

**Cognitive impairment in older people: its implications for future demand for services and costs.**

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January 2003

**EXECUTIVE SUMMARY**

1. This study aimed to make projections, for the next 30 years, of future numbers of older people with cognitive impairment, their demand for long-term care services and the future costs of their care under a range of specified assumptions. Cognitive impairment is one of the manifestations of dementia. The most common dementia syndrome is Alzheimer's Disease (AD), followed by vascular dementia (Henderson and Jorm, 2000).
2. It also set out to explore the factors that are likely to affect future long-term care expenditure associated with cognitive impairment. These factors include, not only future numbers of older people and future prevalence rates of cognitive impairment, but also trends in household composition, provision of informal care, patterns of care services and the unit costs of care.

**Methodology**

3. The study involved the development of a model to investigate the impact of cognitive impairment among older people on future long-term care demand and expenditure, and to explore systematically key factors that are likely to affect future long-term care costs of cognitive impairment.
4. The macrosimulation, or cell-based, model developed for this study builds on an earlier long-term care projections model constructed by the Personal Social Services Research Unit (PSSRU) and described in Wittenberg *et al* (1998 and 2001). The earlier model included all dependent older people and did not distinguish between those with cognitive impairment and those with other types of dependency. The new model developed for this study concentrates on cognitive impairment. It uses a range of data, including in particular data from the Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS).
5. The cognitive impairment model consists of three main parts. The first part divides the projected older population into sub-groups, or cells, by age, gender, cognitive impairment and/or functional dependency, household type and housing tenure. The second part of the model focuses on the receipt of long-term care services, by

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The MRC CFA study is supported by major awards from the Medical Research Council and the Department of Health. We would like to acknowledge the essential contribution of Family Health Authorities, local general practitioners, interviewers and interviewees for their participation in the study.

attaching a probability of receiving health and social care services to each cell. The last part of the model is concerned with long-term care expenditures on services for older people with cognitive impairment.

### **Base case projections**

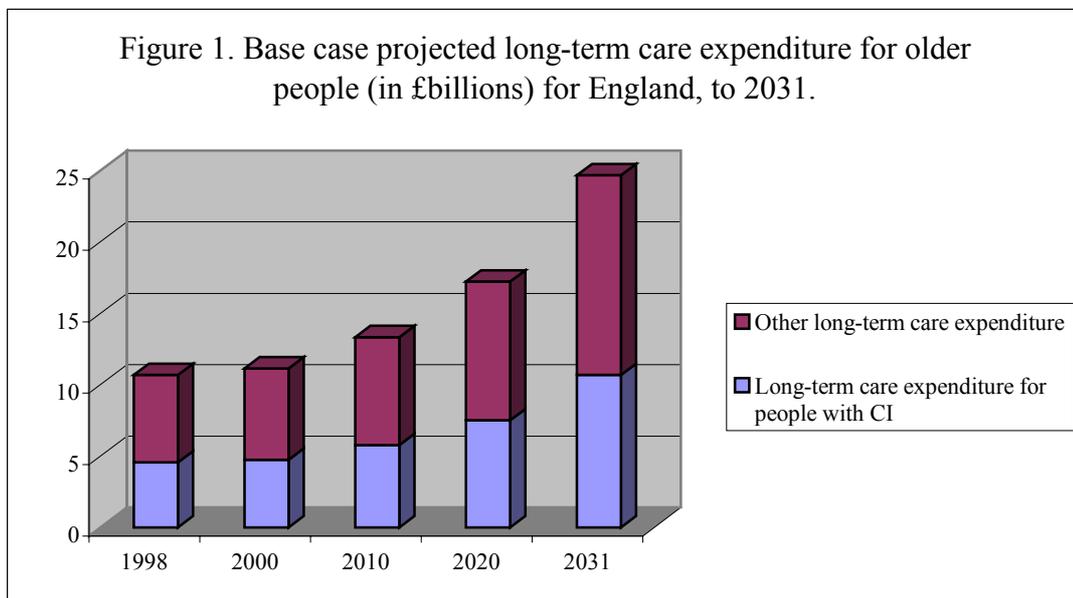
6. The model produces projections under a set of base case assumptions about some of the key factors that will impact on future long-term care expenditure. This base case should be treated as a starting point for examination of the assumptions used in the model, not as a prediction of the future. The base case is a point of comparison when key assumptions are subsequently varied in alternative scenarios. The assumptions that form the base case of the model are summarised in the box below.

#### **MAIN BASE CASE ASSUMPTIONS**

- *The older population changes in line with the Government Actuary's Department (GAD) 2000-based principal population projection*
- *Age/gender specific prevalence rates of cognitive impairment and of problems with activities of daily living remain unchanged.*
- *Marital status rates change in line with GAD 1996-based marital status and cohabitation projections.*
- *There is a constant ratio of single people living alone to single people living with others.*
- *The proportion of older people receiving informal care, formal community care services and residential and nursing home care remains constant for each sub-group by age, dependency, household type and other needs-related circumstances.*
- *Social care unit costs rise by 1% per year and health care unit costs by 1.5% per year in real terms.*

7. The model projects that between 1998 and 2031 the numbers of people with cognitive impairment in England will rise from 461,000 to 765,000 (an increase of 66%). Of these 765,000 people, 376,000 would also have problems with activities of daily living. The model also projects that between 1998 and 2031 the numbers of hours of home care arranged by local authorities for older people with cognitive impairment would need to rise by 67% to keep pace with demographic pressures. The numbers of people with cognitive impairment in institutions would need to rise by 63%, from 224,000 in 1998 to 365,000 in 2031, to keep pace with demographic pressures.
8. The numbers of people with cognitive impairment are projected to increase faster between 1998 and 2031 than the numbers of people with functional disability only (66% and 58% respectively). This implies that demand for long-term care will rise at a faster rate among those with cognitive impairment than would be suggested by projections of the overall demand for long-term care. For example, between 1998 and 2031, the number of people with cognitive impairment in institutional care is projected to increase by 63%, compared to a projected 52% increase in the total number of older people in institutions.

