

SAMPLE CHAPTER FROM:

## **Dementia**

**The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care**

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## **4. DEMENTIA**

### **4.1 INTRODUCTION**

This guideline is concerned with the identification and treatment of, and care for, dementia as defined in the 10th edition of the *International Classification of Diseases* (ICD-10) (World Health Organization, 1992). Care for people with dementia is provided by both health and social care organisations, each bringing its own particular perspectives on both the nature of the dementia and, more particularly, our response to people with dementia. As a result, this guideline has been jointly developed for the Social Care Institute for Excellence (SCIE) and the National Institute for Health and Clinical Excellence (NICE), and we have drawn on the combined knowledge and evidence base of both social and clinical perspectives within the area of dementia care. This has presented challenges for guideline development in analysing and synthesising the two different approaches to ‘evidence’ and the sheer volume of literature needing appraisal, and the need to produce ‘joined up’ practice guidelines to address the sometimes contrasting perspectives in health and social care approaches to dementia care.

For example, from a clinical perspective, dementia can be described as a group of usually progressive neurodegenerative brain disorders characterised by intellectual deterioration and more or less gradual erosion of mental and later physical function, leading to disability and death. This approach has allowed the development and deployment of pharmacological interventions for people with dementia and holds the hope that one day some dementia may be preventable or curable.

Alternatively, from a social perspective, dementia can be viewed as one of the ways in which an individual’s personal and social capacities may change for a variety of reasons, and changes in such capacities are only experienced as disabilities when environmental supports (which we all depend upon to varying degrees) are not adaptable to suit them. Moreover, dementia thought of from a clinical perspective (that is, disease and disability leading to death) may also prefigure our collective social and professional approach to people with dementia as people irretrievably ill and fundamentally different from able-bodied healthy young people. This view may well underpin many of the problems faced by people with dementia and their carers when seeking help and in their experience of care in different settings.

We have found that these two perspectives – the medical and the social – are often not mutually exclusive; good practice that serves the needs of people with dementia and their carers is respectful of both. Thus, we hope that this guideline has gone some way to integrate evidence of the best approaches to dementia care in the medical and social traditions.

#### 4.1.1 Medical model of dementia

Dementia as a clinical syndrome is characterised by global cognitive impairment, which represents a decline from previous level of functioning, and is associated with impairment in functional abilities and, in many cases, behavioural and psychiatric disturbances. Several formal definitions exist, such as that of the ICD-10:

*‘a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. The syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain’.*

By convention, young-onset dementia refers to those who develop dementia before the age of 65 (previously called ‘pre-senile’ dementia); late-onset dementia refers to those who develop the illness after the age of 65 (previously ‘senile’ dementia). The distinction between young- and late-onset illness still has clinical utility because aetiology and characteristics of people with dementia differ between young- and late-onset cases, and people with dementia are thought to require and benefit from a different approach, leading to the widespread, but not yet universal, establishment of local specialist young-onset dementia services (Harvey *et al.*, 2003).

There are a number of conditions that cause the symptoms of dementia. Alzheimer’s disease (AD) accounts for around 60% of all cases; other common causes in older people include cerebrovascular disease (vascular dementia [VaD]) and dementia with Lewy bodies (DLB) (accounting for 15–20% of cases each). In cases of young onset, frontotemporal dementia (FTD) is also a common cause, second only to AD. Numerous other causes exist, including other degenerative diseases (for example, Huntington’s disease), prion diseases (Creutzfeldt-Jakob Disease [CJD]), HIV dementia and several toxic and metabolic disorders (for example, alcohol-related dementia). Dementia also develops in between 30–70% of people with Parkinson’s disease, depending on duration and age (Aarsland *et al.*, 2003). The distinction between Parkinson’s disease dementia (PDD) and DLB lies in the relationship between motor and cognitive impairment. If dementia precedes, or occurs within 12 months of, motor disorder, DLB is diagnosed (McKeith *et al.*, 1996); otherwise the convention is to use the term PDD.

Some conditions have been described that can cause a ‘reversible’ dementia; in other words, a global cognitive decline for which there is some potentially reversible cause. These include psychiatric disorders (particularly the ‘pseudodementia’ of depression), space-occupying lesions, toxic states and metabolic and endocrine abnormalities (for example, vitamin B<sub>12</sub>, folate deficiency and hypothyroidism). The differentiation between depression and dementia can be challenging and has important implications for treatment. The other conditions listed are not common causes of

dementia (less than 5%) in the UK, since such physical problems would often be detected at an earlier stage, before giving rise to cognitive impairment. However, their importance lies in the fact that, when such conditions are detected, appropriate interventions offer a real chance of stabilisation, improvement or even (in rare cases) recovery.

Increasingly it is recognised that mixed cases of dementia (for example, AD and VaD, and AD and DLB) are commonly encountered, especially in older people. It has been shown that different pathologies can each contribute to the clinical expression of dementia (Snowdon *et al.*, 1997); a large UK-based neuropathological study showed that mixed pathology was the most common finding at autopsy in the brains of older people (MRC/CFAS, 2001).

Dementia can be distinguished from the mild and variable cognitive decline associated with normal ageing by the severity and global nature of cognitive impairment and the accompanying functional disability that results. More challenging is its distinction from more subtle patterns of cognitive impairment which fall short of the standard definitions of dementia but which may represent a 'pre-clinical' dementia state. For example, the syndrome of 'mild cognitive impairment' (MCI) has been defined as an isolated cognitive impairment (or impairments) identified as abnormal by a statistical rule (usually 1½ standard deviations below that expected on the basis of age and education) and representing a decline from previous level of function (Petersen *et al.*, 1999). Verification of cognitive difficulties by an informant and/or the individual concerned is required and the cognitive impairment should not be so severe as to affect social or occupational functioning (at which point the diagnosis of dementia would be more appropriate).

Several different types of MCI have now been proposed, including 'amnesic' when memory is affected and 'non-amnesic' reflecting impairments in a non-memory domain. Single-domain and multiple-domain types of MCI have been proposed, depending on the number of cognitive functions affected, though their nosological status is unclear. However, several authors have shown that those with amnesic MCI are at an increased risk of subsequently developing frank dementia, most usually of the Alzheimer type (10–15% per annum) (Bischof *et al.*, 2002). Those with MCI due to cerebrovascular disease also appear to be at an increased risk of subsequently developing dementia (Wentzel *et al.*, 2001). The usefulness of the concept is, firstly, that it provides a means to characterise patients with early cognitive impairments who are increasingly presenting to both primary and secondary care and, secondly, such individuals also represent a group who might also be appropriately targeted for putative disease-modifying therapies (Petersen *et al.*, 2005).

### **4.1.2 Symptoms, presentation and patterns of illness**

AD usually presents with loss of memory, especially for learning new information, reflecting the disturbances of function of the anatomical sites (medial temporal lobe and the hippocampus), which are the primary focus of pathological change. Later in the illness other higher cortical functions (for example language, praxis and executive

function) become affected and behavioural and psychiatric disturbances are seen. These have been referred to in the literature in a number of ways, including behavioural and psychological symptoms of dementia (BPSD), challenging behaviour, neuropsychiatric symptoms and, more recently, behaviour that challenges. Such symptoms commonly include depression, apathy, agitation, disinhibition, psychosis (delusions and hallucinations), wandering, aggression, incontinence and altered eating habits. They are important because they are frequent symptoms, which are often difficult to manage and cause great distress to individuals and carers. They are stronger predictors than cognitive impairment of both carer stress (Donaldson *et al.*, 1997) and entry to institutional care (Bianchetti *et al.*, 1995). Sometimes AD can present initially as behavioural disturbance, language disturbance or praxis but these may also be manifestations of other causes of dementia.

Frontotemporal dementia usually presents with language disturbance and/or behavioural difficulties (either disinhibition or apathy), whilst DLB is characterised by recurrent visual hallucinations, fluctuating cognitive disturbance and motor features of parkinsonism. Associated features in DLB are falls, disturbances of consciousness, autonomic dysfunction and rapid eye movement (REM) sleep behaviour disorder (McKeith *et al.*, 2005).

VaD can present after an acute vascular event (for example, a stroke) or subacutely and insidiously with progressive attentional and executive/planning problems, gait disturbance and apraxia, reflecting ‘subcortical’ frontostriatal dysfunction due to vascular pathology. Focal neurological signs are common (and their presence is required by some diagnostic criteria) as are changes on brain imaging, including cortical infarcts, multiple lacunae and extensive white matter change. Behaviours that challenge are also common in VaD, with depression and apathy seen most frequently (O’Brien *et al.*, 2003).

### **4.1.3 Course and prognosis**

AD is characterised by a progressive decline in cognition and ability to function. Behavioural disturbances can occur early but tend to become more frequent as the severity of dementia increases. As independence is lost, people become unable to care for themselves, dress, wash, eat and toilet. There may be brief plateaus during the illness but decline is fairly consistent, tending to increase or accelerate.

Similarly, DLB and FTD are associated with progressive decline, although often superimposed on the progressive course of DLB is a pattern of fluctuating confusion whereby cognitive function can vary over minutes, hours, days or weeks. Parkinsonism also progresses over time in DLB, although about 25% of people will not develop parkinsonism during the illness. The combination of cognitive impairment and motor disorder in DLB and FTD causes considerably greater impairment in ability of function than that predicted by the degree of cognitive dysfunction present.

The course of VaD is less predictable, since in some cases relative stability may be seen for a period, if underlying VaD can be stabilised. Alternatively, a subsequent vascular event can cause a sudden and ‘stepwise’ deterioration in cognitive function.

## *Dementia*

Overall, decline is usual in VaD, and in naturalistic studies the rate of overall cognitive change is surprisingly similar across all three main types of dementia (AD, DLB and VaD) at 3–4 points per year on the Mini Mental State Examination (MMSE). In clinical trials, people with VaD show a more stable course, possibly because of better management of vascular risk factors (Black *et al.*, 2003). Due to comorbid conditions, people with VaD in particular have increased risk of mortality due to cardiovascular and cerebrovascular disease.

### **4.1.4 Physical and social consequences of dementia**

People with dementia are at increased risk of physical health problems, and dementia is a major risk factor for delirium due to physical illness or medication. There are many reasons for this association. Dementias such as VaD and DLB frequently occur in those with other severe illnesses (such as stroke and Parkinson's disease). Progressive dementia during the course of AD itself can be associated with marked changes in autonomic function, appetite and eating habits, sleep and neurological signs. Decreased mobility and attention to personal care and diet, together with lack of compliance with medical treatments, renders people with dementia more susceptible to other illnesses and causes particular challenges for their treatment. Nutritional problems and weight loss are common problems in dementia, especially as the severity of illness increases. The Alzheimer's Society 'Food for Thought' practice guides and advice sheets were produced specifically to help health and social care staff and carers deal with the challenges experienced by people with dementia concerning food, eating and drinking ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)). These guides are based on research conducted for the Society (Alzheimer's Society, 2000; Watson *et al.*, 2002).

The multiple difficulties and increased risk of physical health problems mean that people with dementia may have multiple contacts with different NHS and social care professionals. By definition, dementia has an impact on activities of daily living (ADL), which in mild cases may consist of difficulties in shopping, maintaining a home and personal care but in more advanced cases may lead to difficulties in mobility, toileting and language skills.

People with dementia, therefore, become increasingly reliant on family, friends and neighbours, and health and social care services. Carers (usually relatives but sometimes friends and neighbours) provide the majority of such care. Carer stress is common, with approximately 30% of carers having significant psychiatric morbidity (Donaldson *et al.*, 1997). Despite much public education over the last 2 decades, dementia remains a stigmatising illness, causing difficulties for both people with dementia and carers.

## **4.2 SOCIAL MODEL OF DEMENTIA**

While the clinical model of dementia presented above describes the changes occurring within the brain, the way that dementia affects a person in day-to-day life will

vary from one individual to the next. For many years, people with dementia were written off as incapable, regarded as little more than ‘vegetables’ and often hidden from society at large. During the 1980s and 1990s, there was a move away from regarding people with dementia as incapable and excluding them from society, and towards a ‘new culture of dementia care’, which encouraged looking for the person behind the dementia (Gilleard, 1984; Kitwood & Benson, 1995; Kitwood, 1997). People with dementia could now be treated as individuals with a unique identity and biography and cared for with greater understanding.

Building on this work, others (notably Marshall, 2004) have advocated that dementia should be regarded as a disability and framed within a social model. The social model, as developed in relation to disability, understands disability not as an intrinsic characteristic of the individual, but as an outcome produced by social processes of exclusion. Thus, disability is not something that exists purely at the level of individual psychology, but is a condition created by a combination of social and material factors including income and financial support, employment, housing, transport and the built environment (Barnes *et al.*, 1999). From the perspective of the social model, people with dementia may have an *impairment* (perhaps of cognitive function) but their *disability* results from the way they are treated by, or excluded from, society. For people with dementia, this model carries important implications, for example:

- the condition is not the ‘fault’ of the individual
- the focus is on the skills and capacities the person retains rather than loses
- the individual can be fully understood (his or her history, likes/dislikes, and so on)
- the influence is recognised of an enabling or supportive environment
- the key value is endorsed of appropriate communication
- opportunities should be taken for rehabilitation or re-enablement
- the responsibility to reach out to people with dementia lies with people who do not (yet) have dementia (Gilliard *et al.*, 2005).

