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Author

TERESA POOLE

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Dementia Care

KING'S FUND
11–13 CAVENDISH SQUARE
LONDON W1G 0AN
Telephone 020 7307 2400
www.kingsfund.org.uk

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DEMENTIA CARE

Teresa Poole

King's Fund

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Introduction

The rising number of people with dementia will be a major determinant of the demand for social care over the next two decades. Longer life expectancy, and the expected big increase in the number of people over the age of 85, is projected to be the main factor in the increase in the number of people with dementia. In the next 20 years, the number of people aged 85+ in England is set to increase by two-thirds, compared with a 10 per cent growth in the overall population (Wanless 2006).

The level of social care needed by those with dementia varies according to the stage of the disease, the support available from informal carers and the need that those carers themselves have for support. In the initial, mild stages, many people with dementia continue to live in their own homes and rely on informal care from family members, sometimes augmented by formal social care services. However, as the disease progresses through the moderate to the severe stages, there is a greater need for formal social care services and an increased likelihood of admission to a residential or nursing care home.

This paper provides some additional background information relating to the issues addressed in the 'Dementia care' section of Chapter 9 ('New influences on care') of this Wanless review (Wanless 2006), including references to recent studies that have been published on these subjects.

The demographics of dementia

Dementia is an age-related condition, with a prevalence that nearly doubles for every five years after the age of 65. It is estimated (Alzheimer's Society 2005b) that there are 652,600 people with dementia in England (using 2001 population data). The symptoms include cognitive impairment, behavioural problems and psychotic symptoms, all of which make considerable demands on carers and the social care system. A number of studies in various countries have been undertaken into the demographics of dementia, and all tend to show similar trends (*see* Table 1 below).

The most common cause of dementia is Alzheimer's disease (55 per cent) (Alzheimer's Society 2005a), followed by vascular dementia (20 per cent), Lewy bodies (15 per cent),

TABLE 1: SUMMARY OF DEMENTIA PREVALENCE DATA IN VARIOUS COUNTRIES, BY PUBLICATION

Age group	Dementia prevalence (%)							
	Hofman *et al* 1991	Henderson and Jorm 2000	Ritchie and Kildea 1995	MRC CFAS 1998		Melzer *et al* 1999		Dewey 2001
				Men	Women	Men	Women	
60–64	1.0	–	–	–	–	–	–	–
65–69	1.4	1.4	1.5	1.4	1.5	2.2[1]	1.6[1]	–
70–74	4.1	2.	3.5	3.1	2.2			–
75–79	5.7	5.6	6.8	5.6	7.1	6.7[2]	6.6[2]	–
80–84	13.0	11.1	13.6	10.2	14.1			–
85–89	21.6	23.6[3]	22.3	19.6[3]	27.5[3]	18.9[3]	22.9[3]	–
90–94	32.2		33.0					–
95–99	–		44.8					–
100+	–		–					64 (49)[4]

Sources: Hofman *et al* 1991, Henderson and Jorm 2000, Ritchie and Kildea 1995, MRC CFAS 1998, Melzer *et al* 1999, Dewey 2001

[1] Aged 65–74 years.

[2] Aged 75–84 years.

[3] Aged 85+ years.

[4] 64% refers to mild, moderate and severe dementia, 49% refers to moderate and severe dementia only.

TABLE 2: ESTIMATED PREVALENCE OF COMBINED COGNITIVE IMPAIRMENT AND FUNCTIONAL DISABILITY AMONG PEOPLE AGED 65+, BY AGE AND GENDER

Age group	Prevalence of cognitive impairment and functional disability (%)					
	Men			Women		
	Cognitive only	Cognitive and functional	All with cognitive	Cognitive only	Cognitive and functional	All with cognitive
65–74	1.6	0.7	2.2	1.2	0.5	1.6
75–84	4.2	2.4	6.7	3.3	3.3	6.6
85+	8.0	10.8	18.9	8.5	13.7	22.2

Source: Comas-Herrera *et al* 2003

fronto-temporal dementia including Pick's disease (5 per cent) and other dementias (5 per cent). Different types of dementia may occur in different proportions in men and women, with Alzheimer's more common in women and vascular dementia more common in men.

Cognitive impairment is often associated with functional disabilities, so that care packages must meet a wide range of very different needs. One study (Melzer *et al* 1999) found that 38 per cent of all disabled people over the age of 65 were cognitively impaired. Other estimates (Comas-Herrera *et al* 2003) for England and Wales (*see* Table 2 above) indicate that after the age of 85 the majority of people with dementia also have functional disabilities and needs, for instance with activities of daily living (ADLs).

