Dementia Part 1

# Early recognition and diagnosis

This, the first of two articles on dementia, focuses on the challenges that dementia presents; its demographics, presentation, risk factors, the importance of early recognition, assessment and the role of primary care

**I**n our aging population dementia poses a significant and increasing challenge to society. Around 750,000 people are living with dementia today<sup>1</sup> and numbers are expected to double over the next 30 years.

Most people living with dementia are over 65, but there are currently 15,000 in whom it has developed earlier in life (early onset). The prevalence of early onset dementia is slightly higher in men than women and a higher proportion of people with dementia from black and minority ethnic groups have early onset dementia. The prevalence of late onset dementia is slightly higher in women than men.<sup>2</sup> Mortality from dementia rises from 2% of deaths at 65 years to 18% at 85–89 years in men, and from 1% at 65 years to 23% at 85–89 years in women.

People with learning disabilities have an increased risk. It has been suggested that individuals with learning disability, Parkinson's disease and those who have

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## LEARNING OUTCOMES

**After working through this article you will be able to:**

- Outline the challenges that dementia presents
- Describe stages of the dementia care pathway and ways in which general practice teams can play a part in that pathway
- Identify key symptoms of dementia
- Describe the more common different types of dementia
- Identify what should be included in an initial assessment for dementia, and what investigations should be done to exclude other causes of dementia-like symptoms
- Recognize the importance of working with specialist diagnostic services in your area

had a stroke should have a baseline cognitive function assessment recorded, since diagnosis can be difficult without a baseline from which to measure change.<sup>3,4</sup>

People who smoke, are obese, have diabetes, hypertension, raised cholesterol or consume excessive alcohol are at increased risk of some common types of dementia. The Health Checks process, designed to identify and address cardiovascular disease risk,<sup>5</sup> may help delay or prevent the onset of dementia in some people. Vascular risk, however, is only one of the risk factors for dementia, and general population screening for dementia is not currently recommended.<sup>6,7</sup>

Some 64% of care home residents have some form of dementia. However, these only account for 36.5% of those living with dementia. The majority (63.5%) live in private households, with implications for

## ACTIVITY 1

Search the practice database for people with a learning disability. Have any of these individuals had a baseline assessment of their cognitive function undertaken? Discuss the implications of your findings with your practice colleagues.