The social model of care seeks to understand the emotions and behaviours of the person with dementia by placing him or her within the context of his or her social circumstances and biography. By learning about each person with dementia as an individual, with his or her own history and background, care and support can be designed to be more appropriate to individual needs. If, for example, it is known that a man with dementia was once a prisoner of war, it can be understood why he becomes very distressed when admitted to a locked ward. If care providers have learned that a person with dementia has a strong dislike for a certain food, it can be understood why the person might spit it out. Without this background knowledge and understanding, the man who rattles the door may be labelled a ‘wanderer’ because he tries to escape and cowers when approached, or the person who spits out food is labelled as ‘antisocial’.

Moreover, a variety of aspects of care may affect a person as the dementia progresses. Some extrinsic factors in the care environment can be modified, for instance noise levels can be highly irritating but are controllable. Other intrinsic factors, such as the cultural or ethnic identity of the person with dementia, may also have a bearing on how needs are assessed and care is delivered. Some aspects will be more important or relevant to one person than to another. The social model of care asserts that dementia is more than, but inclusive of, the clinical damage to the brain.

### **4.3 EXAMPLES OF EXPERIENCES OF CARE**

Dementia by its nature does not lend itself to a clear, sequential care pathway, as it affects people in very individual ways. However, using particular scenarios as examples (Care Examples 1, 2 and 3 below), some key elements and issues can be illustrated, which indicate how clinical and social perspectives interact. The care examples are given to illustrate significant issues; they do not imply that negative experiences are universal.

The diagrams in each care example illustrate the interconnection between the needs of a person with dementia, his or her carer and other relevant services or sources of information. The circles vary in size according to the significance of likely need at that given time. Need is a dynamic concept; in other words, needs will change over time, with consequent changes in their relative level of significance. It should be noted that the scenarios below are independent of one another and do not imply any progression of severity.

### **4.4 INCIDENCE AND PREVALENCE**

There have been several epidemiological studies of dementia. The Eurodem Consortium found prevalence rose from 1% for 60–65 year olds to 13% for 80–85 year olds and 32% for 90–95 year olds (Hofman *et al.*, 1991). Dementia therefore affects around 5% of the over 65s, rising to 20% of the over 80s. The best prevalence data for England and Wales came from the Medical Research Council (MRC)-funded Cognitive Function and Ageing Study (CFAS), which found very similar prevalence rates in six different geographically diverse sites (MRC/CFAS, 1998). This study estimated that there were then 550,000 people in England and Wales with dementia, a figure that has now been revised to nearly 700,000 cases (Alzheimer's Society, 2006, [www.alzheimers.org.uk](http://www.alzheimers.org.uk)). Prevalence is higher in women than men, partly reflecting their greater longevity. Table 2 gives estimates of the number of people over 65 years of age with dementia in England and Wales for 5-year age bands according to prevalence estimates for England and Wales from the MRC CFAS study (MRC/CFAS, 1998) and population data for 2005 (the most recent actual population data available from the Office for National Statistics). Table 3 gives estimates of the number of people over 65 years of age with AD in England and Wales for 5-year age bands according to prevalence estimates calculated from European population-based studies of people aged 65 and older (Lobo *et al.*, 2000) and population data for 2005. Incidence studies have shown rates of 1–3 per 1000 for those aged 65–70, rising to 14–30 per 1000 for those aged 80–85 (Fratiglioni *et al.*, 2000; Jorm & Jolley, 1998). In most studies, women also seem to have an increased incidence rate, suggesting their higher prevalence figures are not entirely due to greater life span. Possible explanations include confounding effects of education and possible hormonal influences.

Prevalence rates for VaD are generally lower than for AD (Lobo *et al.*, 2000), with prevalence calculated to double every 5.3 years as opposed to every 4.5 years for AD (Jorm *et al.*, 1987). Table 4 gives estimates of the number of people over 65 years of age with VaD in England and Wales for 5-year age bands according to prevalence estimates calculated from European population-based studies of people aged 65 and

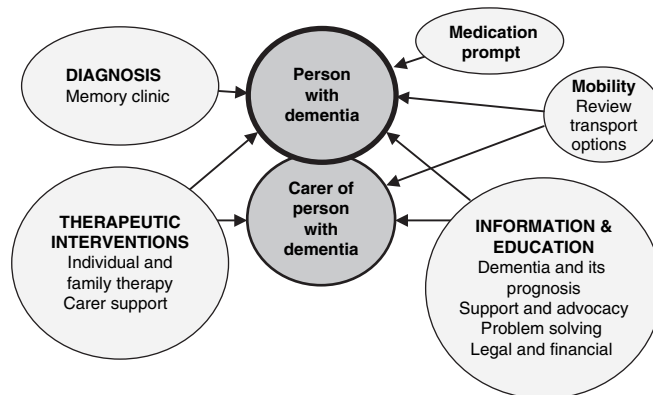
**CARE EXAMPLE 1**

Mr R is 54 years old and married, with two daughters aged 20 and 14. He lives with his wife and youngest daughter; his eldest daughter lives locally. Mr R has his own textile company, which he has managed successfully with a business partner and close friend for many years.

There is a familial history of young-onset AD; his mother developed the condition in her late 50s, which eventually resulted in her requiring nursing-home care, and died in her mid 60s.

In the months prior to referral, Mrs R had noticed increasing incidents of forgetfulness in her husband; he would forget conversations and repeat questions. She also noted that he would be searching the house for things he had misplaced and, on occasion, accuse her of hiding or losing items. He had forgotten instructions and planned tasks. This resulted in him forgetting to collect the youngest daughter following a school trip and not arriving at pre-arranged meeting places. He had taken his wife into town and, after visiting a shop on his own, had driven home without her.

His business partner had also, on an increasing number of occasions, contacted Mr R's wife to enquire as to his whereabouts, as he had not turned up to an arranged appointment. This was having a detrimental effect on business, and customers were expressing their annoyance. Despite prompting and careful and supportive organising of his workload by his partner and secretary, the situation was deteriorating rapidly.



Mr R did not appear to be aware of these difficulties at the time and felt it was 'just his age'. He did however mention that people were concerned about his memory when visiting his GP regarding an unrelated health matter, resulting in a referral to the local memory clinic. Mr R was diagnosed with AD and offered acetylcholinesterase inhibitor medication.

Their daughters were also extremely distressed; the oldest was able to talk over some of her concerns with her mother, but the younger daughter found this very difficult and became quite withdrawn and declined the option of talking to a member of the clinical team.

On commencing treatment, there were issues regarding concordance with Mr R's medication. He had a good rapport with the nurse specialist and during discussion stated, 'If I accept that I need the medication I have to accept that I have the condition'. There seemed to be resolution following this discussion and to date Mr R is fully concordant with the treatment.

Mr R decided to sell his company in order to 'do the things we always wanted to do while I'm still able'.

Each member of the family said they would like to talk to someone in a similar situation.

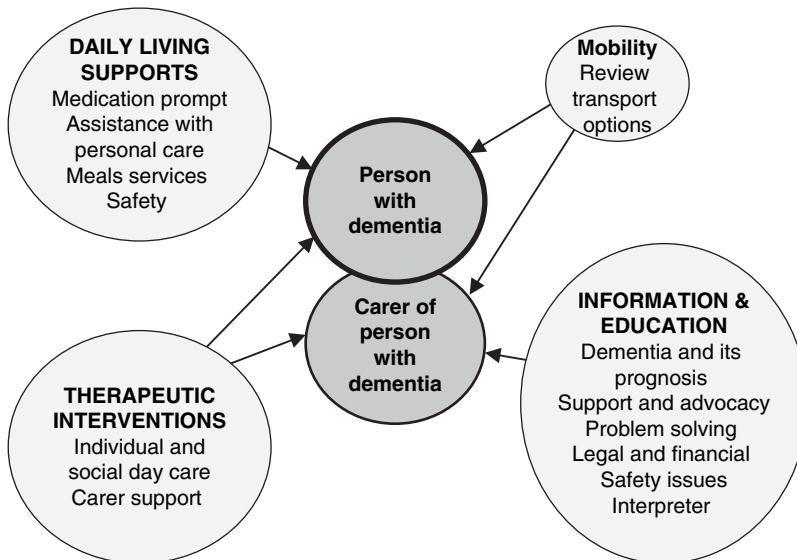
Unfortunately, Mr R quickly developed visuospatial problems and was told he should stop driving. He saw this as a 'devastating blow' and angrily challenged this directive. He underwent a driving assessment at the DVLA centre, the outcome of which supported clinical opinion, and his licence was withdrawn. This had a far-ranging and major effect on the family. Mrs R did not drive, and there were no local shops. They used to spend the family holidays touring in their caravan.

Mrs R had a part-time job and was understandably worried that her husband would become more isolated and housebound.

**CARE EXAMPLE 2**

Mrs H is 79 years old, with a diagnosis of multi-infarct dementia, and lives alone in a 19th century mid-terraced house in an isolated rural village. She moved to this country from Bangladesh with her husband and has never learned to speak English. She was widowed 2 years ago, when her husband died of lung cancer. She has two daughters; J lives 15 miles away in the same county and N lives 140 miles away in North Yorkshire. Both work full time and have teenage children.

Mrs H was first diagnosed with dementia 5 years ago and, as is characteristic, experienced several small strokes over these years, causing further impact on her ability to care for herself independently. She often failed to remember to take prescribed medication and was unable to effectively manage her personal care.



Mrs H was referred by her GP to social services, who have undertaken the first contact assessment within the Single Assessment Process. The Social Services Access team is trying to encourage Mrs H to accept a care package of day care for 2 days a week and meals services for the remaining days, a medicine prompt and a safety check in the evening by a home carer. Communication difficulties and family concerns about whether the food preparation meets Mrs H's cultural needs, together with Mrs H's sense of independence and lack of insight, have led to her refusal of all offers of help.

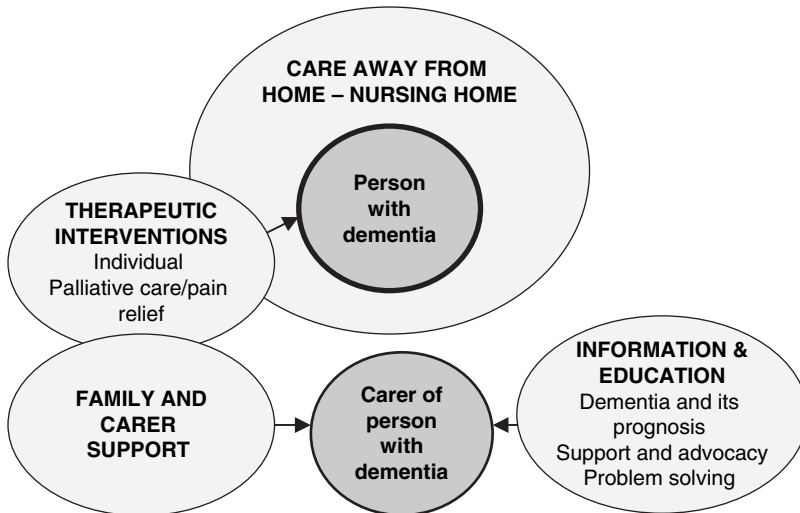
J is frequently called by neighbours when her mother wanders from her home at inappropriate times and is often not dressed appropriately for the weather conditions. She tends to leave home with the door open, which means her home is unsafe.

J is becoming very stressed and expresses concerns that she knows little about the diagnosis her mother has received and its likely progression. She also fears the stigma of the condition within her culture. Without any knowledge of the care possibilities, and with pressure from family members to continue caring for Mrs H, J feels that there is no alternative but to care for her mother herself and is considering working part-time to do this. However, this will create a lot of financial stress and difficulty for her own family; having been made redundant, her husband is currently not working and J is the main earner of the household.

**CARE EXAMPLE 3**

Mr J was diagnosed with AD 8 years ago. He and his wife lived together in their detached suburban house with minimal support for at least 6 of these years. Mrs J was a very able and committed carer who provided for almost all of her husbands needs.

During the course of the AD, Mr J was also diagnosed with bowel cancer, which resulted in a colostomy. Mrs J continued to care for her husband and fulfilled the additional needs of colostomy care. Mr J can become extremely distressed during the daily care of his colostomy and it is believed that he suffers a high degree of associated pain since the surgical procedure.



During the Christmas period, Mrs J suffered a significant stroke; Mr J was admitted to a local private nursing home for emergency respite care. Mrs J made a good recovery over a period of months and returned home. Due to the effects of the stroke, Mrs J now required home help twice daily to support her with personal care, which meant that she was no longer physically able to care for her husband at home. Mr J's placement in the nursing home was made permanent.

Mrs J has found it very difficult to 'let go' of the direct caring role she had with her husband and feels guilty that she is unable to care for him. She visits Mr J every day for several hours and often complains to the home manager that the standard of care is not adequate.

older (Lobo *et al.*, 2000) and population data for 2005. Incidence rates are higher in males (1.2 per 1000 for males aged 65–70; 0.3 per 1000 for females aged 65–70) but females catch up at older ages (prevalence 6 per 1000 for both males and females aged 85–90). There have been too few studies on DLB to determine incidence and prevalence; the one population-based UK study published to date found DLB was the cause of 11% of dementia cases in a sample taken from north London (Stevens *et al.*, 2002). A study of young-onset dementia revealed a prevalence of 54 per 100,000 people aged 30–64 (Harvey *et al.*, 2003), suggesting that there would currently be around 14,000 people with young-onset dementia in England and Wales<sup>30</sup>. Table 5 gives estimates of the number of people under 65 years of age with dementia in

<sup>30</sup> Based on mid-2005 population estimates (available at: [www.statistics.gov.uk](http://www.statistics.gov.uk)).