The Personal Social Services Research Unit/London School of Economics (PSSRU/LSE) model (Comas-Herrera *et al* 2003) projects that between 1998 and 2031 the number of people with cognitive impairment in England will rise from 461,000 to 765,000, of whom approximately half will also have ADL problems. The model's associated projections for the change in demand between 1998 and 2031 are:

- the numbers of hours of home care arranged by local authorities for older people with cognitive impairment would need to rise by 67 per cent
- the numbers of people with cognitive impairment in institutions would need to rise by 63 per cent, from 224,000 in 1998 to 365,000 in 2031 (this compares with a 53 per cent increase in the total number of older people in institutions).

The progression of dementia is normally described in three stages: mild, moderate and severe. Alzheimer's disease usually progresses from diagnosis to death in about 5–7 years. One 15-year study (Ganguli *et al* 2005) found that the mean (and standard deviation) duration of survival with Alzheimer's disease was 5.9 (3.7) years. This often results in a heavy burden for carers, particularly spouses, over several years.

The demands on and for informal carers are very heavy. A study conducted in the United States (Langa *et al* 2001) looked at the need for informal care (defined as assistance with ADLs or IADLs (instrumental activities of daily living) from a relative or unpaid non-relative). It found that, after adjusting for socio-demographic characteristics, co-morbidities and potential care-giving networks, the number of hours needed increased sharply as the dementia progressed:

normal cognition	received an average of 4.6 hours per week of informal care
mild dementia	received an average of 13.1 hours per week of informal care
moderate	received an average of 39.4 hours per week of informal care
severe	received an average of 46.1 hours per week of informal care.

Risk factors and research

Any change in future prevalence rates for dementia will have an impact on the demand for social care. The rates might be affected by various risk factors associated with dementia. The increase of obesity in our society could be cause for concern. A study (Whitmer *et al* 2005) of more than 10,000 people showed that obesity was associated with a 74 per cent increased risk of dementia 25–30 years later, while overweight people had a 35 per cent greater risk. Previous work has linked high blood pressure and high cholesterol with increased risk of Alzheimer's disease. A Finnish study following a group of 1,449 people between 1972 and 1998 found that those with raised systolic blood pressure in midlife had 2.3 times the risk of developing Alzheimer's in later life. Participants with cholesterol levels above 6.5 in midlife had 2.1 times the risk of developing the disease (Kivipelto *et al* 2001).

Conversely, physical activity may help preserve cognitive function. A study (Podewils *et al* 2005) at Johns Hopkins Medical Institutions in Baltimore, Maryland, found that study members who engaged in four or more physical activities, from gardening to biking, had about half the risk of dementia compared with those who engaged in one or none. The effect was mainly seen in those without the ApoE4 gene variant, which is associated with an increased Alzheimer's risk.

Time spent in full-time education also appears to be negatively associated with dementia. A study reported in *Science* (Marx 2005) of identical twins in Sweden, where one had been diagnosed with dementia and the other had not, found that the twin with dementia had significantly less education. Research at Case Western University in Cleveland (United States) has also suggested a possible link between a reduced risk of Alzheimer's disease and people with mentally demanding jobs, while researchers at the Albert Einstein College of Medicine have shown an association between higher levels of leisure activities and a lower risk of developing Alzheimer's. Hence the 'use it or lose it' approach to avoiding dementia.

The Nun Study is a longitudinal research programme into Alzheimer's disease, run by David Snowdon at the University of Kentucky, and has followed 678 nuns who agreed to give complete access to their historical personal and medical records, and to participate in annual examinations of their mental and physical function. All agreed to donate their brains after death, and to date almost 500 brains have been investigated. The nuns have shared a common environment since early adulthood, and the convents have maintained detailed archives on each woman, including examples of their early writing skills. Key findings so far include: low linguistic ability in early life is a strong predictor of poor cognitive function and Alzheimer's disease in late life; a preventable disease such as a stroke can trigger the symptoms of dementia in a person with an Alzheimer brain; and deficiency in the vitamin folic acid appears to accelerate the brain-damaging effect of Alzheimer's disease. Thus improved schooling, greater access to higher education, and the demands of the knowledge economy might all act to reduce the prevalence of dementia in England over the next 20 years.

In August 2005, results from the Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS) showed that improved health and mortality were not likely to guard against the risk of developing dementia (MRC CFAS 2005) The study interviewed 13,004 individuals aged 65 years and above from five diverse locations across England and Wales. It concluded that there was no convincing evidence of variation in dementia rates across England and Wales, despite variations in health and mortality. It was suggested that these differences may have been insufficient to influence the incidence of dementia, whereas in many parts of the world the differences in incidence of dementia between countries have been large enough to be easily detectable.