## ACTIVITY 2

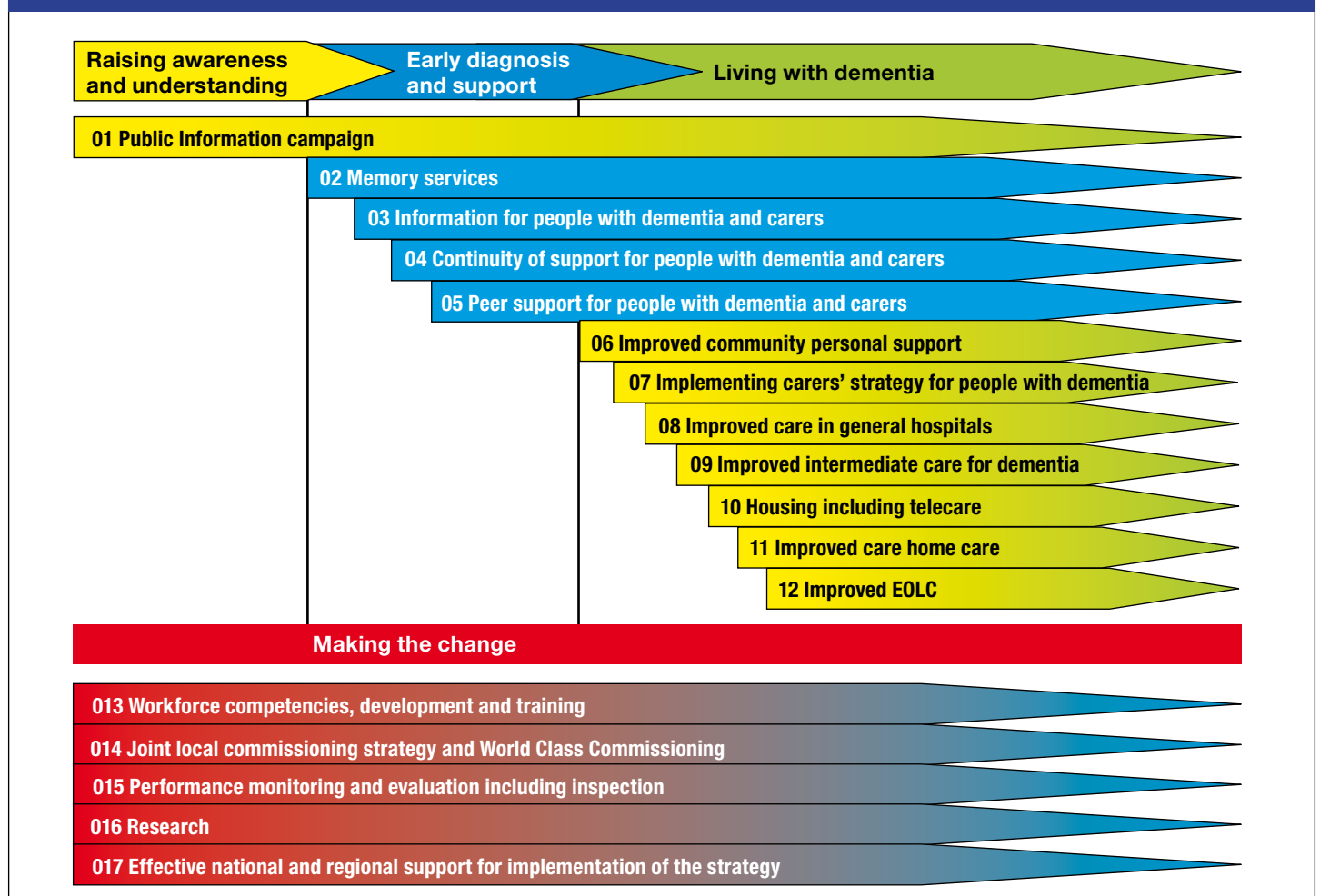
Access the dementia map available at <http://www.alzheimers.org.uk/dementiamap>. Click on the map to identify the prevalence and diagnosis rates of dementia in your area. Does your practice register reflect local prevalence rates?

This series is developed by distance learning specialists Education for Health. Module 11.14 Dementia: Early recognition and diagnosis is part one of two articles



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FIGURE 1. NATIONAL DEMENTIA STRATEGY CARE PATHWAYS



the carers and families involved. The cost to the UK economy of dementia has been estimated at £23 billion,<sup>6</sup> with 55% of that cost being met by unpaid carers.

### THE CHALLENGES

Terry Pratchett, in the foreword to the Alzheimer's Society report,<sup>7</sup> said: 'It occurred to me at one point that it was like I had two diseases – one was Alzheimer's and the other was knowing I had Alzheimer's.'

Dementia is feared by many, but understood by few. There is a persistent stigma.<sup>7</sup> The biggest challenges for many GP practices are the opening conversations, acknowledgement of that fear, and the time that the process of initiating appropriate referral for diagnosis must take in order to exclude other causes of symptoms and deal sensitively with those involved.

The importance of early diagnosis cannot be underestimated. It allows patients to start treatments that may

delay disease progression and gives them and their carers time to plan better for their future. Although nothing can reverse the decline of brain function, pharmacological interventions can treat some of the symptoms. Fear in the patient and family, lack of training for primary care practitioners, and inconsistencies in the approaches of specialist services and use of the available diagnostic tools all contribute to the gap between the estimated number of dementia sufferers and number of diagnoses made.<sup>8</sup>

Nice, Map of Medicine, and the Department of Health, as a part of the National Dementia Strategy (Figure 1),<sup>7,8,9</sup> emphasise the importance of:

- Early recognition;
- Competent assessment; and
- Early diagnosis.

Once diagnosis is confirmed support and care can more easily be planned and patients, families and carers can begin to adjust and find ways to cope. Information and support throughout the process are

highlighted as crucial to a more positive patient experience.

### WHAT IS DEMENTIA?

We must first understand what dementia is and find ways of talking confidently and positively about it. As Terry Pratchett said: 'The first step is to talk openly about dementia because it is a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name.'<sup>7</sup>

Dementia is an umbrella term describing a syndrome. It can be caused by a number of illnesses and manifests in decline in multiple areas of function, most notably mental and social function and ability to carry out activities of daily living (ADL).