**Table 2: Number of people with dementia in England and Wales aged over 65**

Age group	Prevalence of dementia (rate/100 people)		Population in England & Wales (2005)		Estimated number of people with dementia (England & Wales)	
	Males	Females	Males	Females	Males	Females
65–69	1.4	1.5	1,158,600	1,238,000	16,220	18,570
70–74	3.1	2.2	963,100	1,103,700	29,856	24,281
75–79	5.6	7.1	750,500	980,800	42,028	69,637
80–84	10.2	14.1	508,000	816,700	51,816	115,155
≥85	19.6	27.5	318,900	741,100	62,504	20,3803
<b>Total (≥65)</b>			<b>3,699,100</b>	<b>4,880,300</b>	<b>202,424</b>	<b>431,446</b>
			<b>All: 8,579,400</b>		<b>All: 633,870</b>	

Source: prevalence of dementia (MRC/CFAS, 1998), population statistics (Office for National Statistics).

**Table 3: Number of people with AD in England and Wales aged over 65**

Age group	Prevalence of AD (rate/100 people)		Population in England & Wales (2005)		Estimated number of people with dementia (England & Wales)	
	Males	Females	Males	Females	Males	Females
65–69	0.6	0.7	1,158,600	1,238,000	6,952	8,666
70–74	1.5	2.3	963,100	1,103,700	14,447	25,385
75–79	1.8	4.3	750,500	980,800	13,509	42,174
80–84	6.3	8.4	508,000	816,700	32,004	68,603
85–89	8.8	14.2	Data not available		–	–
≥90	17.6	23.6	Data not available		–	–

Source: prevalence of AD (Lobo *et al.*, 2000), population statistics (Office for National Statistics).

**Table 4: Number of people with VaD in England and Wales aged over 65**

Age group	Prevalence of VaD (rate/100 people)		Population in England & Wales (2005)		Estimated number of people with VaD (England & Wales)	
	Males	Females	Males	Females	Males	Females
65–69	0.5	0.1	1,158,600	1,238,000	5,793	1,238
70–74	0.8	0.6	963,100	1,103,700	7,705	6,622
75–79	1.9	0.9	750,500	980,800	14,260	8,827
80–84	2.4	2.3	508,000	816,700	12,192	18,784
85–89	2.4	3.5	Data not available		–	–
≥90	3.6	5.8	Data not available		–	–

Source: prevalence of VaD (Lobo *et al.*, 2000), population statistics (Office for National Statistics).

**Table 5: Number of people with young-onset dementia (aged under 65) in England and Wales**

Age group	Prevalence of young-onset dementia (rate/100 people)		Population in England & Wales (2005)		Estimated number of people with young-onset dementia (England & Wales)	
	Males	Females	Males	Females	Males	Females
30–34	0.0126	0.0128	1,847,800	1,864,400	233	239
35–39	0.0054	0.0105	2,054,300	2,070,600	111	217
40–44	0.0053	0.0255	2,016,100	2,053,500	107	524
45–49	0.0363	0.0298	1,764,900	1,792,800	641	534
50–54	0.0659	0.0591	1,602,100	1,637,200	1,056	968
55–59	0.2002	0.1027	1,714,700	1,760,400	3,433	1,808
60–64	0.2045	0.1294	1,347,100	1,409,900	2,755	1,824
<b>Total (30–64)</b>			<b>12,347,000</b>	<b>12,588,800</b>	<b>8,335</b>	<b>6,114</b>
			<b>All: 24,935,800</b>		<b>All: 14,449</b>	

Source: prevalence of dementia (Harvey *et al.*, 2003), population statistics (Office for National Statistics).

England and Wales for 5-year age bands according to prevalence estimates calculated from a relatively small population sample in England (Harvey *et al.*, 2003) and population data for 2005. Demographic changes in the next 30 years, with a substantial increase in the proportion of people in the 'old old' age groups, mean that prevalence of dementia is set to more than double in the next 30–50 years (Wancata *et al.*, 2003).

## **4.5 AETIOLOGY**

Some risk factors are common to most types of dementia and others are specific to particular types. The summary below refers to dementia or a specific diagnostic category as appropriate to the evidence. Risk factors can be considered as genetic, environmental and genotypic. Genetic and genotypic risk factors will modify an individual's reaction to those environmental risk factors to which he or she is exposed.

### **4.5.1 Genetic factors**

At least three genes with multiple mutations can be identified for familial young-onset AD, all of which are rare (Hardy, 1996; Schellenberg *et al.*, 1991; Cruts *et al.*, 1998).

- A family history of late-onset AD or VaD is associated with an increased risk of developing the condition in any individual, but no single chromosomal abnormality has been identified to account for this.
- Discrete chromosomal abnormalities account for some cases of frontotemporal degeneration (Spillantini *et al.*, 1998).
- Down's syndrome is the most common genetic disorder and is the result of a chromosomal abnormality. The risk of developing AD is significantly higher for those with Down's syndrome than the general population (Rabe *et al.*, 1990). The risk rises with increasing age, but the age of onset is considerably younger than in the general population (Visser *et al.*, 1997; Tyrell *et al.*, 2001).

Apolipoprotein E is a polymorphic lipoprotein found in the brain. Its role is unclear, though it has been implicated in repair of the nerve sheath (Mann *et al.*, 1996). There are three common variants of the gene that codes for ApoE. These are known as ApoE  $\epsilon$  2, ApoE  $\epsilon$  3 and ApoE  $\epsilon$  4. The ApoE  $\epsilon$  4 allele has been identified as a risk factor for the development of late-onset AD in particular and reduces the age at which one could expect to develop the condition (Strittmatter *et al.*, 1993; Poirier *et al.*, 1993). However, the effect is not equal across different racial groups (Tang *et al.*, 1996). Possession of the ApoE  $\epsilon$  4 allele is not causative of AD on its own but tends to modulate when and whether the disease will become manifest under the influence of other aetiological factors (Kuusisto *et al.*, 1994; Skoog *et al.*, 1998).

### **4.5.2 Environmental factors**

The risk of developing dementia rises with increasing age (Jorm *et al.*, 1987; Hofman *et al.*, 1991; Copeland *et al.*, 1992; Boothby *et al.*, 1994). Age may be a risk factor in

itself or may reflect the effect of increasing time during which other factors can exert their influence.

Cardiovascular risk factors are smoking (Ott *et al.*, 1998), high blood pressure (Lindsay *et al.*, 1997), diabetes (Desmond *et al.*, 1993) and hyperlipidaemia (Moroney, 1999a). All of these are independent risk factors for the development of VaD and predispose to the development of atherosclerosis, which is associated with dementia of all clinical types (Hofman *et al.*, 1997). These risk factors also predispose to acute stroke, which is well established as a risk factor for the development of dementia (Tatemichi *et al.*, 1992, 1993). Smoking (Launer *et al.*, 1999; Prince *et al.*, 1994), high blood pressure (Stewart *et al.*, 1999; Skoog *et al.*, 1996) and diabetes mellitus (Leibson *et al.*, 1997) are all independent risk factors for the development of AD.

Earlier evidence linked an increased risk of developing AD with a history of depression earlier in life. More recent general population studies have identified an increased risk of all dementias with a past history of severe psychiatric problems, schizophrenia and depression being the most common diagnoses found (Cooper & Holmes, 1998).

Although earlier work described an association between head injury and AD (Mortimer *et al.*, 1985; Mayeux *et al.*, 1993), a more recent meta-analysis did not support these findings (Launer *et al.*, 1999). There is also currently no evidence for a causative link between occupational exposure to solvents or lead and the development of AD (EURODEM studies). While it is clear that ingestion of aluminium can be neurotoxic, it is unclear whether it is responsible for the chronic neurodegeneration of AD (Doll, 1993; Altmann *et al.*, 1999). Clustering of cases of AD in industrial areas could point to an environmental toxin not yet identified (Whalley *et al.*, 1995).

High educational attainment or higher premorbid IQ has been shown across different cultures to exert a protective effect against the development of dementia (Canadian Study of Health and Ageing, 1994; Zhang *et al.*, 1990; Schmand *et al.*, 1997; Snowdon *et al.*, 1996).

Research into the aetiology of dementia is confounded by the current classification systems (ICD-10 and DSM-IV-TR), which have been based on end-stage pathological findings that assume, in part, aetiology. Often an individual may have been given a clinical diagnosis of a particular type of dementia but, on post mortem examination, there can be a mixture of the pathological characteristics of AD, DLB and VaD. The relationship of these different pathological processes to each other and their roles in causing the cognitive decline experienced by people with dementia remains to be fully explained.

## **4.6 DETECTION AND ASSESSMENT**

### **4.6.1 Detection**

The changes that occur in cognition, emotion or capabilities as possible early signs of dementia can be recognised by the person him or herself and/or his or her family and friends, general practitioner (when he or she consults about other problems), or

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nursing or social care staff (providing services in his or her home or in a residential institution).

Detection of the early changes of dementia syndromes may occur when the person affected or those around him or her actively seek help, usually, but not exclusively, from his or her general practitioner. It may also occur when professionals become suspicious of changes in the individual, even when the individual and others around him or her are not concerned. A third route to recognition is through revelatory moments, for example when the sudden incapacity of a carer reveals the dementia processes in the person concerned, for whose cognitive losses the carer had compensated. These three routes to recognition of dementia create their own problems of investigation, diagnosis and disclosure, which will be discussed further in this guideline.

Detection of dementia, particularly in its early stages, depends on pattern recognition, deductive reasoning and accumulation of diagnostic evidence from multiple sources. These processes tend to be iterative and may be relatively prolonged. Factors inhibiting the detection process include denial on the part of affected individuals, families and professionals, and limited impact on families of changes in the individual, as well as limited awareness of the dementia syndromes and limited diagnostic skills amongst practitioners in different disciplines. Dementia syndromes can emerge as changes in cognition, emotion or capability, and their manifestation is influenced by the personality of the person affected. Delays in recognition can occur because of the difficulties in distinguishing novel changes from pre-existing characteristics or behaviour traits.

There is as yet no simple, accurate and cost-effective method for identifying individuals with early dementia syndromes through population screening, although there may be a case for targeted screening of sub-populations.

### **4.6.2 Assessment and diagnosis**

Diagnosis of dementia syndromes can be a prolonged iterative process, particularly in the early stages of the condition. The time from first symptoms to diagnosis can be as much as 12 months, for a number of reasons.

The usual components of the diagnostic process in a primary-care setting are:

- the individual's self-report of changes in memory, capability or mood
- informant histories that support self-report and add significant new details of changes
- exclusion of depression and delirium as primary pathologies, using the information from the personal and informant histories
- measurable cognitive losses, using a standardised instrument
- absence of 'red flag' symptoms suggesting alternative diagnoses (for example, urinary incontinence or ataxia in apparent early dementia).

By custom, a number of other conditions that can induce cognitive impairment are excluded at this stage by blood tests, including vitamin B<sub>12</sub> deficiency, hypothyroidism, diabetes and disorders of calcium metabolism.

Further clarification of the extent and probable cause of a dementia syndrome requires more complex cognitive function testing (and so referral to a

specialist memory assessment service) and/or CT scanning (following referral to specialist care).

Disclosure of the emerging diagnosis is a complex and sensitive task, and all professional groups find this difficult. However, the rising public awareness of AD means that discussion about the possible causes of changes in cognition can begin earlier in the diagnostic process.

Needs assessment of the person with dementia, and of his or her family, are more commonly carried out in specialist services or by social services, than in primary care.

#### 4.6.3 Assessment in learning disabilities and dementia

'Learning disability' is a term used almost exclusively in the United Kingdom to cover the ICD-10 categories for mental retardation (F70–79) in people of all ages. The two main components are low cognitive ability (defined as a full-scale IQ of less than 70) and diminished social competence characterised by impairment of skills that becomes apparent during the developmental period (that is, before the age of 18 years). IQ is used to define four categories of severity (mild, moderate, severe and profound). People with learning disabilities have a higher than expected rate of both physical and mental health problems. A catalogue of special diagnostic criteria, the DC-LD, has been produced for psychiatric disorders in this population to complement ICD-10 (Royal College of Psychiatrists, 2001). Other practice guidelines for diagnosis of mental health problems in learning disability also exist (Deb *et al.*, 2001).

The White Paper *Valuing People* (Department of Health, 2001a) estimated that there were more than 1.4 million people with learning disabilities in England. Of these people, 210,000 have severe and profound learning disabilities (of whom 12% are older people). The White Paper suggested that the number of people with severe learning disabilities of any age would increase by approximately 1% per year for the next 15 years, for various reasons.

Although the National Service Framework for Older People sets out a framework for services for older people (Department of Health, 2001b), the White Paper *Valuing People* (Department of Health, 2001a) points out that the ageing process for people with learning disabilities may begin much earlier and that planning for the needs of older people with learning disabilities may need to include a more extended population, perhaps from age 50 years upwards. It was assumed that local Partnership Boards would ensure coordination between learning disability services and older people's services so that people can use services most appropriate to their needs. In particular, people at risk of developing young-onset AD, such as people with Down's syndrome, were mentioned, and the White Paper stated that the Government will expect learning disability services to work with specialist mental health services to ensure that appropriate supports are provided for younger people with learning disabilities suffering from dementia.