It is, of course, possible that new treatments will emerge to prevent, delay or alleviate the symptoms of dementia, but such optimism has proved unfounded in the past. Dementia is most common at an advanced age, so a fairly modest delay of a few years in the onset of the disease or on its progression could potentially mean a significant reduction in the number of affected people and the demand for social care. For instance, a decline of 1 per cent per year in the prevalence of moderate to severe cognitive impairment could broadly offset the impact of the expected increase in the overall numbers of older people between 1998 and 2031 (Comas-Herrera *et al* 2003). A study in Australia estimated that, if the onset of Alzheimer's disease could be delayed by five years, by 2050 there would be a 49 per cent reduction in the total number of cases projected (Access Economics 2004). However, there are as yet no immediate candidates to provide such a breakthrough among the wide-ranging research.

At the moment, there are no cures for dementia and only relatively few drugs available that in some cases seem to slow down the progression of Alzheimer symptoms: donepezil (Aricept), rivastigmine (Exelon), galantamine (Reminyl) and memantine (Ebixa). They are not effective for everyone, and improvements may be only temporary. These drugs are licensed specifically for Alzheimer's disease, and not other forms of dementia, but their cost-effectiveness has been challenged by the National Institute for Health and Clinical Excellence (NICE) (see Annex).

Research into preventing and treating dementia is following a number if different paths.

- **Vaccines**. Work into an anti-Alzheimer's vaccine has looked at ways to stimulate the immune system to produce antibodies against beta-amyloid, the protein associated with plaques in the brain. Unfortunately, the first clinical trial had to be stopped in 2002 because a number of patients developed inflammation of the brain. Monitoring of the patients continued, even though participants had not received all the planned doses. In May 2005, *Neurology* reported on the main findings, which showed that vaccine recipients did not do better than the control group on memory, thinking and overall function but those with the highest levels of antibodies to beta-amyloid declined less in their average performance. Brain autopsies of vaccine recipients showed lower than expected levels of plaques, and the vaccine also appeared to have reduced levels of the tau protein, which is associated with Alzheimer brain tangles. Strangely, those with high antibody levels showed more brain shrinkage, but this shrinkage was not accompanied by the expected greater decline in function. Further work is under way.

- **Enzymes**. The beta-amyloid found in the plaques is derived from a larger protein called the amyloid precursor protein (APP), which is then broken down into fragments by enzymes in a series of events called proteolytic processing. Two enzymes – beta- and gamma-secretase – help APP to form beta-amyloid, and much work is being done to try to inhibit these enzymes.
- **Gene therapy**. The University of California, San Diego, is working on a treatment that involves genetically engineering a person's own skin cells to produce nerve growth factor. This was then injected into several brain regions that are normally affected by Alzheimer's in the hope that this would improve function and slow the decline of other cells. The study treated six people in the early stages of Alzheimer's (two more patients died). An update in April 2005 found that, two years after treatment, the patients had declined more slowly than the expected average rate, and scans showed increased brain activity compared with untreated individuals. However, observers cautioned that the study involved such a small number of people that the apparent benefit could be due to normal differences between individuals. The study was designed primarily to test safety. Earlier clinical trials of drugs that stimulated the brain's own nerve growth factors had mixed results.
- **Non-steroidal anti-inflammatory drugs (NSAIDs).** Various studies have indicated that medium- and long-term use of NSAIDs (for example, ibuprofen) is associated with a significantly reduced risk of developing Alzheimer's later in life. One study found that those who had taken NSAIDs for more than two years had an 80 per cent reduction in Alzheimer's risk. However, it was not clear why this happened or whether there was an indirect effect – in other words, people were taking the drug for a reason such as arthritis, and that people with arthritis are less susceptible to Alzheimer's disease for some reason. It should be noted that existing NSAIDs are not suitable as long-term treatment because of side effects. A similar study is under way into the effect on Alzheimer's of the more specifically targeted Cox-2 inhibiting arthritis drugs.
- **Anti-oxidants**. Various studies have suggested that diets rich in anti-oxidants such as vitamin C, Japanese green tea, vitamin E, and even curcumin (found in spices such as turmeric) can lower the risk of developing Alzheimer's.
- **Hormone replacement therapy (HRT)**. Some long-term studies have suggested that women taking oestrogen-based HRT have a lower risk of developing Alzheimer's disease in the long term. However, the results are mixed, and it is not understood why there might be this link.

Models of dementia care

Current living arrangements

People with dementia represent a large proportion of those in institutional care, although a move into a care home does not usually take place before the disease has progressed past the initial stages. Various figures are available. One study (Matthews and Dening 2002) of the prevalence of dementia in institutional care found that 34 per cent of people with dementia lived in institutions, and that within institutions dementia prevalence was 62 per cent. This is in agreement with earlier research (Kavanagh *et al* 1993) on those with advanced cognitive impairment, which found that 13 per cent lived alone, 50 per cent lived with others, and 37 per cent in residential settings (including NHS). The decision to move into a residential or nursing home is most common among those who suffer both cognitive impairment and ADL disability. The MRC CFAS figures (see the Introduction to the Wanless Review (Wanless 2006) for information about this survey) show that 17 per cent of those with only cognitive impairment and 52.8 per cent of those with combined disability lived in institutions. Its data showed that overall 46 per cent of all those living in institutions had diagnostic levels of cognitive impairment, somewhat lower than the earlier figure due to a relatively strict definition.