Recognition of dementia is not easy because its onset is often insidious and the symptoms variable. Symptoms are dependent on the area of the brain most affected and on the personality of the person affected.

**BOX 1: PROBLEMS COMMONLY REPORTED BY PEOPLE WITH DEMENTIA<sup>4</sup>****Cognitive problems**

- Memory problems such as forgetfulness, repetitive questioning, difficulty finding names and other words, not knowing common facts
- Misunderstanding spoken and written communication
- Disorientation

Challenging behavior, psychiatric symptoms, and personality changes

- Withdrawal or apathy
- Depression, agitation, anxiety
- Blunting of emotions and disinterest, social withdrawal
- Disinhibition, inappropriate friendliness, flirting
- Suspiciousness, fearfulness, aggression, psychosis (delusions, hallucinations)
- Insomnia

- Restlessness, wandering, agitation, noisiness

**Neurological symptoms**

- Gait disturbances, apraxia (loss of ability to perform learned purposeful movements)

**Difficulties with activities of daily life**

- Difficulty with orientation, getting lost, loss of driving skills
- Taking prescribed drugs erratically – for e.g. you might find somebody on warfarin whose doses have always been stable, having wildly varying INRs
- Forgetting recipes when cooking, neglecting household chores, trouble with shopping, difficulty handling money
- Neglecting hygiene or self-care, deterioration in personal appearance, or a reduction in social roles
- Making mistakes at work

**BOX 2: WAYS OF DESCRIBING DEMENTIA TYPES<sup>12</sup>**

- Cortical dementia - dementia where the brain damage primarily affects the brain's cortex, or outer layer. Cortical dementias tend to cause problems with memory, language, thinking, and social behavior
- Subcortical dementia - dementia that affects parts of the brain below the cortex. Subcortical dementia tends to cause changes in emotions and movement in addition to problems with memory
- Progressive dementia - dementia that gets worse over time, gradually interfering with more and more cognitive abilities
- Primary dementia - dementia such as Alzheimer's disease (AD) that does not result from any other disease.
- Secondary dementia - dementia that occurs as a result of a physical disease or injury, or as a result of another disease process such as Parkinson's disease or following a stroke.

**ACTIVITY 3**

Ask your colleagues whether they can name the most common types of dementia seen in the UK

Perception of symptoms in terms of their severity and the need for investigation and support can differ. For those living in a family or with carers, symptoms can be hidden for quite a long time, as they may be helped with ADL. People who rely on cognition in their occupation may experience problems earlier.<sup>4</sup> Few cases of dementia are diagnosed in the early stages and it may take up to a year, or even longer, for a formal diagnosis to be made.

The Clinical Knowledge Summaries guidance (Box 1) includes a list of the problems commonly reported by people with dementia, or by people close to them, as being new or deteriorating.

**TYPES OF DEMENTIA**

Dementia can be classified according to the part of the brain affected, its cause,

**ACTIVITY 4**

Review the records of ten patients with a recorded diagnosis of dementia. Look at the process of investigation and assessment before referral and diagnosis. In light of what you have read so far, can you identify any ways in which the process could be improved?

and its degree of progression (Box 2), as well as by name. The most common types are Alzheimer's dementia, vascular dementia, and dementia with Lewy bodies (DLB).

**Alzheimer's dementia (AD)**

AD is a progressive cortical dementia. Clumps of protein known as plaques and 'tangles' develop around brain cells causing them to malfunction. Cortical dementias cause problems with language, memory, cognition and social behaviour.

AD accounts for around 60% of dementia. Early onset AD may be a genetically linked variation of the disease, but there is no known genetic link for

later onset AD. The average lifespan from diagnosis is 7–10 years, although some live longer. Gradual decline in all brain functions occurs and death is commonly from aspiration pneumonia as a result of difficulty in swallowing in the very late stage of disease.

**Vascular dementia**

This, the second most common type of dementia, accounts for around 20% of all dementias. It is caused by brain damage from cerebrovascular or cardiovascular problems - usually strokes. It also may result from genetic diseases, endocarditis, or amyloid angiopathy - where amyloid protein builds up in the blood vessels in the brain causing intra-cerebral haemorrhage.