People with Down's syndrome are at risk of developing AD about 30–40 years earlier than the rest of the population, although lifetime risk may not be different (Holland *et al.*, 1998).

The prevalence of dementia in people with learning disabilities without Down's syndrome is generally found to be two or three times that expected in people over 65 (Patel *et al.*, 1993; Cooper, 1997), although at least one study did not concur (Zigman *et al.*, 2004). Single-photon emission computed tomography (SPECT) scan findings in people with Down's syndrome who do not meet the criteria for clinical dementia are often abnormal and resemble the changes associated with AD in the rest of the population (Deb *et al.*, 1992; Kao *et al.*, 1993), so such testing is of limited diagnostic value, and for the most part the diagnosis of dementia in this population relies on history and observation.

Deterioration in functioning and other features that may suggest the onset of dementia might also occur in people with learning disabilities as a result of visual or hearing impairments, or other physical conditions that can, for example, impair mobility. The differential diagnosis of decline has to be very wide because there may be problems communicating with the person with the condition. People with Down's syndrome are at special risk throughout life of developing thyroid disease, particularly hypothyroidism, which can present with deterioration and dementia-like features. Partly for these reasons, *Valuing People* emphasised the role of health facilitation, involving regular health checks, in primary care services.

A particular challenge is ascertaining cognitive decline in people with learning disabilities whose performance might naturally fall outside the reference range for most psychological tests, although there have been attempts at consensus statements (Aylward *et al.*, 1997). The MMSE is generally unhelpful when used with people with Down's syndrome, although the Cambridge Cognitive Examination (CAMCOG) may be useful (Hon *et al.*, 1999). Other attempts at adapting tools developed in the general population include the modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) (Ball *et al.*, 2004). A test battery proposed by an international working party in 2000 (Burt & Aylward, 2000) includes, among other items, two informant-based questionnaires that are widely used, the Dementia Questionnaire for Mentally Retarded Persons (DMR) devised by Evenhuis (Evenhuis *et al.*, 1990; Evenhuis, 1996) and Gedye's Dementia Scale for Down Syndrome (DSDS) (Gedye, 1995). The DSDS, although developed particularly for use in people with Down's syndrome, can also be useful in diagnosing dementia in the non-Down's population with learning disabilities. It should only be administered by a clinical psychologist or psychometrician. The DSDS is generally useful for diagnosis, whereas the DMR seems to be sensitive to change and can be used to track the progress of dementia over time. The DMR can be administered by non-psychologists. Changes in general condition can also be monitored using Dalton's Brief Praxis Test (BPT) (Dalton & Fedor, 1998), which some clinicians find useful to record on video so that changes over time can be better observed.

The diagnosis of dementia in people with learning disabilities is therefore a multi-stage process. Firstly, carers may note deterioration in functioning, or else deterioration is noted as a result of screening the population at risk. Secondly, alternative causes of the person's presentation must be investigated and excluded in a systematic way. This will involve checks of vision, hearing and mobility, together with general health screening including thyroid function tests. Consideration must be made as to

whether the symptoms are related to stress, recent life events such as bereavement, or another intercurrent mental health problem. When screening for sensory problems, it is important to use tests appropriate for the population concerned, for example optometry in people with learning disabilities may be best carried out using the Cardiff Acuity Test (Adoh & Woodhouse, 1994; Johansen *et al.*, 2003). If no other causes are identified, or if after identifying such problems and treating them, there is still cause for concern, the third stage is to carry out more specific dementia assessment tests such as the DSDS, DMR and BPT; where dementia is diagnosed, the progress of the condition may continue to be monitored using the DSDS and BPT. At the time of diagnosis, an assessment using the Assessment of Motor and Process Skills (AMPS) (Fisher, 2003), carried out by an occupational therapist, may be used as part of the development of an appropriate care plan.

#### **4.6.4 Social care assessment**

The assessment of a person with dementia for social services (social care) rests on the powers given to local authorities under the NHS and Community Care Act 1990. Local authority policies and practices vary and few social workers or care managers employ standardised assessment tools (Challis & Hughes, 2002). Thresholds for entitlement to social care services have also varied but the Fair Access to Care (FAC) initiative (Department of Health, 2003) is now prompting greater uniformity of eligibility criteria. Examples of people with dementia are used in this Department of Health guidance to illustrate how local authorities must prioritise their services; some of these are provided by the local authority, but the majority are commissioned from the independent sector.

The single assessment process is not yet fully under way and various local models are emerging (Glasby, 2004), revealing the variations in assessment practices. The Department of Health is developing a Common Assessment Framework that builds on the Single Assessment Framework (Department of Health, 2006a). The initial contact or first screening process may trigger a specialist or comprehensive community care assessment or mental health assessment by social services. Where an individual may be in need of community care services, they should receive a comprehensive community care assessment which is likely to involve multidisciplinary contribution of information, from the GP or community nurse for example. The duty to conduct an assessment is not dependent on whether the individual is likely to be entitled to services or on his or her financial circumstances. As a result of the assessment, a package of care services may be put in place, with attention being given to the person's wishes where possible. A small but growing number of carers and people with dementia choose to use direct payments, where they receive cash instead of care services and use this cash to purchase their own support. This may expand if the new proposals of the White Paper 2006 (Department of Health, 2006a) are put into place, extending direct payments (and piloting individual budgets) in scale and scope.

Part of the assessment by social services involves an assessment of the individual's capital and income, since social care in the UK is means tested (with some variation in Scotland). Such financial assessments generally include advice or assistance with

claims for financial benefits for the individual or the carer. Evidence from campaigning groups indicates that this process is difficult and stigmatising and that under-funding of the social care system is considerable (Social Policy on Ageing Information Network, 2001).

Other assessments may be made of individuals' health needs and mental health problems arising from their dementia. These impact on the assessment of care. First, an assessment of eligibility for NHS-funded continuing care may determine that the NHS should have full or partial responsibility for care funding, rather than the local authority or individual. The establishment of a national framework for continuing care is currently under review. Evidence from carers collected by the Alzheimer's Society (2005) shows that many carers find this system unfair and complex, and individuals may find it helpful to seek independent advice from the voluntary sector. Second, if a person's mental health is placing him or her at risk of severe harm to self or others, an assessment under the Mental Health Act 1983 may be carried out by the local authority approved social worker, who follows a code of practice and national procedures. Social care provided under this Act is not means tested. Other assessments that may create nuances in the care provided include risk assessments and adult protection assessments; these are likely to be locally determined.

Social-care assessment of people with dementia is therefore a 'hierarchy' – the bulk of social services resources, including assessment, is now spent on intensive home support and residential provision (Sutherland, 1999), with less support of those who have only minor or emerging impairment related to their dementia (although many people with mild dementia are assessed because of physical problems or disabilities). Some social-care assessments involve community equipment services and occupational therapists, who may carry out their own assessments to determine individuals' needs for aids and equipment, and advice about housing and environmental issues.

However, many people with dementia remain outside social services assessments as their income or capital is high enough to exclude them from support (Challis *et al.*, 2000). While social services are obliged to undertake assessments, there is evidence that they do not offer them to people who will have to make their own arrangements; as a result, rehabilitation and other needs remain unmet (Challis *et al.*, 2000). When a person's assets have reduced to the point where they qualify for financial support, an assessment will follow, but self-funding residents in long-term care settings may pay substantially more for their care than other residents (Wright, 2003).

Within local social care services, each provider is likely to have its own assessment process, whether formal or informal. This will assess the suitability of the person with dementia for its support, for example, to have a volunteer befriender, to take up a place in a day centre or to have a telephone alarm service. The complexity of local variations is frequently reported as difficult and frustrating by carers of people with dementia (Audit Commission, 2000).

Assessment for social-care support for carers themselves largely falls under the Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004. These Acts lay a duty on local authorities to offer carers an assessment of their needs, to work collaboratively with other agencies and to take account of carers' wishes and circumstances. Review of the impact of the 1995 Act confirms the lack of

a standardisation of assessments and the difficulty of meeting carers' needs, with many care managers not undertaking such assessments or feeling that they have little to offer (Seddon & Robinson, 2001). Respite and short-break care have emerged as the most likely services to be offered following an assessment (Arksey *et al.*, 2004) and carers of people with dementia are often positive about these services. Other triggers for full or comprehensive community care assessment are admission to hospital or a carer's illness, or death. When events such as these precipitate a change in an individual's circumstances, urgent assessment may be necessary to address his or her changing needs. Adult services departments (or local authorities/councils with social services responsibilities) may also be 'fined' if they delay the discharge from hospital of a person with dementia.

## **4.7 RISK, ABUSE AND NEGLECT**

### **4.7.1 Vulnerability of people with dementia**

The vulnerability of people with dementia to abuse and neglect is widely recognised (Compton *et al.*, 1997; Bond *et al.*, 1999; Bonnie & Wallace, 2003), although incidence, prevalence and precise risk factors are not well established (House of Commons Health Committee, 2004a). Practitioners working with people with dementia are required to follow policy and practice guidance (Department of Health/Home Office, 2000) that requires multi-agency responses for the protection of vulnerable adults from abuse. Training in the protection of vulnerable adults is not mandatory but is seen as good practice for people working in dementia services (Manthorpe *et al.*, 2005), and while we do not know what precise forms of training are effective, it is reported to lead to better identification of abuse (a random controlled trial by Richardson and colleagues (2002) provides good evidence of this). Agreed multi-agency policy and practice guidance is available at local level and identifies the approaches to be taken when abuse or neglect are suspected.

A national recording system for referrals of adult abuse has been piloted (Department of Health, 2005b), which found that older people with mental health problems were among those referred to local authorities' adult protection systems; a variety of interventions were adopted, although information on the outcomes is not available. Recommendations from a series of high-profile inquiries into care settings in hospitals (for example, Rowan Ward, Department of Health/Care Services Improvement Partnership, 2005) are relevant to commissioners, regulatory bodies and practitioners in seeking to lower the risk of abuse. The law in this area is developing and the Mental Capacity Act 2005 introduces a new criminal offence of ill treatment or neglect of a person who lacks capacity.

### **4.7.2 Impact of dementia on sexual relationships**

Dementia can affect the sexual relationship between the person with dementia and his or her partner, who frequently plays the major care-giving role, in both

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heterosexual and homosexual partnerships. The sexual interests and attitudes of the person with dementia may change (Hanks, 1992). He or she may become less interested in sex, fail to respond to or reject expressions of affection by his or her partner or not demonstrate affection (Harris & Weir, 1998; Kuhn, 1994). People with dementia who continue to be sexually interested may experience sexual difficulties due to physical problems or because of the effects of dementia on their short-term memory, concentration and cognitive sequencing (Kuhn, 1994; Davies *et al.*, 1998).

Both the person with dementia and the carer may feel unloved, just at the time when they would normally expect emotional support from their partner as they learn to cope with the illness. This lack of support may cause feelings of rejection in one or both partners, leading to feelings of depression, despair, frustration and anger. However, where an intimate relationship can be maintained, this may help the partnership to endure (Davies *et al.*, 1998). As something the person with dementia and his or her partner can share together, intimacy may enable the person with dementia to both maintain his or her role identity and give something of value to his or her partner (Kuhn, 1994; Davies *et al.*, 1998). For the carer, intimacy may be an important source of support and a means of coping with his or her partner's devastating illness (Ballard, 1995).

Although sexual apathy is the most likely change in the sexual behaviour, some people with dementia at some stage develop an increased sex drive (Harris & Weir, 1998). When increased sexual behaviour occurs, it may be one of the more difficult problems encountered by a couple living with one partner's dementia (Kuhn, 1994). The person with dementia may behave without any apparent feeling or consideration for his or her partner, who may be emotionally and physically exhausted by the caring role and may find it difficult to respond to the person with dementia's sexual demands (Kuhn, 1994). Where the person with dementia's partner attempts to regulate the frequency of sex, this may cause conflict (Kuhn, 1994).

As dementia progresses, the person with dementia's partner may seek to avoid sex because the person with dementia no longer seems like a lover or spouse (Hanks, 1992; Kuhn, 1994). Partners of people with dementia may feel distressed about sexual overtures from someone who no longer knows their name or at times does not recognise who they are (Davies *et al.*, 1992), or may no longer find their partner sexually desirable due to the intimate tasks required in helping with toileting, washing and maintaining hygiene (Hanks, 1992). Partners of people with dementia may also experience worry and guilt about intimacy because they feel that the person with dementia cannot fully consent or participate in sex (Hanks, 1992; Kuhn, 1994).

If the person with dementia lives in a care home, opportunities for partners to express physical affection may be severely limited by the lack of privacy, as people may feel embarrassed to hold hands or kiss in public or to have sex in the resident's room. The lack of intimacy may cause frustration and anger in the person with dementia, which could contribute towards periods of behaviour that challenges while at the same time causing his or her partner to feel even more lonely and miserable.

## 4.8 DISCLOSURE/STIGMA

Assessment and reaching a conclusion about the diagnosis leads to a point where this information should be shared with the person with dementia. This is especially challenging in dementia for a number of reasons:

- the difficulty of accurate diagnosis
- the challenge of imparting ‘bad news’
- uncertainty about whether or not the person will understand what is being said
- uncertainty about whether or not the person will retain what is said
- lack of follow-up support.