Table 3 below shows a detailed comparison of dependency and living arrangements for those over 65 based on 1998 data (Comas-Herrera *et al* 2003). Some 85 per cent of those with both ADL limitations and cognitive impairment were living in institutions.

TABLE 3: PERCENTAGE OF THE POPULATION AGED 65+, BY DEPENDENCY AND LIVING ARRANGEMENTS

Living arrangement	Level of dependency			
	No dependency (%)	Cognitive impairment only (%)	ADL limitation only (%)	Combined (%)
Alone without informal carer	28	21	14	1
Alone with informal carer	9	22	25	4
Single with others	6	7	7	2
Couple	56	38	29	8
All in community	**100**	**88**	**75**	**15**
Residential home	–	7	15	51
Nursing home	–	4	9	30
Hospital	–	1	2	4
All in institutions	**0**	**12**	**25**	**85**
Total number by dependency	**6,548,000**	**234,000**	**770,000**	**227,000**

Source: Comas-Herrera *et al* 2003

TABLE 4: PERCENTAGE OF THE POPULATION AGED 65+ LIVING OUTSIDE INSTITUTIONS, BY DEPENDENCY AND TYPE AND SOURCE OF HELP

	Level of dependency	
	Cognitive impairment only (%)	**Combined cognitive and physical impairment (%)**
Receiving any help	49	80
Type of help received		
Personal and household	2	38
Personal only	0	0
Household only	47	43
Type of helper		
Spouse only	21	21
Other informal	13	25
Mixed (including formal)	2	11
Formal services only	14	23

Source: Comas-Herrera *et al* 2003

The MRC CFAS data also provides a detailed breakdown of the level of demand that people with dementia living outside institutions present to the social care system. Table 4 above demonstrates that even the most dependent group relies heavily on help from spouses and informal carers, boosting calls for significantly more support for carers of people with dementia.

TABLE 5: PERCENTAGE OF THE POPULATION AGED 65+ LIVING OUTSIDE INSTITUTIONS, BY DEPENDENCY AND USE OF HOSPITAL AND COMMUNITY SERVICES

Service	**Level of dependency**	
	Cognitive impairment only (%)	**Combined cognitive and physical impairment (%)**
Any hospital contact	61.8	64.0
Acute care	38.2	54.4
Outpatient care	42.9	36.1
Day hospital	11.2	14.7
Community nursing services[1]	38.4	59.5
Social worker	11.8	15.5
Specialist community services[2]	36.5	56.7
Day centre	14.6	19.4
Any of the above community services	64.2	80.5
Home care services[3]	31.9	52.4
Meals on wheels	12.4	22.2
Home help	25.2	43.4

Source: Comas-Herrera *et al* 2003

[1] Doctor and community nurses (including psychiatric and Marie Curie nurses), health visitors and continence advisers.

[2] Chiropodists, physiotherapists, audiologists and occupational therapists.

[3] Meals on wheels, laundry, home help, private domestic help and incontinence services.

Table 5 (*see* p 9)demonstrates the overlap between acute hospital and long-term care. Just over 38 per cent of those with only cognitive impairment used acute services in the two years after initial interview, and almost 62 per cent had some kind of hospital contact. The figures are higher for those with combined cognitive and physical disabilities. The close co-operation between long-term care arrangements and acute care hospitals is often key to preventing the need for admission and achieving early discharge and rehabilitation.

The challenges of dementia care

Services for people with dementia in the United Kingdom are often criticised for failing to provide what users and their families really want and need (Godfrey *et al* 2005). Care packages for individuals with dementia need a variety of elements to achieve the best outcomes, something that the Department of Health recognised in November 2005 with the publication of *Everybody's Business, Integrated mental health services for older adults* (Department of Health/Care Services Improvement Partnership 2005). The rising number of people with dementia over the next two decades will require new types of service provision to meet the varying needs. A well-designed social care package can promote the independence of someone with dementia, provide assistance towards maintaining an active life and help avoid admission into a care home (unless that is the preference).

Meeting carers' needs is a particularly acute issue, especially as many of the informal carers of people with dementia are themselves elderly. Partners and relatives have to cope with the emotional toll of seeing a loved one's cognitive abilities decline, as well as the challenging behavioural aspects of dementia, including aggression, wandering, and insomnia. All these symptoms can contribute to the mounting loss of ADL abilities, and it is the combination of cognitive impairment with ADL disabilities that creates particular challenges for carers. The Alzheimer's Society's response (Alzheimer's Society 2005c) to the Green Paper on adult social care stressed that the government's aim of increasing choice, independence and control should not increase the workload or stress of carers, who were often already at breaking point.