Vascular dementia can begin suddenly after a stroke, or be insidious in onset. Patients may have a history of high

**Answers to self-assessment, page 47**

1.c. 2. Four from: • the elderly • those with a learning disability • people with a disease such as Parkinson's disease, diabetes, or who have had a stroke, • people whose lifestyle increases the vascular risk (people who smoke, are obese, have a raised blood pressure, raised cholesterol) • people who drink excessively • Some dementias have familial/genetic patterns. 3. Raising awareness, early diagnosis and intervention; quick competent assessment, sensitively communicating diagnosis; working with other providers and providing ongoing information and support. 4. Alzheimer's dementia, vascular dementia and dementia with Lewy bodies. 5. (See box 1) Cognitive problems; Challenging behavior, psychiatric symptoms, and personality; Neurological symptoms; Difficulties with activities of daily life. 6. Five from: routine haematology; urea & electrolytes; calcium levels; glucose levels; renal and liver function; thyroid function; serum vitamin B12 and folate levels. 7. Three from: Mini mental state examination (MMSE); 6-item cognitive impairment test (6-CIT); GP assessment of cognition (GPCOG); 7 Minute Screen. 8. Five from: Language spoken; sensory impairment; prior level of functioning and attainment; education levels; skills; psychiatric illness; neurological problems. 9. Two from: To establish a definitive diagnosis; to commence appropriate medications and treatments as indicated; to increase access to the specialist multidisciplinary team.

### BOX3: CONDITIONS CAUSING DEMENTIA-LIKE SYMPTOMS

- Pernicious anaemia
- Hypoglycaemia
- Thyroid disease
- Electrolyte disturbances
- Infection
- Dehydration
- Deficiency of vitamin B1 (which can occur with chronic, excessive alcohol consumption)
- Meningitis
- Untreated syphilis
- Advanced AIDS
- Leukemia

blood pressure, vascular disease, or previous strokes or heart attacks. Vascular dementia may or may not be progressive; in some cases, symptoms may get better with time. Deterioration often occurs in a stepwise manner. Vascular dementia with brain damage in the mid-brain, however, will be progressive, with cognitive impairment that appears similar to AD. Some people with vascular dementia maintain their personality and normal levels of social and emotional responsiveness until their disease reaches the later stages.

People with vascular dementia commonly wander at night and often have other problems in common with people who have had a stroke, including depression and incontinence. Vascular dementia is sometimes referred to as multi-infarct dementia (MID) which, as the name implies, is caused by numerous small strokes, often imperceptible to the patient when they occur. The small strokes might happen in one area of the brain, when the damage can be described as 'focal' rather than 'global' (the latter being much more common in AD). Not all strokes cause dementia, but a stroke can damage the brain enough to cause dementia. This is described as single-infarct dementia (SID) and is more common if the stroke affects the left side of the brain and/or the hippocampus (the brain structure responsible for memory).

Rarer forms of vascular dementia, eg cerebral autosomal dominant arteriopathy with subcortical infarct and leukoencephalopathy, may have a genetic component. Other causes of

### BOX 4: INVESTIGATION AND ASSESSMENT

#### Investigations

- Routine haematology
- Urea & electrolytes
- Calcium levels
- Glucose levels
- Renal and liver function
- Thyroid function
- Vitamin B12 and folate

No current guidelines suggest that routine testing for syphilis is appropriate without having first taken a history that might indicate that it is a possible cause of symptoms.

Clinical presentation, such as presence of a raised body temperature, cough, irregular/rapid pulse, or nature of onset should be the guide as to whether a midstream urine test, chest X-ray or ECG should be performed.

vascular dementia include profound hypotension, vasculitis, brain lesions caused by haemorrhage, systemic lupus erythematosus and temporal arteritis.

#### Dementia with Lewy bodies (DLB)

This is a progressive form of dementia. It can occur in people with no family history, but can, more rarely, have a familial pattern. It is related to AD and Parkinson's disease and there are similarities in the pattern of damage to the brain. There are plaques associated with AD and a protein present that is associated with Parkinson's disease.

Although the disease is progressive, with an average period of time from diagnosis to death of around seven years, the early stages are characterised by short periods of apparent remission and the return of some abilities. This can lead to a perception from people close to the patient that the symptoms are 'put on'.

Depression and hallucinations are very common with DLB. Anti-psychotic medications can be very dangerous to people with DLB.