Studies, in which people with dementia have been invited to tell the story of how they reached a memory assessment service and what the assessment process felt like, indicate that this is not an easy journey for them (Keady & Gilliard, 2002). Often, they have been aware of their memory difficulties for some time before sharing this information with others (usually, but not always, their close family). This awareness may occur in quite private activities, like doing crossword puzzles. In the meantime, those who are closest to the person may also have been aware of the difficulties but have fought shy of sharing their concerns. Disclosing their concerns to each other is often what triggers a visit to the GP and referral to a memory assessment service (Keady & Gilliard, 2002).

People have reported that their visits to the memory assessment service can also be quite an ordeal (Keady & Gilliard, 2002). This is often like no other outpatient clinic. The doctor may speak to the carer separately from the person being assessed, leading to suspicion about what is being said. The assessment process itself may prove embarrassing, even humiliating. People report that they are aware that some of the questions are simple and feel foolish that they are unable to answer. They may establish strategies for managing this (Keady & Gilliard, 2002).

Whilst recognising that most people are seeking to make sense of what is happening to them, it is important to acknowledge that some will find it hard to listen to their diagnosis and there will be some who will not want to be told at all. They know they have a problem with their memory and that they are not able to function as they once did or as their peers do. They want to know what is wrong with them, and they need the clinician to be honest with them. Telling someone that he or she has a memory problem is only telling him or her what he or she already knows. People should be told their diagnosis as clearly and honestly as possible.

The moment of sharing the diagnosis may not be comfortable for any of those concerned – neither the clinician, nor the person with dementia, nor his or her carer (Friel McGowan, 1993). Without this knowledge, people cannot begin to make sense of what is happening, nor can they plan effectively for their future. They should be given a choice of treatments and need information about practical support and entitlements, like Lasting Powers of Attorney and advance decisions to refuse treatment (more information can be found in Section 4.9.4 and in the Mental Capacity Act 2005 [The Stationery Office, 2005]). They will want to make decisions about how they spend their time before life becomes more difficult for them (for example, visiting family abroad).

Following the disclosure of the diagnosis, people with dementia and their families may want further support and opportunities for talking. Pre- and post-assessment counselling services should be part of the specialist memory assessment service. Recent work (Cheston *et al.*, 2003a) has shown the value of psychotherapeutic support groups for people with dementia, allowing them space to share their feelings with others. Joint interventions with the person with dementia and family carers, such as family therapy, recognise the fact that the diagnosis does not impact on just one person but on a whole family system (Gilleard, 1996). Other services have used volunteer ‘befrienders’ to maintain contact with people who are newly diagnosed and who can offer both practical support and information together with a ‘listening ear’. People with early dementia are also taking responsibility for their own support by forming groups, which may meet regularly or may be virtual networks using the internet (see, for example, [www.dasninternational.org](http://www.dasninternational.org)).

Sensitivity is required in ensuring that information about the diagnosis is given in a way that is easily understood by the person concerned and acceptable to the family. Gentle questioning at an early stage will help to ascertain what people can, and want, to be told. There is much we can learn from earlier work on sharing the diagnosis with people with cancer (for example, Buckman, 1996). It is especially important to be aware of different cultural sensitivities and the stigma that dementia holds for many people. This can range from subjective feelings of shame to a real exclusion from community and family life. Age and ethnicity are both factors in the sense of stigma associated with a diagnosis of dementia (Patel *et al.*, 1998).

## **4.9 BASIC LEGAL AND ETHICAL CONCEPTS IN CONNECTION WITH DEMENTIA CARE**

### **4.9.1 Introduction**

The ethical problems that arise in the context of dementia mainly relate to autonomy, which is compromised in dementia to varying degrees. Respect for autonomy is recognised as a key principle in health and social care (Beauchamp & Childress, 2001). Many of the ethical tensions that arise in looking after people with dementia do so because of, on the one hand, the requirement that autonomy ought to be respected and, on the other, the reality of increasing dependency, where this entails a loss of personal freedom.

Person-centred care is a means of respecting personal autonomy wherever it is threatened (Kitwood, 1997). As Agich has stated, ‘Autonomy fundamentally importantly involves the way individuals live their daily lives; it is found in the nooks and crannies of everyday experience’ (Agich, 2003).

Hence, respecting the person’s autonomy will involve day-to-day interactions and will be achieved if the person with dementia is not positioned in such a way as to impede his or her remaining abilities. Such ‘malignant positioning’ can be the result of inappropriate psychosocial structures. The fundamental way to combat this

tendency, which undermines the person's selfhood, is to encourage good-quality communication (Kitwood, 1997; Sabat, 2001).

Another way in which selfhood might be undermined is through structural or procedural barriers to good-quality care, and service providers should take an active role in promoting the individual's autonomy and his or her legal and human rights. Furthermore, services may discriminate against people with dementia if eligibility criteria are drawn up in such a way as to exclude them or because of an assumption that people with dementia cannot benefit from a service because staff lack confidence and skills in working with this group. Discrimination may also occur if a service does not offer people with dementia the support they may need in order for them to be able to make use of the service. The Disability Discrimination Acts (1995 and 2005), which include dementia within the definition of disability, aim to end the discrimination that many disabled people face in their everyday lives by making direct or indirect discrimination against disabled people unlawful in a range of areas including access to facilities and services and buying or renting property.

The discussion that follows will briefly focus on human rights, consent, capacity and confidentiality.

#### **4.9.2 Human rights**

Human rights are enshrined, as far as the United Kingdom is concerned, in the *Convention for the Protection of Human Rights and Fundamental Freedoms* (Council of Europe, 2003). The relevant UK legislation is the Human Rights Act 1998, which came into force in 2000. The principle of respect for autonomy is implicit throughout the Convention. A number of the articles of the Convention are potentially relevant to people with dementia. For example, Article 2 asserts that everyone has a right to life, Article 3 prohibits torture, but also "inhuman or degrading treatment", and Article 8 concerns the right to respect for the person's private and family life.

Article 5 asserts the right of people to liberty and security. It states that "No one should be deprived of his liberty", except in very specific circumstances. It also asserts that if someone is deprived of his or her liberty, there should be recourse to a court. Article 5 was central to the 'Bournewood' case. The European Court declared, amongst other things, that the man concerned (who had a learning disability) had been deprived of his liberty, in contravention of Article 5 (see Department of Health, 2004, for further information).

The crucial distinction to emerge from the case was that between *deprivation* of liberty and *restriction* of liberty. Whilst the former is illegal, except insofar as there are legal safeguards of the sort provided by the Mental Health Act 1983 (HMSO, 1983), the latter may be permissible under the sort of circumstances envisaged by Section 6 of the Mental Capacity Act 2005 (TSO, 2005). This discusses using restraint as a proportionate response to the possibility of the person suffering harm. Guidance on the distinction between 'restriction' and 'deprivation' of liberty has been provided by the Department of Health and the National Assembly for Wales (Department of Health, 2004).

### **4.9.3 Consent**

In brief, for consent to be valid it must be:

- informed
- competent
- uncoerced
- continuing.

Each of these concepts requires interpretation and judgement, as none of them is entirely unproblematic (Department of Health, 2001a). For instance, people can be more or less informed. The ‘Sidaway’ case (1984) established that the legal standard as regards informing a patient was the same as for negligence (see the ‘Bolam case’, 1957). In other words, the person should be given as much information as a ‘responsible body’ of medical opinion would deem appropriate. However, since then, there has been a shift away from a professional-centred standard towards a patient-centred standard. In the ‘Pearce’ case (1998), one of the Law Lords declared that information should be given where there exists ‘a significant risk which would affect the judgement of a reasonable patient’.

Department of Health guidelines (Department of Health, 2001c) have pointed out that, although informing patients about the nature and purpose of procedures may be enough to avoid a claim of battery, it may not be sufficient to fulfill the legal duty of care. There may be other pieces of information relevant to the individual patient that it would be negligent not to mention. Hence the General Medical Council (GMC)’s insistence that doctors should do their best ‘to find out about patients’ individual needs and priorities’ (GMC, 1998). The GMC guidance goes on to say: ‘You should not make assumptions about patients’ views’.

These points are very relevant when it comes to consent in the context of dementia. It should be kept in mind that consent is not solely an issue as regards medical procedures. The ‘nooks and crannies of everyday experience’ (Agich, 2003) – what to wear or to eat, whether to go out or participate in an activity and whether to accept extra home or respite care – are all aspects of life to which the person with dementia may or may not wish to consent. If the person has capacity with respect to the particular decision, but does not wish to consent, he or she should be supported in making an autonomous decision.

### **4.9.4 Decision-making capacity**

In England and Wales, a lack of capacity has been defined thus:

*‘... a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain’ (Mental Capacity Act 2005 [TSO, 2005, Section 2]).*

A person is further defined as unable to make a decision if he or she is unable:

- (a) to understand the information relevant to the decision,*
- (b) to retain this information,*
- (c) to use or weigh that information as part of the process of making the decision, or*
- (d) to communicate his decision (whether by talking, using sign language or any other means)' (Mental Capacity Act 2005 [TSO, 2005, Section 3(1)]).*

The Mental Capacity Act 2005 (TSO, 2005), which will apply in England and Wales<sup>31</sup>, sets out a framework for making decisions for people who are unable to make decisions for themselves. Its detailed provisions, along with its Code of Practice (currently in draft form [DCA, 2005]), should be referred to by all those involved in such decision making. In outline, the main provisions of the Act:

- offer a definition of lack of capacity (Sections 2–3)
- outline a process for the determination of a person's best interests (Section 4)
- create Lasting Powers of Attorney, which allow a person to appoint a donee to make decisions about his or her health and welfare (Sections 9–14)
- establish the Court of Protection in a new form, with powers to make declarations and appoint deputies in difficult cases or where there are disputes concerning decisions about a person's health and welfare (Sections 15–23)
- bring under statute and clarify the law regarding advance decisions to refuse treatment (Sections 24–26)
- set out safeguards concerning research with people who lack the capacity to consent (Sections 30–34)
- outline the requirement to appoint an independent mental capacity advocate if the person who lacks capacity requires 'serious medical treatment' or a change in long-term accommodation but lacks anyone else, other than those engaged in his or her care or treatment, to offer support or advice (Sections 35–41).

The SCIE practice guide on assessing the mental health needs of older people outlines the key dimensions of the Mental Capacity Act 2005 (SCIE, 2006) and the Department of Health is currently preparing a code of practice to support the implementation of the Act.

#### **4.9.5 Confidentiality**

People with dementia, no less than any others, have a right to expect that information given in confidence to professionals will be kept confidential. Guidance from professional bodies (for example, GMC, 2004; Royal College of Psychiatrists, 2006a) outlines the circumstances under which confidential information can be shared. These circumstances tend to be extreme, such as when public safety is threatened. Generally speaking, however, if a professional intends to break confidence this should be discussed with the

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<sup>31</sup>The Mental Capacity Act 2005 is on the statute book but not yet introduced. It will come into force in April 2007.

person concerned and his or her agreement should be sought. This remains true when the person has dementia. An example of this sort of situation is when the professional feels it necessary to inform the Driver and Vehicle Licensing Agency (DVLA) that the person has a condition that may impair his or her ability to drive. In these circumstances, good practice suggests that, in the first instance, the person should be encouraged to contact the DVLA him- or herself. Thus, from an ethical point of view the issue of confidentiality in dementia care illustrates the delicate balance that has to be maintained between respecting the person's autonomy and recognising the complex ways in which people in a society are mutually dependent and inter-related (Hughes & Louw, 2002).

#### **4.10 TREATMENT AND CARE OF PEOPLE WITH DEMENTIA IN ENGLAND AND WALES**

##### **4.10.1 Detection, recognition and referral**

There is evidence of delays in the recognition of dementia syndromes in primary care, and of sub-optimal management, although there is also anecdotal evidence that diagnostic skills have improved in the last decade. Delays in recognition are due to a variety of factors, including the complex and variable ways in which cognitive impairment shows itself; the person with dementia and his or her family's reluctance to acknowledge changes in cognition and behaviour as problematic and to seek help; and professional attribution of changes to 'normal ageing' or other explanations (De Lepeleire & Heyrman, 1999; van Hout *et al.*, 2000).

General practitioners describe themselves as under-skilled in the recognition and management of dementia syndromes, and a significant minority believe care of people with dementia is the responsibility of specialist services (Audit Commission, 2000). However, there is also evidence that general practitioners' diagnostic skills for dementia are better than reported and that the main difficulties lie with disclosure of the diagnosis in the early stages (De Lepeleire *et al.*, 1998; De Lepeleire & Heyrman, 1999) and with management of behaviour changes in the later stages of the disease.

A perception that specialist services are absent or unresponsive can inhibit the recognition of dementia syndromes (Ilfie *et al.*, 2006); the development of dementia collaboratives can address and may modify this perception.

Postgraduate professional development programmes are available to support dementia education in the community, of which at least one has been shown to change recognition rates in a randomised controlled trial (Downs *et al.*, 2006).