Important aspects of dementia care include:

- early diagnosis so that the person who is developing dementia can take decisions about their future care and plan ahead
- continuity in care staff, so that the person with dementia is not unsettled by regular changes in domiciliary care staff
- giving staff specific training in dementia care
- an emphasis on maintaining physical health, despite the mental deterioration
- high-quality day care centres for leisure and social contact
- 'memory clinics' – effectively a 'one-stop-shop' offering assessment, diagnosis, support and counselling, information, monitoring of treatment, and education and training, these have been shown significantly to improve the quality of life of carers and patients
- regular respite care as part of a package of measures to relieve the burden on informal carers
- clear information given in all settings about the costs associated with long-term care, particularly the break-down between nursing and personal care.

Age Concern and the Mental Health Foundation commissioned a review (Godfrey *et al* 2005) of successful models of dementia care provision in Europe, the United States and

Australasia. One study compared the provision of integrated family support services with psychiatric day care attendance and found that family support was more beneficial in improving behavioural problems and increasing engagement. Work conducted in Finland found that offering intensive community-based support from a dementia family care co-ordinator for two years significantly reduced admission into institutional care during the first months of the intervention but by the end of the period the institutionalisation rates were the same. Institutionalisation was thus delayed but not avoided. There is little published research relating to specialist domiciliary care for older people with dementia in terms of improving and maintaining well-being and quality of life, and little in the literature on what constitutes quality home care for people with dementia.

Care homes often lack the type of design features that enhance the environment for those with dementia, such as high light levels, non-institutional dining areas, highly visible toilets and the use of colour and decor to ease corridor negotiation. This is despite the high proportion of residents who have dementia symptoms, and the fact that many with advanced dementia have no alternative to residential care. The Age Concern/Mental Health Foundation review cites a UK study that compared nursing home 'intermediate care' (aimed at rehabilitation and discharge back home) with permanent 'home for life' nursing home care for people with dementia. The behaviour of participants in the intermediate care group deteriorated more than those in permanent settings, and those who moved back to their own home fared worst of all. So, high-quality care homes have an important role to play.

Many of the interventions that have proved most effective for people with dementia do not demand specialist technology or housing inputs. Behaviour therapy, activity programmes, planned walking, pet therapy, and music and light therapy are among various interventions that for some people with dementia can improve behaviour and well-being, although the lack of randomised controlled trials makes firm conclusions difficult.

Extra care housing and telecare

Extra care housing, a form of home-based care, can offer an alternative to residential care for some people with dementia. There is a reasonable consensus that if a person who is already living in extra care housing develops dementia then it is usually possible for them to remain living in the accommodation. This is because they are already familiar with the surroundings and have built relationships with neighbours. It may be more challenging if someone moves into extra care housing after the dementia has developed beyond the early stage. Separately, there is still considerable debate whether 'dementia wings' should house dementia residents together within extra care housing schemes, or whether they should be integrated among other elderly residents.

Several extra care housing pilot schemes have been designed specifically for dementia residents with the aim of keeping people out of care homes. In Northern Ireland, for instance, the Fold Housing Association opened the Seven Oaks Dementia Care Unit in March 2001. It includes facilities for those with severe dementia, and bungalow accommodation for couples. The layout uses copies of landmarks in the local town of Derry to promote familiarity, often using the names of real local shops and streets. The aim is to recognise the progressive nature of the illness and to provide increasing levels of support as needed. A number of extra care case studies are summarised in Background Paper 8 of the appendices('Housing options for older people').

Technology, including ‘wander monitors’, can make it considerably safer than otherwise for someone with dementia to remain living in an extra care unit or in their existing home, although there are ethical issues including the question of obtaining informed consent for the installation of monitoring devices. The range of telecare devices usually includes safety and security sensors, which monitor whether taps and cookers are left on, if doors are not closed, and if a person leaves the bed in the middle of the night and does not return for a long time (see Background Paper 7 of the appendices (‘Telecare and older people’) for details and case studies).

The Northamptonshire ‘Safe at Home Project’ is the biggest telecare pilot scheme (with 233 people with dementia) and has achieved promising results in helping people remain living in their own homes in the community and relieving stress on carers. It also offers a basic evaluation of cost-effectiveness. The most frequently used items were calendar clocks and medication dispensers but in total more than 50 kinds of technology were used during the study. An evaluation in April 2005 found that relatives and carers said the technology reduced levels of concern about risk and that it had not led to any reduction in social contact with the patient. The technology appeared to enable people with dementia to remain living independently for longer and could address some of the reasons given by carers for a person with dementia seeking admission to hospital or residential/nursing care. Some 28 per cent of the Safe at Home group were admitted to live in residential care during the 21-month period, compared with 54 per cent in a comparator group in Essex. The proportion that died was also smaller, at 12 per cent compared with 21 per cent. An analysis of the care packages showed that Safe at Home users received fewer services, visits and hours of service than the Essex group both at the point of referral and at the end of the project or when they left the community. However, the designers of the Northamptonshire project have argued strongly that technology should not be seen as a way to reduce formal carer costs as the cost-benefits will in any case flow because of the potential for reduced hospital and care home admissions (Woolham 2005).