#### Other types of dementia

These include the frontotemporal dementias (FTD). Degeneration and atrophy occurs in the frontal and temporal lobes of the brain. The predominant protein found in the brain is different to that of AD; instead of mainly amyloid

### BOX 5: COGNITIVE TESTING INSTRUMENTS

#### Investigations

- Mini mental state examination (MMSE) – available to purchase online
- 6-item cognitive impairment test (6-CIT) – available on some GP practice systems
- GP assessment of cognition (GPCOG) – available online in English and other languages
- 7 Minute Screen

#### ACTIVITY 5

Find out what cognitive assessment tool is used in your practice. Access it and familiarise yourself with it.

plaques there is often disruption of the tau protein in the brain so that the ability of nerves and brain pathways to send messages is damaged. Again tangles disrupt normal cell activity and cause cells to die.

The FTDs are usually familial, early onset, and progressive in nature. People live with FTD for an average of 5 to 10 years after diagnosis. Often the frontal and temporal involvement causes patients to have problems with interacting appropriately, and behaviour may deviate from social norms quite markedly. Pick's disease is the best known of the FTDs.

There are many other rarer diseases that may lead to dementia, including progressive supranuclear palsy, Korsakoff's syndrome (related to excessive alcohol intake), Binswanger's disease, HIV/AIDS, and Creutzfeldt-Jakob disease (CJD). Some people with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease may also develop dementia as a result of disease progression. These are known as secondary dementias.

#### DIFFERENTIAL DIAGNOSIS

Depression has some similar presenting features and, in the elderly in particular, can present as a diminishing of daily functional activities.<sup>13</sup> Depression tends to develop over a shorter period of time, but the picture can be confused since depression can co-exist with dementia.

Delirium is an acute delusional or confused state, with symptoms similar

▶ to dementia, developing over hours or days. The symptoms are often worse at night, and include confusion, distress, irritability and aggression, paranoia and hallucinations.<sup>7</sup> Causes of delirium are infection (most commonly urinary tract or chest), side-effects of medication, biochemical imbalance and alcohol withdrawal. Somebody with known dementia can develop delirium so this should be considered in the context of any sudden worsening of symptoms.

Many people present with concerns about symptoms that are a part of normal ageing. It is common to have some lapses of memory and mild cognitive impairment (MCI). Where these do not interfere with ADL or the ability to interact socially or occupationally then this does not lead automatically to a diagnosis of dementia. However, signs of MCI may initiate a referral into memory assessment services because more than 50% of people with MCI develop dementia later.<sup>3</sup>

There are also a number of other conditions that can cause dementia-like symptoms (Box 3).

Previous, as well as current, exposure to poisons such as heavy metals or recreational drugs can cause brain damage that persists beyond the end of exposure. Exacerbations and deterioration of respiratory and cardiac conditions may reduce oxygen supply to the brain with resultant confusion, personality changes, hallucinations or memory loss.

Medication may also produce dementia-like symptoms, as a result of single drug toxicity or drug interactions.<sup>12</sup> For all these reasons, if dementia is suspected, diagnosis and investigation

must be comprehensive. A person in whom dementia is suspected will ultimately require referral to a specialist team for brain imaging (eg CT, MRI or perfusion scanning) formal diagnosis and classification. Initially, however, general practice is well placed to start the investigative process; excluding conditions that can cause dementia-like symptoms, involving the patient and family/carers in the process, addressing concerns and identifying resources.<sup>1,3,4</sup>

### ASSESSMENT AND INVESTIGATION

Assessment includes history taking, review of current medication, cognitive and mental state assessment, physical examination and investigations (Box 4). Investigations and assessments should be sensitively explained to the patient. If they wish to involve a family member, or other person close to them, that should be encouraged.

Mentioning the possibility of dementia at an early stage, in the context of excluding other causes and explaining tests, allows individuals time to come to terms with the diagnosis later on and to identify people they would like to support them during later consultations.

### Cognitive assessment

Initially this involves asking about the nature of the problems experienced by the patient, eg memory, speech, orientation and confusion problems, and ability to perform key functions. Formal cognitive assessment tools may then be utilised. There are a number of instruments listed in the current Nice guidance (Box 5).<sup>3</sup> Whatever tool is used, factors that might impact on the outcome (eg language, sensory impairment, prior level of functioning and attainment and educational levels and skills) should be noted and considered. Psychiatric illness and neurological problems may also affect outcome.