##### **4.10.2 Assessment and coordination of care**

The organisational arrangements for needs assessment and case management of people with dementia are highly variable, with decisions about key-worker roles being decided according to local resource availability and priorities. The consequence

of this local variation is that there is no comprehensive system of case management comparable to that of other long-term conditions like diabetes or asthma, and individuals may not receive the assessments and care that they need, particularly at the earlier stages of the disease. The new contract for general practice now includes targets for dementia care within its quality outcomes framework, so there is a link between performance in dementia care and remuneration. However, this is as yet only limited and does not extend to details of concordance with diagnostic and management guidelines.

The involvement of family members or others as organisers and advocates may determine how much care and support is available. Voluntary organisations can play an important educational, advisory and support role. For example, they often provide or signpost sources of support such as benefits advice and advice about eligibility for continuing care, but many individuals with dementia are not in contact with them. While in some areas voluntary organisations either do not have a presence or do not provide a full range of services, some organisations do provide national helplines that people with dementia and carers can use to access information and advice or support.

However, there are a variety of disciplines with expertise in dementia care in many communities, from social work to community nursing, and these skills need to be mobilised if assessment and care coordination are to be optimised. There is an argument for developing a generic system of case management for people with dementia, using locally available skills to create the kind of multidisciplinary assessment and management team needed (Challis *et al.*, 2002). The widespread involvement of general practitioners in this re-engineering of services would probably require further change in the GP contract.

### **4.10.3 Pharmacological treatment**

Dementias have often been regarded as untreatable, with the exception of dementias of uncommon aetiology such as that caused by folic acid deficiency. However, careful assessment and the development of comprehensive multidisciplinary care plans to address personal, social, medical and behavioural problems associated with dementia have become the mainstay of treatment and care programmes in the delivery of high-quality care for people with dementia and their carers.

The search for more specific treatments began in the 1980s and 1990s with the introduction of codergocrine mesylate, which was used as an adjunct in the management of elderly people with mild to moderate dementia. Naftidrofuryl oxalate was introduced for the management of cerebral vascular disorders and thought to be of relevance in the treatment of VaD. However, neither of these drugs proved to be particularly effective in the treatment of any form of dementia and both fell into disuse.

New approaches to the pharmacological treatment of dementia, and in particular to AD, began with the introduction of the acetylcholinesterase inhibitors, which inhibit the breakdown of acetylcholine, a neurotransmitter thought to be important in the chemical basis of a number of cognitive processes including memory, thought and judgement. Acetylcholine was also thought to be involved in some behavioural

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disturbances, although this is speculative. Acetylcholinesterase inhibitors used in clinical practice include rivastigmine, donepezil and galantamine.

More recently, memantine has been introduced for the treatment of moderate to severe AD, again primarily used for its effect upon cognition, although some behavioural effects have been noted. Memantine works primarily through its action upon glutamate transmission and more specifically on particular subtypes of receptors within glutamate systems particularly related to memory (N-methyl-D-aspartate [NMDA] receptors).

### *Dosing of medication in Alzheimer's disease*

Donepezil is the simplest drug to use, being a tablet given once a day and having only two different doses (5 mg and 10 mg), both of which are considered to be effective doses. Rivastigmine is given twice daily with morning and evening meals. There are four capsule strengths: 1.5 mg, 3 mg, 4.5 mg and 6 mg. Dosing commences with 1.5 mg twice daily, whilst the effective dose is 3–6 mg twice daily. Galantamine is also given twice daily (preferably with the morning and evening meal) as tablets, beginning at 4 mg and increasing to 8 mg and 12 mg. The effective dose is 8–12 mg twice a day. More recently, a once-daily formulation of galantamine has been made available with capsules to be taken in the morning, preferably with food, beginning at 8 mg and increasing to 16 mg and 24 mg.

In 2001, a NICE technology appraisal (TA019) recommended that these drugs should be made available as a component of the management of people with mild and moderate AD whose score on the MMSE was 12 or above. The appraisal advised that drug therapy should be initiated by a specialist following assessment, which should include tests of cognitive, global and behavioural functioning and of activities of daily living; general practitioners should only take over prescribing under an agreed shared-care protocol. Treatment should only be continued in people with dementia where, usually 2–4 months after reaching the maintenance dose of the drug, there was an improvement or no deterioration in the MMSE score, together with evidence of global improvement on the basis of behavioural and/or functional assessment. Assessment should be repeated every 6 months, and the drugs should normally only be continued with an MMSE score of above 12 and where the individual's global, functional and behavioural condition remains at a level where the drugs are still considered to be having a 'worthwhile effect'.

At the same time as developing this guideline, NICE undertook a fresh technology appraisal (and a review of the existing guidance TA019), examining the use of donepezil, rivastigmine, galantamine and memantine in the treatment of AD. The Guideline Development Group did not have any responsibility for the development of the technology appraisal. Nevertheless, its recommendations were incorporated into this guideline when the technology appraisal was finalised (where one of these recommendations appears, it is indicated as NICE, 2006).

#### **4.10.4 Physical healthcare**

Coexistent medical problems are very common in people with dementia. Most people with dementia are elderly and are therefore likely to suffer from other illnesses, both

acute and chronic. It is very important not to assume that every physical or mental problem a person with dementia experiences arises because of the dementia (Jones, 2000). Elderly people with dementia frequently have other therapeutically important medical conditions. Problems such as urinary incontinence or increased confusion can arise for a number of reasons. One prospective study of 200 elderly outpatients with dementia identified 248 other medical diagnoses in 124 of them; 92 of the diagnoses were new (Larson *et al.*, 1986).

Coexistent medical problems require careful management. Another illness can increase a person's confusion either temporarily or chronically. Drugs used to treat other conditions may themselves be responsible for worsening cognition. Whilst other medical problems may have an adverse effect on the quality of life for people with dementia and carers, their over-zealous treatment, particularly at the end stage of dementia may be distressing as well. The existence of dementia may require modification in the treatment of other medical conditions. For example, dementia appears to be a significant independent determinant of non-treatment with aspirin or warfarin when otherwise indicated for the prevention of recurrent stroke (Moroney *et al.*, 1999b). In addition, there is an understandable reluctance to use warfarin in people with a condition like AD if compliance cannot be guaranteed because of the risk of overdose, which may lead to haemorrhage.

Medical problems and their treatment can be aggravated by the inability of a person with dementia to report his or her own symptoms, so that regular review is essential. This becomes especially important when there has been acute deterioration in either cognition or behaviour. Common conditions may present in an atypical or non-specific manner. For example, a significant association between an impaired mental test score and atypical presentation of myocardial infarction has been observed (Black, 1987). It is also easy to overlook standard health measures such as an annual immunisation against influenza and regular eye checks.

The physical health problems that are a common feature of increasing longevity pose an additional difficulty for people with dementia. The presence of dementia increases the risk of delirium with any concurrent physical illness (Elie *et al.*, 1998). Delirium can cause increased confusion, behavioural problems and sleep disturbance. The delirium or the underlying physical problem will frequently precipitate an admission to a general hospital for physical treatment and this poses a further challenge for those with dementia and the services trying to care for them. For the person with dementia, he or she is unwell, possibly more confused and moved from familiar surroundings into a strange and frightening environment.

In a typical general hospital of 500 beds, 330 of those beds will be occupied by older people (Department of Health, 2001b), of whom 102 will have dementia (Royal College of Psychiatrists, 2005a). For inpatients in a General Hospital, dementia is an independent predictor of poor outcome, including increased mortality, increased length of stay, loss of function and higher rates of institutionalisation (Holmes & House, 2000).

Improving outcomes has important implications for people with dementia and the utilisation of resources. For instance, in a population of people with hip fracture, care from an intensive, specialist, multidisciplinary rehabilitation team achieved a

reduction in length of stay in those with mild to moderate dementia. Those with mild impairment were as successful at returning to independent living as those without dementia (Nightingale *et al.*, 2001). Such a team would increase the awareness, in general hospital staff, of the problems associated with dementia. Through education and training, the team could facilitate the acquisition of basic skills in assessment and treatment.

Admission to a general hospital may be the first opportunity to identify dementia and all staff need to be able to recognise the symptoms, give information and advice to patients and carers, and be able to refer for a specialist assessment.

#### **4.10.5 Psychological interventions**

Psychological interventions for people with dementia have a long history. An evaluation of the effects of a variety of activities on people who would now be described as having dementia was published nearly 50 years ago (Cosin *et al.*, 1958). One theory likened the experience of dementia to sensory deprivation, with the person typically receiving little stimulation, whether at home or in an institution (Bower, 1967). Stimulation programmes of various kinds were developed and are still evident in the widespread use of music and other forms of sensory stimulation in dementia care. The disorientation typically observed in dementia was also targeted early on through the development in the US of reality orientation programmes, which did appear to be associated with small improvements in cognitive function (Taulbee & Folsom, 1966; Brook *et al.*, 1975; Woods, 1979). This approach led to widespread use of orientation aids and signposting in most dementia care facilities.

There are a wide range of psychological interventions currently provided in the UK for people with dementia, but their availability varies greatly. In the early stages of dementia, individual psychological treatment may be offered; this may focus on enhancing adjustment and mood, using cognitive behavioural therapy (CBT) (Scholey & Woods, 2003) or life review, and/or on strategies to improve memory, using a cognitive rehabilitation approach (Clare, 2003). In some areas, group activities for people in the early stages of dementia may be offered, with a similar range of goals (Cheston *et al.*, 2003a; Kipling *et al.*, 1999).

Interventions for people in the later stages may include a variety of group activities, including cognitive stimulation, reminiscence, music, and arts and crafts (Spector *et al.*, 2003; Holden & Woods, 1995; Gibson, 2004). These may be offered in day-care centres or in care homes. Well-being and quality of life are the aims here, helping the person to participate in enjoyable activities, often in a social context, and to be engaged with others rather than withdrawn into an inner world.

Increasingly, the intervention is provided personally in day-to-day contact with the person with dementia, whether through a family carer or a care worker. Psychological approaches to maintaining the person's self-care abilities and independence have been developed and involve good communication skills, prompting and providing just enough help for the person to complete the task for him- or herself (Woods, 1999). Training and support are needed for carers and care workers to be

able to put these approaches into practice. This is also the case when the carer or care worker finds aspects of the person's behaviour difficult to manage. Behavioural approaches aim to help in finding ways of understanding where the problem lies and responding to the difficulty; sometimes, difficult behaviour can be averted by the carer or care worker modifying his or her approach or changing something in the environment (Moniz-Cook *et al.*, 2003). Although guidelines recommend that such behavioural management approaches be pursued before considering the prescription of psychotropic medication (Howard *et al.*, 2001), this is often not the case in practice.

In the late stages of dementia, sensory stimulation is the primary form of psychological intervention. The aim is often to provide relaxing stimulation and to reduce agitation and distress (multi-sensory stimulation equipment is widely used for this purpose); hand massage and aromatherapy are sometimes offered (Baker *et al.*, 1997; Burns *et al.*, 2002). Music and supported contact with trained pet dogs and other animals are other forms of stimulation that are available in a number of centres.

Whilst interventions with individuals or groups are important, a need for the whole care setting to support and facilitate a psychological approach is often highlighted. For example, changes to the regime of care in a care home will arguably have a much greater impact on the well-being of residents than a once-weekly group session (Brane *et al.*, 1989). Such a change involves changes in attitudes and behaviour, and sometimes changes to the physical as well as the social environment. The principles of person-centred care, as set out by Kitwood (1997) have achieved a broad consensus of support in dementia care in the UK, but it is readily acknowledged that their implementation is a challenge for those responsible for the management of care. Dementia care mapping is one observational method that has been developed to assist in helping care workers and managers to reflect on and develop their practice (Brooker *et al.*, 1998). Staff training and supervision are key issues in the implementation of a psychological approach, with a need in many settings to retain staff so that a consistent approach may be developed.

Psychological interventions for family carers are available in many areas. These include individual psychological treatment (such as CBT) for depression and anxiety in the significant proportion of carers where the difficulties of providing care contribute to a mental health problem (Marriott *et al.*, 2000). Individual work on problem-solving and coping skills may also be available. Groups for family carers are widely available and encompass a broad range of models of intervention, from the psychotherapeutic to peer support (Pusey & Richards, 2001). Interventions need to be geared to the different stages of the care-giving career, with particular issues arising for those carers where the person with dementia has been admitted to a long-term care facility and some requiring support after the death of the person.

Joint interventions with the person with dementia and family carers are now developing. These include applications of family therapy (Gilleard, 1996) and groups where people with dementia and family carers are involved together. The aims of this work may include improving the quality of the relationship, which potentially has an impact on quality of life and well-being for all concerned.

#### **4.10.6 Social care**

Social care covers all the different types of support that people of all ages may need to live as independently, safely and fully as possible, provided by local councils, private companies and voluntary organisations. It covers a diverse range of services, including care homes, sheltered housing, respite or short-break care, day services, home care and meals services, and often operates alongside other services, such as health or housing.