The April 2005 evaluation looked at the costs of the care of 233 Safe at Home users compared with those of the comparator group in Essex. This covered the total costs of the telecare project, and the costs of residential, nursing and hospital care for the two groups of people with dementia over the 21-month period. The net saving emerged as £3,690 per person for each of the 233 people who received help from the project. However, it did not include costs of the community-based care package, mostly because of shortcomings in the data. Nevertheless, the evaluation concluded that even after a significant adjustment for this, there would still be considerable cost savings.

The Alzheimer’s Society has reported that people with dementia and their carers ‘feel that they would benefit enormously from assistive technology, but access to it is limited’ (Alzheimer’s Society 2005c). Its assessment identified the following technology as potentially useful: alarms, emergency cords, sensors to detect whether a person has left the bed or house to minimise harm, flood detectors and telephones in each room of the house.

Although many pilot studies include a relatively small number of people, there is a mounting body of evidence that is broadly positive about the potential for new forms and settings for service provision for people with dementia. This will increase the choice of care packages even if, in the late stages when needs become complex and unpredictable, a nursing home environment may become appropriate.

Implications for long-term care expenditure

Estimates and forecasts of the costs of dementia care tend to vary greatly depending on whether they attempt to include the costs of informal care, and on which methodology is used to estimate those costs (McDaid 2001). Studies also differ in the extent to which health care costs are included. The overall funnel of doubt can be huge. For example, Lowin *et al* (2001) estimated the gross annual costs of Alzheimer's disease in the United Kingdom to be between £7.06 billion and £14.93 billion, mainly because of different assumptions about the volume and value of informal care. The Audit Commission (Audit Commission 2000) quotes total costs for dementia at £6.1 billion (at 1998/9 prices) for the 320,000 people in England with advanced cognitive impairment based on the 1991 OPCS study, with £3.3 billion attributed to health and social services.

A 2001 demographic model (McNamee *et al* 2001) has estimated that the costs of health (including acute health services) and social care in England and Wales for people with cognitive impairment would rise from £6.30 billion in 1994 to £13.50 billion in 2031 (at 1994/5 prices) to keep pace with demographic changes (*see* Table 6 below). Included in the estimate were medical (including inpatient hospital stays) and social care services. This represents a more than doubling in costs, compared with a 53 per cent rise in the 65+ population. There is a steady rise in costs of £1–1.4 billion every decade up to 2021, and then a more dramatic increase due to greater numbers of women aged over 80. For costs to remain constant, future dementia prevalence rates would need to decline over each decade by 0.5 per cent, 1 per cent and 2 per cent for people aged 75–79, 80–84, and 85+ respectively.

The PSSRU/LSE model (Comas-Herrera *et al* 2003) found that expenditure on long-term care services for older people with cognitive impairment in England was projected to rise from around £4.6 billion in 1998 to around £10.9 billion in 2031, at 2000/1 prices. This does not represent the total costs to society, for which one would need to include a wider range of services to a wider range of public agencies and service users and the opportunity costs of informal care. It does include long-term health and social care services but not acute health services. Sensitivity studies found that expenditure projections were arguably more sensitive to assumptions about rises in care costs than to assumptions about future

TABLE 6: ESTIMATED TOTAL COSTS OF HEALTH AND SOCIAL CARE FOR PEOPLE WITH COGNITIVE IMPAIRMENT, ASSUMING DEMENTIA PREVALENCE RATES REMAIN CONSTANT, ENGLAND AND WALES

Year	Costs of health and social care (£billion)	
	Men	Women
1994	0.95	5.35
2031*	2.34	11.20

Source: McNamee *et al* 2001
* 2031 costs based on 1994/5 prices.

TABLE 7: ESTIMATED COST OF CARE FOR PEOPLE WITH DEMENTIA AGED 75+, BY CARE SETTING

Care location	**Estimated annual cost (1996 prices)**
Living alone in a private household	£12,331
Living with others in a private household	£14,132
Residential accommodation	£24,801

Source: Stewart 1997

mortality, prevalence rates, availability of informal care and patterns of care. (Details of all the sensitivity studies are in the full report.) A decline in the prevalence of moderate to severe cognitive impairment of 1 per cent per year could broadly offset the impact of the expected increase in the overall numbers of older people between 1998 and 2031 by leaving long-term care expenditure unchanged at 1.44 per cent of GDP. The model projected the impact of reducing by 10 per cent per year between 2000 and 2020 the numbers of people with moderate to severe cognitive impairment in residential and nursing homes, substituting this with 16 hours of home care and three district nurse visits a week. The impact of this assumption on expenditure was slight.