Cognitive tests are an essential step towards deciding the likelihood of dementia and need for referral to a specialist service for definitive diagnosis. A new 10-minute iPad test for cognitive impairment has just begun pilot testing in general practices. The Paired Associates Learning (PAL) test is a visual memory test and is not dependent on language. It

is said to be effective for discriminating between MCI as a normal result of aging and early dementia. It is suggested that this test could form the basis of a widespread screening programme in the future and lead to earlier detection and diagnosis.

### SPECIALIST SERVICES

Specialist services for dementia assessment may be within a mental health team, via a memory assessment clinic,

### RESOURCES

- **Collection of factsheets about all types of dementia**  
<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137>
- **Scottish Alzheimer's disease resource**  
<http://www.alzscot.org/pages/info/about.htm>
- **Social care institute for excellence resource for dementia**  
<http://www.scie.org.uk/publications/misc/dementia/index.asp>
- **NICE guidance written for patients and carers (available in word or PDF format)** <http://www.nice.org.uk/CG42>
- **NHS Choices site (includes questions about planning for future care)**  
<http://www.nhs.uk/Conditions/Dementia/Pages/Introduction.aspx>  
<http://www.nhs.uk/Conditions/Dementia/Pages/Treatment.aspx>
- **Lewy Body Society**  
<http://www.lewybody.co.uk/>
- **Pick's disease**  
<http://www.pdsig.org.uk/>
- **Research and facts about dementia (for health professionals)**  
[http://www.ninds.nih.gov/disorders/dementias/detail\\_dementia.htm](http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm)
- **Advice for people caring for a relative or friend at home**  
<http://www.carersuk.org/>
- **Statistics and facts about dementia in the UK (for health professionals)**  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341)
- **Advice and information about mental capacity and planning for the future**  
<http://www.publicguardian.gov.uk/>
- **Information portal for dementia via the Department of Health website**  
<http://dementia.dh.gov.uk/>

### LEARNING POINTS

- Dementia is a growing and significant challenge for health, social and informal care
- Dementia remains a condition that provokes fear in patients and their families
- Dementia is under diagnosed within primary care
- Prompt recognition of dementia and initial assessment, leading to early diagnosis can reduce the distress for individuals and families living with the condition

or within an elderly care team. It should aid early diagnosis and be fully integrated with support for carers, local community health (including primary care), social care and voluntary organizations.

It is advantageous for general practice to work with the specialist service. This can reduce duplication of effort and unnecessary anxiety

### WHEN A DIAGNOSIS IS CONFIRMED

Following initial diagnosis, Nice recommends that patients and families/carers receive ongoing support.<sup>3</sup> Unless the patient indicates to the contrary, written information should be provided.

There are a number of organisations that provide professional, patient friendly factsheets and links to help individuals and families plan for their future and understand options for care. Many of these sources of information are listed within the Map of Medicine dementia care pathway and others are listed in the resources section.

### CONCLUSION

Professionals in primary care need to recognise the fear and stigma of dementia. Managing the assessment and early support processes competently and sensitively will make a big difference. The diagnostic process and ongoing review, support and care mean that a person with dementia will be in contact with many people from primary care, hospitals, voluntary organizations and social care.

To help all concerned understand what is meant by a high standard of care, Nice have published quality standards.<sup>14</sup> These standards are written in plain English and provide outcome measures that reflect the national dementia strategy. They are a resource for you to access before the second article in this series. ●

**The second article will explore the support and care, in primary care and the community as a whole, necessary to meet the needs of individuals with dementia, their families and carers.**

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## SELF-ASSESSMENT

1. How many people in the UK (approximately) are living with dementia?

- a) 7,500    b) 75,000    c) 750,000

2. List four groups of people at increased risk of dementia.

3. What key areas of the dementia care pathway can primary care contribute to?

4. Name the three most common types of dementia seen in the UK.

5. List the four types of problems often reported as symptoms of dementia.

6. List five of the routine blood tests undertaken as part of the initial investigation of dementia.

7. List three cognitive assessment tests suitable for use in primary care.

8. List five factors that might affect the accuracy and effectiveness of cognitive tests.

9. Identify two reasons for referral of a patient with suspected dementia to specialist services

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