Most people with dementia are able to live in their own homes for most of their lives, and most care is given by families. Between 36% and 53% of people with mild to moderate dementia live in the community, and 35% of those with high-level needs live at home supported by carers (Melzer *et al.*, 1997, cited Parsons, 2001). The ability to provide care usually depends on proximity, and co-resident care is where the greatest intensity of care takes place. In most cases, this means care by a spouse or partner (Tinker, 2000), and requests for additional support from services are often precipitated by the ill health of carers (Parsons, 2001). The ensuing process of assessing need, planning and implementing a combination of services is referred to as 'care management'. An overriding objective for social-care service commissioners is to maintain people in their own home for as long as possible, including intensive home care schemes (Department of Health, 2001b & Department of Health/Care Services Improvement Partnership 2005). Thus, social care for dementia has largely centred on the deployment of domiciliary (home care) support, respite or short-break care and day care to support carers to cope with the increasing disability of people living with dementia or, if people live alone or have no carers, to support them in independent living for as long as possible. These services may be supplemented by adaptations to the home, undertaken by local councils, housing agencies or private providers, to reduce risks associated with failing memory and increasing disorientation. As well as providing physical care, home-based services should aim to provide a positive experience for the person with dementia, with opportunities for him or her to continue with his or her preferred activities.

Very sheltered housing with enhanced facilities, such as 24-hour care on site and provision of some meals, is another service option when people's needs are too great to be met through domiciliary support. When this is not sufficient, a move to residential care may be considered. Long-term residential care is usually prioritised for people with physical or persistent non-cognitive symptoms, such as behaviour that challenges. Shortage of places and greater life expectancy has led to higher concentrations in care homes of more frail and disabled older people and more people with dementia. At the same time, residential care work has remained low in status, with little training, and there are few homes led by staff with professional qualifications (Means, 2000). Nevertheless, as expectations of more person-centred approaches to dementia care develop, there is a little evidence of more diversified and personalised approaches to residential care (Judd *et al.*, 1997, cited Marshall, 2001).

Various issues have emerged in social care for people with dementia that have been under-recognised (Stanley & Cantley, 2001) in whatever setting care is delivered; these

include recognition of the needs of people from black and ethnic minorities, including those for whom English is not a first language; the complexities of working alongside people with learning difficulties and dementia; managing behaviour that challenges in residential and day services, including ‘wandering’; and ensuring the protection of people living with dementia from abuse and neglect.

#### **4.10.7 Current care allowances**

A diagnosis of dementia will have an impact on a person’s financial status due to the extra costs arising from the illness and, in some circumstances, on the carer’s financial status as well, as he or she may, for instance, have to work part-time or take early retirement to undertake full-time care.

Financial assistance is available to people with dementia and their carers from the state, the local council and the NHS. The main state benefits for people with dementia are Attendance Allowance for people aged 65 and over and Disability Living Allowance for people under the age of 65, neither of which is related to income or savings. People with dementia aged 60 and over with state pensions and/or low incomes may qualify for Pension Credit. People with dementia below the age of 60 who are unable to work full time may be entitled to Incapacity Benefit or Income Support. Carers who are unable to work full time because they are caring for a person with dementia for at least 35 hours a week may apply for Carer’s Allowance, but it can only be claimed once the person with dementia’s Attendance Allowance or Disability Living Allowance has been agreed. To qualify for Carer’s Allowance, the carer must be on a low income (currently the level is less than £84 per week) and not in education for more than 21 hours per week. A carer cannot receive Carer’s Allowance for more than one disabled person and two carers cannot share the allowance.

The allowances available to people with dementia differ depending on their living circumstances, for example living alone, living alone but with a carer who claims Carer’s Allowance, living with a partner who provides care or living with a carer who is not a partner. Other allowances include exemption from council tax for people living alone who receive either Attendance Allowance or Disability Living Allowance (where they live with one other person, then a 25% discount can be claimed), Housing Benefit, and other grants and assistance (for example, grants from the Social Fund to purchase essential kitchen appliances or pay for adaptations or repairs to the home, Community Care Grants and help with health costs). Assistance with travel costs to and from hospital appointments may be available from the NHS.

Both the person with dementia and the carer need to be made aware of the long-term implications of the illness on the management of their finances and property and should be encouraged to seek advice concerning Lasting Power of Attorney (more information can be found on the Department for Constitutional Affairs website).

Advice on benefits and other financial support can be obtained from council benefits officers and benefits advisers at voluntary organisations. Some social workers and nurses may be able to offer advice but this is not usually their role.

#### **4.10.8 Inpatient dementia services**

The central tenet of this guideline is that people with dementia should be assessed and treated as far as possible within their own, familiar environment and exercising as much choice and self-determination as possible. Brodaty and colleagues (2003c) suggests that with skilled teams in the community, such as outreach services and crisis resolution and home treatment teams, less than 1% of people with dementia should require treatment in an inpatient unit. However, inpatient services may be required to assess and treat people with dementia in the following circumstances:

- the person with dementia is severely disturbed and is required to be contained for the safety of his- or herself and/or others, including those liable to be detained under the Mental Health Act 1983
- assessment in a community setting is not possible, for example where a person with dementia has complex physical and psychiatric problems.

The role of the inpatient unit is to provide a safe environment, staffed by clinicians who are trained in the care of people with dementia, the assessment and management of those with behaviour that challenges and the management of aggression and violence. Admission to an inpatient unit should have a clear objective that is shared from the outset with the person with dementia, the carer and the multidisciplinary team. When the objective has been achieved, there should be an efficient discharge process, supported by community resources.

Given the high incidence of physical morbidity within the client group (see Section 4.10.4), an inpatient assessment unit for people with dementia is best placed on a district general hospital site to give prompt access to physical care when needed. Ideally the unit would be staffed by dual-trained nursing staff and/or would be managed jointly by physicians for the care of the elderly and old age psychiatrists. There should be full multidisciplinary input to the inpatient service including physiotherapy, occupational therapy, speech and language therapy, and psychological therapy to ensure a multi-skilled approach for people with dementia. Careful consideration should be given to the physical design of the unit, taking into account recommendations given in Section 5.4.3, with a high proportion of single rooms and a safe, low-stimulation area available for the management of those who are severely disturbed. Given the high level of need, the units should have no more than 12 residents.

Inpatient units should also act as a source of expertise to offer advice and provide training to other areas of the service in the management of behavioural and psychological symptoms of dementia.

### **4.11 PALLIATIVE CARE, PAIN RELIEF AND CARE AT THE END OF LIFE FOR PEOPLE WITH DEMENTIA**

#### **4.11.1 Introduction**

The definition of palliative care emphasises its ‘total’ nature, encompassing not only physical symptoms, but also the psychological, social and spiritual aspects of

non-curable diseases. The aim is to achieve ‘the best quality of life for patients and their families’ from an early point in the disease (World Health Organization (WHO), 1990). NICE has produced a manual on improving supportive and palliative care for adults with cancer (NICE, 2004a) and, although this manual is focused on services for adult patients with cancer and their families, it may inform the development of service models for other groups of patients. The NICE manual recommends three tools to support high-quality care for end of life: the Gold Standards Framework (see [www.goldstandardsframework.nhs.uk/](http://www.goldstandardsframework.nhs.uk/)) (Thomas, 2003), the Liverpool Care Pathway for the dying patient (see [www.lcp-mariecurie.org.uk/](http://www.lcp-mariecurie.org.uk/)) (Ellershaw & Wilkinson, 2003) and the Preferred Place of Care Plan (see [www.cancerlancashire.org.uk/ppc.html](http://www.cancerlancashire.org.uk/ppc.html)). The NHS End of Life Care Programme aims to improve care at the end of life for all and the programme website (<http://eolc.cbcl.co.uk/eolc/>) provides good practice, information and resources including links to the three tools recommended by the NICE palliative care manual (NICE, 2004a).

There is now considerable interest in the notion of palliative care for older people and in dementia (House of Commons Health Committee, 2004b; Hughes *et al.*, 2005a; WHO, 2004; National Council for Palliative Care, 2006). Retrospective case-note studies in the UK in psychiatric and acute hospital wards have suggested there is inadequate palliative care for people with dementia (Lloyd-Williams 1996, Sampson *et al.*, 2006). In a retrospective survey of carers (McCarthy *et al.*, 1997), the most commonly reported symptoms suffered by the person with dementia in the last year of life were confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). More recent research from the USA continues to paint a picture of sub-optimal palliative care for people with dementia in nursing homes and in hospital (Mitchell *et al.*, 2004a; Mitchell *et al.*, 2004b; Aminoff & Adunsky 2004). A similar picture emerges from a more recent synthesis of the research evidence (Davies, 2004), and a survey of care more generally for people with dementia in private and NHS facilities in the UK leaves little room for optimism (Ballard *et al.*, 2001). Given the need for improvement in terms of quality of care and the lack of evidence to support arguments concerning what constitutes good-quality palliative care in dementia, the need for further research is paramount (Bayer, 2006).

#### 4.11.2 Defining palliative care in dementia

Palliative care can be thought of as a spectrum ranging from the palliative care approach to specialist palliative care (Addington-Hall, 1998). The palliative care approach should be integral to all clinical practice involving chronic, terminal disease and equates to good-quality person-centred care in dementia (Hughes *et al.*, 2005b). Specialist palliative care, especially care in the last few days of illness, will be much the same in dementia as it is in cancer (NICE, 2004a). Most people with dementia die in long-term care or in hospitals, with only about 19% dying at home (Kay *et al.*, 2000) and very few using hospices (McCarthy *et al.*, 1997). Between the palliative care approach and specialist palliative care lie palliative interventions, which are non-curative treatments aimed at improving symptoms and signs of distress in order to

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maximise quality of life. In dementia, an area of focused intervention might be in the field of the behavioural and psychological signs of dementia (BPSD).

### **4.11.3 Specific issues at the end of life in dementia**

The issue of the definition of palliative care in dementia is not without consequence. For instance, whilst it seems intuitively clear that the palliative care approach is applicable, a recent systematic review found little evidence to support its use in dementia (Sampson *et al.*, 2005). The reviewers commented, however, that the result might reflect ethical difficulties surrounding such research, prognostic uncertainty and the lack of clear outcome measures. In addition, there may be specific issues (some of which are dealt with below) relevant to palliative care where the evidence base is to be found elsewhere.

### **4.11.4 Ethics and the end of life in dementia**

Palliative care in dementia raises many difficult ethical issues (Purtilo & ten Have, 2004). In order to deal with ethical dilemmas appropriately, clinicians must rely on background ethical or moral theories. For instance, the doctrine of double effect states that it is lawful to pursue treatments where bad effects can be foreseen but are not intended. A less contentious doctrine, which informs much of palliative care, is that of ordinary and extraordinary means. This suggests that where there is a lack of proportion between the proposed intervention and the likely clinical benefit, either because the intervention is too burdensome or lacking in efficacy, there is no moral obligation to pursue the treatment (Jeffrey, 2001). Some of the difficult issues to do with care at the end of life are dealt with in professional guidance (for example, see *Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making*, GMC, 2002, and Section 3.9.4 of the 2005 Mental Capacity Act).

The possibility of diverse and disputed values in the area of end-of-life care suggests the applicability within this field of values-based medicine (VBM) (Fulford, 2004). VBM can be regarded as a complement to evidence-based medicine, but with the emphasis on weighing up contrasting values, in addition to the weighing up of evidence that is a necessary part of good medical practice (Woodbridge & Fulford 2004).

### **4.11.5 Artificial nutrition and hydration**

Swallowing problems become increasingly noticeable as dementia worsens, with the possibility of aspiration pneumonia in the severer stages (Feinberg *et al.*, 1992). Nasogastric and percutaneous endoscopic gastrostomy tubes would seem to provide a safer way to feed people with severe dementia and dysphagia. However, a review of the evidence in 1999 found no relevant randomised clinical trials comparing tube

feeding and oral feeding. On the basis of the available data, the reviewers concluded that the best evidence did not support the use of tube feeding in dementia (Finucane *et al.*, 1999). Ethical commentary, making use of this review, concluded that, although there may be individual cases in which tube feeding is not futile, ‘balancing the risks and benefits leads to the conclusion that [feeding tubes] are seldom warranted for patients in the final stages of dementia’ (Gillick, 2000). More recent research continues to support such views (Sanders, 2004; Alvarez-Fernández *et al.*, 2005). A palliative approach and the use of advance directives decrease reliance on tube feeding (Monteleoni & Clark, 2004). The alternative is to manage dysphagia conservatively, using food thickeners with appropriate posture and feeding techniques. Locally implemented protocols exist but require further evaluation (Summersall & Wight, 2005). More recently, NICE published a guideline on nutritional support that includes recommendations for artificial nutrition and hydration (see NICE guideline no. 32, *Nutrition Support in Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition*, [www.nice.org.uk/cg032niceguideline](http://www.nice.org.uk/cg032niceguideline)).

#### **4.11.6 Fever and infection**

Pneumonia remains a common cause of death in people with dementia (Chen *et al.*, 2006). The use of antibiotics to treat fever or intercurrent infections is controversial and under-researched in dementia. Some research shows no difference in the mortality rate of people receiving antibiotics and those receiving only palliative care (Fabiszewski *et al.*, 1990). Subsequent work has shown, in a controlled but non-randomised study, that aggressive treatment with antibiotics (as opposed to palliative measures such as antipyretics and analgesia) was associated with a worsening of dementia (Hurley *et al.*, 1996). A more recent study demonstrated substantial suffering caused by pneumonia, irrespective of antibiotic treatment, in people with dementia (van der Steen *et al.*, 2002). An associated concern is that transfer to hospital from long-term care homes for treatment of pneumonia may not be indicated because the outcome in hospital is poorer (Fried *et al.*, 1995; Thompson *et al.*, 1997).