The Technology Assessment report (Loveman *et al* 2004) prepared for NICE during its review of the Alzheimer's drugs reviewed the available literature on costs, though some of the figures date back several years. Two of the studies it quotes reviewed the estimated annual cost per individual of different care locations (*see* Table 7 above) and as the severity of the disease increased (*see* Table 8 below). Both confirmed that admission to residential care in the final stages is a major driver of expenditure, and will be a significant burden on families and societies as the number of people over the age of 85 increases.

There is no conclusive evidence on the additional cost of a residential or nursing care place for people with dementia as compared with those with a disability who are non-cognitively impaired. A literature review (Henderson 2003) on care costs and dementia found that estimates of additional costs range from slight to more than one-third higher. However, one can obtain an indication of the added cost to local authorities by looking at the figures compiled by Laing & Buisson (Laing & Buisson 2004) on the baseline fee rates for residential and nursing care in England, and published in July 2004. By comparing the

TABLE 8: ESTIMATED ANNUAL COST OF CARE FOR PEOPLE WITH DEMENTIA, BY SEVERITY OF SYMPTOMS

Severity of dementia symptoms	**MMSE* score**	**Estimated annual cost (1998 prices) Mean (standard deviation)**
Mild	>20	£8,312 (£5,602)
Mild to moderate	15–20	£11,643 (£7,808)
Moderate	10–14	£15,681 (£9,509)
Severe	<10	£22,267 (£14,507)

Source: Wolstenholme *et al* 2002
* The Mini Mental State Examination (MMSE) is the most commonly used test for complaints of memory problems or when a diagnosis of dementia is being considered.

TABLE 9: WEEKLY AVERAGE LOCAL AUTHORITY MINIMUM BASELINE CARE HOME FEE IN ENGLAND, 2004

Type of care home	**Weekly fee**
Elderly residential	£301.72
Elderly mentally impaired residential	£344.19
Elderly nursing	£410.05
Elderly mentally impaired nursing	£429.29

Source: Review calculations based on data from Laing & Buisson

averages of the minimum weekly fee rates for elderly and elderly mentally ill (EMI) for both residential and nursing home fees, one arrives at the figures in Table 9 above.

Thus, residential care was 14.1 per cent higher for EMI residents, and nursing care was 4.7 per cent higher for EMI residents. In producing these calculations, however, it should be noted that the stated baseline fees or bands may not always be adhered to by local authorities, which may pay more if they cannot secure a place at the price. The figures also take no account of third party top-ups, and the higher fees sometimes paid by self-funding residents.

Conclusions

The need for greater provision of all dementia-specific care services remains. The Alzheimer's Society argues for more ring-fenced funding for dedicated services, saying that people with dementia tend to lose out otherwise. One example of such ring-fencing is Australia, which in January 2005 launched the development of a National Framework for Action on Dementia to co-ordinate a 'strategic, collaborative and cost-effective response' to dementia. In its 2005 budget, the Australian government announced A$320.6 million (£136 million) over five years to support people with dementia and their carers, as well as training and support for health care professionals and care workers. This included A$225 million for an extra 2,000 'care at home' places specifically targeted at people with dementia.

The number of people with dementia is set to increase very significantly over the next 20 years, and the consequent increased cost of long-term care will be substantial even without any improvement in the care available. In conclusion, it is worth reiterating the points made by the Wanless Social Care Review (Wanless 2006).

- The burden on informal carers is particularly acute with dementia care, and this cost to society needs to receive greater attention.
- There also needs to be a big increase in the number of carers and care home staff with specialist dementia training and skills.
- The scope for greater provision of dementia-specific care services remains, and consideration should be given to ring-fenced funding for dedicated services.
- Basic information is lacking for planning in that there remains a shortage of dementia-specific data, including the cost of care at home, details of the services that people with dementia receive, and the number of people in contact with an 'old age' psychiatrist.
- Residential care will remain a core option for people with severe dementia and more high-quality care homes will be needed that are specifically designed to meet the living and care needs of people with dementia.

Annex : The NICE appraisal and cost issues

On 1 March 2005, the National Institute for Health and Clinical Excellence (NICE) published for consultation (NICE 2005) its preliminary recommendations that donepezil (Aricept), rivastigmine (Exelon), galantamine (Reminyl) and memantine (Ebixa) should not be used in the NHS (except that memantine could still be prescribed as part of ongoing or new clinical studies on long-term outcomes, disease progression, quality of life and costs). In each case, after an analysis of available evidence, it was judged that the drugs lay outside the range of cost-effectiveness that might be considered appropriate for the NHS. NICE assessed all the available evidence on clinical effectiveness and cost effectiveness, and also undertook its own economic analyses.

The assessment opened up the debate on the opportunity costs of informal care. Users and their families argued that assessment of the cost-effectiveness of dementia care should include the hidden costs of informal care. NICE did consider whether carer costs should be included in the model, as well as carer utilities (quality of life). But the Appraisal Committee said that relevant NICE guidance states that only costs related to NHS and Personal Social Services resources were appropriate to include. So NICE did not pursue this option.

This near-400 page Technology Assessment Report (Loveman *et al* 2004), produced by Southampton Health Technology Assessments Centre, provided the bulk of the evidence that NICE considered. It included a short section (page 182) on implications for other parties, including informal carers. On the one hand, any improvement in symptoms also benefited the carers. On the other hand, if drugs delayed a move into institutional care then there was continued need for support from carers and the wide range of agencies that provide support in the community. Funds for drugs therefore need to be considered against the need for funds, for example, for support for carers of those with Alzheimer’s disease.

The report found that the literature was sparse on the costs associated with Alzheimer’s disease, but that a significant proportion of these costs fell on patients and carers. A review of nine studies on costs for community-based people with Alzheimer’s disease estimated that the proportion of total costs represented by informal care ranged between 36 per cent and 85 per cent. (McDaid 2001). The wide range was in part due to differences in the type of costs included and the methods used to quantify and value carers’ time. A cost study for Ireland found that family care accounted for almost 50 per cent of the overall resource burden for Alzheimer’s (based on an opportunity cost valuation of carer time) (O’Shea and O’Reilly 2000).

The Technology Assessment Report said ‘it was difficult to estimate the impact on informal costs, and/or caregiver time, from treatment with the pharmaceuticals discussed in this review, due to the varied methodology and coverage of these issues in published cost and cost-effectiveness studies, but consideration should be given to the significant inputs of time and resource by caregivers to the treatment of Alzheimer's, and to the costs met by Alzheimer's patients themselves in the management of this disease'.

There was a robust reaction to the NICE preliminary recommendations, with families and pressure groups up in arms at the suggestion that the drugs should not be prescribed by the NHS. On 22 March, the then Health Secretary, John Reid, put out a statement (Department of Health 2005) saying he had brought a number of issues to NICE's attention, including the following.

- Whether NICE had carried out an analysis of the cost effectiveness of this medication compared to non-drug interventions for cognitions, behaviour, activity of daily living and carer burden.
- If NICE would consider reassessing cost effectiveness including a factor of carer time in the outcome. The Department of Health response asked: 'Has NICE considered whether there would be a different answer if the costs of carers as opposed to the benefits were included? Would this make a difference? It is our understanding that NICE generally only considers NHS costs. Is it satisfied that this is sufficiently wide-ranging to cover adequately all the potential benefits of the drugs involved?' It asks whether NICE would be prepared to consider 're-assessing cost-effectiveness including a factor for carer time in the outcome', using randomised controlled trial data on reduction in carer time as a benefit from these medications.
- The Department of Health pointed out that the use of a cost per quality-adjusted life year (QALY) approach was not used in 2001 when NICE recommended the prescription of donepezil, rivastigmine and galantamine for mild to moderate Alzheimer's, and the recent recommendations also refer to the methodological weaknesses in the QALY approach. The Department asked NICE to elaborate on why it had changed its view on using the QALY methodology.
- The Department of Health made the point that the 2001 prescribing guidelines meant that the drugs are continued only when it is considered that the patient had benefited. Had the recent appraisal taken this into account?

The assessment group's model assumed that the drugs were given to all dementia patients, who then continued to take them. In practice, only those who have responded positively to the medication are kept on the drugs. About 30 per cent do not respond.

In January 2006, NICE issued a revised appraisal (NICE 2006a) saying that donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl) should be available on the NHS but only to those with moderate Alzheimer's disease. In the economic modelling, an adjustment was made to cover the quality of life (utility) gains of carers that arose when an Alzheimer's patient in receipt of one of the drugs did not progress to later and more difficult stages of the disease within five years or because of death. However, it was decided that it was not appropriate for carer costs to be included in the economic model. It cited the potential for double counting if the effect on carers was incorporated both as improvements in utilities and some monetary value of the opportunity costs. In addition, it reiterated that NICE guidance called for the use only of NHS and personal social services resources to be included. The hopes of users' groups that NICE's report might set a precedent for the opportunity costs of carers to be taken into account when assessing the cost-benefits of social care models were unfulfilled.

Draft recommendations from NICE at the end of May 2006 (NICE 2006b) confirmed NICE's decision that for newly diagnosed patients donepezil, rivastigmine and galantamine should be considered as options only in the treatment of people with Alzheimer's disease of moderate severity. Memantine was not recommended as a treatment option for people with moderately severe to severe Alzheimer's disease except as part of clinical studies.

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