Against this evidence, clinical experience suggests that the usefulness of antibiotics in a given situation ought to be determined by the specific circumstances: the severity of the dementia, comorbidity, immobility, nutritional status and the virility of the infection will all determine to what extent the use of antibiotics is warranted. In other branches of palliative care, there is evidence that, even in the terminal stages of illness, antibiotics can relieve the distress caused by infected bronchial secretions (Spruyt & Kausae, 1998; Clayton *et al.*, 2003).

#### **4.11.7 Resuscitation**

The evidence is that, in severe dementia, cardiopulmonary resuscitation (CPR) is unlikely to be successful. Furthermore, there is evidence from the US that most older

## *Dementia*

people are against life-sustaining treatments, even when contemplating only the milder stages of dementia (Gjerdingen *et al.*, 1999). Outside the hospital setting, the chances of survival following CPR are very slim and the procedures themselves are burdensome (Awoke *et al.*, 1992; Zweig, 1997; Conroy *et al.*, 2006). Even in hospital, CPR is three times less likely to be successful in cognitively impaired patients compared with cognitively intact patients: the success rate is almost as low as it is in metastatic cancer (Ebell *et al.*, 1998). The futility and burdensome nature of CPR in this population, therefore, indicates a lack of proportion between the treatment and the likely outcome. This suggests that it would be reasonable to regard CPR as an extraordinary treatment, which there would be no moral imperative to pursue in someone with severe dementia. Further discussion of the issues around resuscitation can be found in publications by the Resuscitation Council ([www.resus.org.uk](http://www.resus.org.uk)), including a joint statement on decisions relating to cardiopulmonary resuscitation from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (Resuscitation Council (UK), 2001).

### **4.11.8 Pain**

Amongst older people in long-term care, pain is a common symptom (Ferrell *et al.*, 1990; Sengstaken & King, 1993). There is evidence that pain goes undetected amongst people with dementia and in part this reflects difficulties with communication and the recognition of pain by clinicians (Marzinski, 1991; Ferrell *et al.*, 1995; Cook *et al.*, 1999). Along with problems of detection, there is increasing evidence of under-treatment (Horgas & Tsai, 1998; Morrison & Siu, 2000; Balfour & O'Rourke, 2003; Nygaard & Jarland, 2005).

The initial task is to detect pain. For people in the mild to moderate stages of dementia, clinicians should be aware of the possibility of pain and routinely enquire about it. There has been a tendency to use self-report pain scales where the person can still communicate (Closs *et al.*, 2002) and observational scales as verbal communication becomes more difficult. Research that takes into account the underlying physiology of pain suggests that observational scales should be used, whatever the cognitive status of the person (Scherder *et al.*, 2005).

A number of observational pain assessment tools now exist and these have been systematically reviewed (Zwakhalen *et al.*, 2006). The review was unable to recommend any particular scale unequivocally because they all showed only moderate psychometric properties. A further complexity exists because pain is only one cause of distress. There is a concern that pain assessment tools might detect distress caused by other factors (Regnard & Huntley, 2005). The need to consider, therefore, the possible relationships between pain, distress and BPSD is paramount (Cipher & Clifford, 2004; Zwakhalen *et al.*, 2006).

In principle, the management of pain in dementia should be much the same as it is in other branches of medicine; the cause of the pain should determine the treatment (Regnard & Huntley, 2005). The World Health Organization's analgesic ladder is a useful resource (WHO, 2006). In the final days of life, a palliative care pathway might

encourage appropriate management of symptoms, including pain (Thomas, 2003; Ellershaw & Wilkinson, 2003). Non-pharmacological treatments might also be useful (for example, massage, aromatherapy and transcutaneous electrical nerve stimulation (TENS)); however, there is a lack of good-quality evidence to support the use of such means (Cameron *et al.*, 2003). It should not be forgotten that BPSD might be a manifestation of pain (Manfredi *et al.*, 2003; Chibnall *et al.*, 2005), but putative pain behaviour (that is, distress) might have some other cause, so blanket prescribing of analgesia would not be good practice.

#### 4.11.9 Services to support palliative care in dementia

Services specifically designed to provide good-quality palliative care in dementia are few. There are several possible models but little research to support the use of one in particular (Sampson *et al.*, 2005). There is evidence from the US that both professionals and family members of people with dementia, especially if they have experience of terminal care, favour a palliative care approach (Luchins & Hanrahan, 1993). The question is how this might be provided (Evers *et al.*, 2002).

Ahronheim and colleagues (2000), in a randomised controlled study of 99 patients with severe dementia admitted to an acute hospital over the course of 3 years, found it difficult to effect a palliative care approach. They concluded that it would be better to identify patients prior to their arrival in an acute hospital.

In the US, dementia special care units (DSCU) have acted as specialist hospices (Volicer *et al.*, 1986). When the provision of care in the DSCU was compared with that in the traditional long-term care unit, the DSCU showed more evidence of advanced care planning and less invasive care, with lower costs (Volicer *et al.*, 1994). This study, however, was neither randomised nor blind. There are problems associated with the use of such units on a large scale (Hughes & Robinson, 2005).

The PEACE programme (Shega *et al.*, 2003) attempted to integrate palliative care into primary care from the time of the diagnosis until death. The focus was on advance care planning, symptom management (with special attention to pain, behavioural problems and depression), education, carer support, optimal use of community resources and improved coordination of care. The programme – neither randomised, nor controlled – relied upon two clinical nurse specialists. There are only preliminary results, but they suggest ‘high rates of satisfaction with the quality of care, adequate pain control, appropriate attention to prior stated wishes, and patients dying in desired locations’ (Shega *et al.*, 2003). Despite the support, however, carers still experienced significant stress. Family carers of people with dementia face particular stresses and it is known that their bereavement reactions are different in comparison with those bereaved through cancer (Albinsson & Strang, 2003).

Palliative care teams working in the community would help to keep people in their familiar surroundings, but there is still the problem of a lack of familiarity with dementia. If palliative care in dementia involves a broader role – with, for example, greater awareness of BPSD and its treatment – then specialist palliative dementia care nurses

would be required (Robinson *et al.*, in press). Their role might be to coordinate care and a palliative approach wherever the person with dementia be located: in hospital, in long-term care or at home.

#### **4.12 THE ECONOMIC COST OF DEMENTIA**

Addressing the different aspects of care of people with dementia, and meeting the individual's needs and those of his or her carers, requires an extensive and complex network of health and social care services, as well as care provided informally by family and friends. The diversity of this network is illustrated by the cost estimates for dementia in the UK, ranging from £1 billion to over £14 billion per year. Bosanquet and colleagues (1998) estimated the annual cost of AD in the UK to be between £5.4 and £5.8 billion at 1996 prices, which included health and social care costs, social security, out-of-pocket expenses and the cost of providing informal care which was estimated using the equivalent formal wage rate. Lowin and colleagues (2001) estimated the annual societal cost to be between £7.06 and £14.93 billion at 1999 prices, dependent on prevalence, amount of informal care provided and the wage rate used to cost informal care.

McNamee and colleagues (2001) estimated the formal health and social care costs associated with dementia in England and Wales at £0.95 billion for men and £5.35 billion for women in 1994, rising at an expected £2.35 billion for men and £11.20 billion for women with dementia in 2031 (1994/95 prices). The increase in costs was attributed to an anticipated rise in the elderly population, especially women aged 80 years and above. The same study reported that if dementia prevalence rates declined smoothly over each decade by 0.5%, 1%, and 2% for people aged 75–79 years, 80–84 years and 85 years and over, respectively, then health and social care costs were likely to fall far below the initial projected estimate, reaching £1.01 billion for men and £5.77 billion for women with dementia in 2031. Likewise, if mental and physical functioning of people with dementia improved over time, as reflected in a hypothetical fall of 0.5 in overall MMSE and ADL scores, respectively per decade, then formal care costs were expected to drop at £1.65 billion for men and £7.87 billion for women with dementia. However, with a projected increase of 66% in the number of people with cognitive impairment between 1998 and 2031 (Comas-Herrera *et al.*, 2003), of which an estimated 72% will have AD (Ott *et al.*, 1995), the costs associated with formal care of people with dementia are expected to grow at even higher levels in the future than estimated figures.

The finding of McNamee and colleagues (2001) that the level of mental functioning is significantly associated with the costs of health and social care for people with dementia has been reproduced in a Swedish study that aimed at identifying the determinants of formal and informal care costs for people with AD (Jönsson *et al.*, 2006). The study found that the costs of community care for this population (which accounted for about half of total formal and informal care costs of AD in Sweden) increased sharply with increasing cognitive impairment, as expressed by declining MMSE scores. Informal care costs were also strongly associated with the level of

disease severity. In contrast, the magnitude of medical care costs (inpatient and outpatient care and pharmaceuticals) was not substantially affected by the level of disease severity. The association between costs of care for people with AD and the level of cognitive impairment was confirmed both in comparisons across people with various levels of disease severity, as well as within patients with increasing severity over time. The study also demonstrated the significant influence of behavioural disturbances, measured with brief Neuropsychiatric Inventory (NPI) scores, on total costs of care. The latter finding has also been reported by Murman and colleagues (2002), who estimated that a one-point increase in the NPI score of people with AD would result in an annual increase of between \$247 and \$409 in total cost of care (2001 prices), depending on the value of unpaid care-giving.

Due to the nature of dementia, the majority of service provision falls on care rather than treatment, and with the large demand on time that care requires, it is unsurprising that informal care is identified as the main cost driver overall (Souetre *et al.*, 1999). Schneider and colleagues (2003) warn of the potential to significantly underestimate the total cost of care if informal care costs are not included, estimating that informal care accounts for up to 40% of the total cost of dementia. Caring for the person with dementia at home can mean that up to 75% of associated care costs are out-of-pocket expenses and informal care (Bosanquet *et al.*, 1998). Time invested in informal care-giving alone is estimated to account for on average 6.8 hours per day (Souetre *et al.*, 1999), 44 hours per week (Schneider *et al.*, 2002) and, for individuals with behaviour that challenges, 79% of the week (Kirchner *et al.*, 2000). The majority of time is taken up with general and domestic tasks and supervision that would otherwise be carried out by home care and mobile meals services. Based on the hourly rate for a Local Authority home care worker (Curtis & Netten, 2005), the substitution of informal care for formal care services is estimated at £15,885 per year. The potential cost savings of not employing formal care services will be considerable. Care provided by family carers enables many individuals to remain in their own home, delaying or preventing placement in residential care. With the additional cost of moving a person with AD into residential care calculated at up to £20,668 per year (Holmes *et al.*, 1998), alongside the monetary value placed on the care provided by family and friends, the potential cost savings provided by the informal carer are substantial. However, caring for people with dementia can be stressful and is associated with depression and anxiety that may reduce the quality of life of the carer. Moore and colleagues (2001) identified use of healthcare services as a component, albeit minor, of costs associated with informal care.

Due to the common late onset of the disease, the impact of lost productivity on industry associated directly with people with dementia is minimal, but the cost to industry due to caring is an important aspect. Souetre and colleagues (1999) estimated that, for those carers who had not reached retirement age, on average between 15 and 61 working days over a 3-month period were lost, depending on the severity of the condition. A study estimating the cost of AD to US business in 2002 found that absenteeism due to care-giving cost businesses \$10 billion, productivity losses due to absenteeism cost \$18 billion and the replacement cost of people taking early retirement to care for individuals cost \$6 billion. The total cost associated with these factors of care-giving alone was \$34.5 billion to US industry (Koppel, 2002). The largest component

of direct carer costs was lost earnings due to early retirement, reduced working hours, refusing promotion, lateness and absence (Moore *et al.*, 2001).

Providing care for people with dementia requires a wide range of services from a wide range of sources. Although the exact economic cost of dementia is unknown because of the informal nature of a large amount of the care provided, it can be concluded that dementia has substantial economic implications.

## **4.13 HEALTH AND SOCIAL CARE RECOMMENDATIONS**

### **4.13.1 Diversity, equality and language**

- 4.13.1.1 People with dementia should not be excluded from any services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities. [For the evidence, see sections 4.6, 4.9 and 5.2.2]
- 4.13.1.2 Health and social care staff should treat people with dementia and their carers with respect at all times. [For the evidence, see sections 4.9 and 4.11]
- 4.13.1.3 Health and social care staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), religion and personal care. Care plans should record and address these needs. [For the evidence, see sections 4.2, 4.3, 4.9 and 4.10.6]
- 4.13.1.4 Health and social care staff should identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities. Care plans should record and address these needs. [For the evidence, see sections 4.6.3 and 4.10.4]
- 4.13.1.5 Health and social care staff, especially in residential settings, should identify and, wherever possible, accommodate the preferences of people with dementia and their carers, including diet, sexuality and religion. Care plans should record and address these preferences. [For the evidence, see sections 4.2, 4.9.1 and 4.10.6]
- 4.13.1.6 People who are suspected of having dementia because of evidence of functional and cognitive deterioration, but who do not have sufficient memory impairment to be diagnosed with the condition, should not be denied access to support services. [For the evidence, see sections 4.6.1, 4.6.2, 4.10.1, 4.10.2 and 6.4.2]
- 4.13.1.7 If language or acquired language impairment is a barrier to accessing or understanding services, treatment and care, health and social care professionals should provide the person with dementia and/or their carer with:
  - information in the preferred language and/or in an accessible format
  - independent interpreters
  - psychological interventions in the preferred language. [For the evidence, see section 4.10.6]