9. Expenditure on long-term care services for older people with cognitive impairment in England<sup>3</sup> is projected to rise from around £4.6 billion in 1998 to around £10.9 billion in 2031 (figure 1). This amounts to a rise from around 0.61% of Gross Domestic Product<sup>4</sup> (GDP) in 1998 to around 0.70% of GDP in 2031 (if real GDP grows by 2.25% per year). It is important to recognise that these figures do not comprise the total costs of cognitive impairment and Alzheimer's Disease to society. That would require the inclusion of the costs of a wider range of services to a wider range of public agencies and service users and the opportunity costs of informal care.
  
10. It has been estimated that people with Alzheimer's Disease represent 72% of the total number of people with cognitive impairment (Ott *et al*, 1995). Assuming that the use of services is the same for those with AD as for those with other types of dementia, the long-term care costs of AD in England would be £3.3 billion in 1998 and would rise to £7.9 billion by 2031.

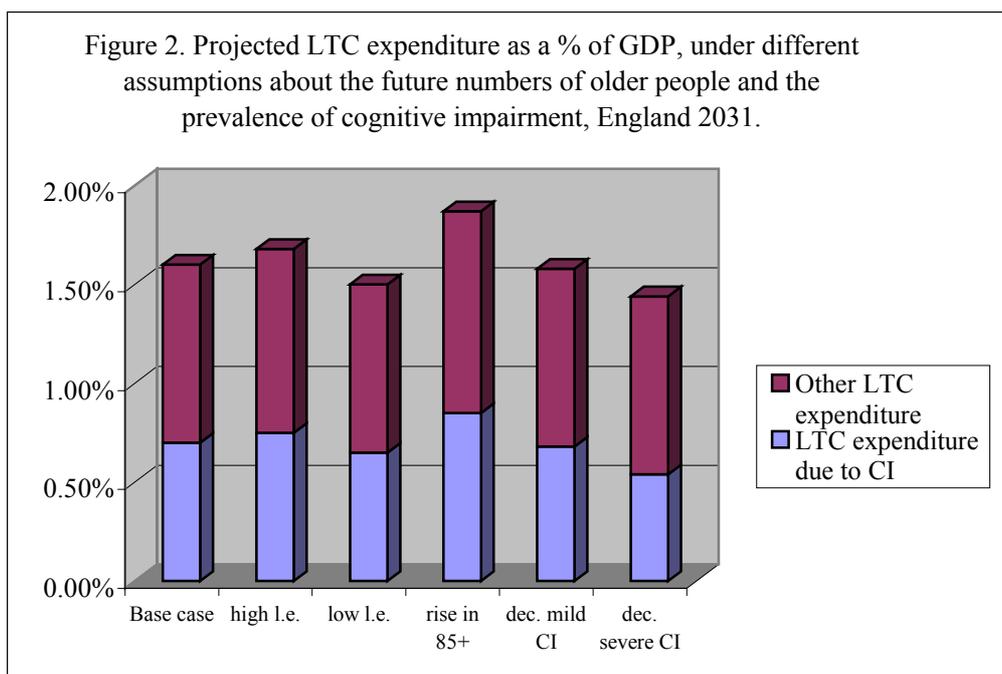


### Changes in the future numbers of people with cognitive impairment

11. One of the main factors that will affect the future demand for long-term care for older people and associated expenditure is the future number of older people with cognitive impairment. It depends partly on future mortality rates and resultant life expectancy and partly on future prevalence rates of cognitive impairment. The latter may be affected in the future by improvements in the treatment of the causes of dementia such as, for example, new drugs for the treatment of Alzheimer's disease. Figure 2 below shows projected long-term care expenditure in England, in 2031, as a % of GDP under different assumptions, compared to the base case.

<sup>3</sup> In 2000/1 prices, i.e. with expected real increases but not nominal changes in care costs.

<sup>4</sup> Used as an indication of the wealth of the country.



12. The second and third columns in figure 2 show, respectively, the impact of using the high life expectancy and low life expectancy variants to the Government Actuary's Department (GAD) principal population projections. These have a relatively small impact on future long-term care expenditure<sup>5</sup>. The fourth column shows the results of assuming that the numbers of people aged 85 or more will grow 1% per year faster than projected by GAD. This corresponds roughly to the extent of past under-estimation of the numbers of very elderly people in past population projections. The impact of this assumption is rather greater.
13. The fifth column shows the impact of a decline of 1% per year in the prevalence of mild cognitive impairment, and the last column shows the impact of a decline of 1% per year in the prevalence of moderate to severe cognitive impairment. This latter assumption aims at illustrating the possible impact of a delay in the progression of cognitive impairment to the more severe stages. In terms of long-term care expenditure as a % of GDP, a decline in the prevalence of moderate to severe cognitive impairment of this magnitude 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 as a % of GDP unchanged at 1.44%.

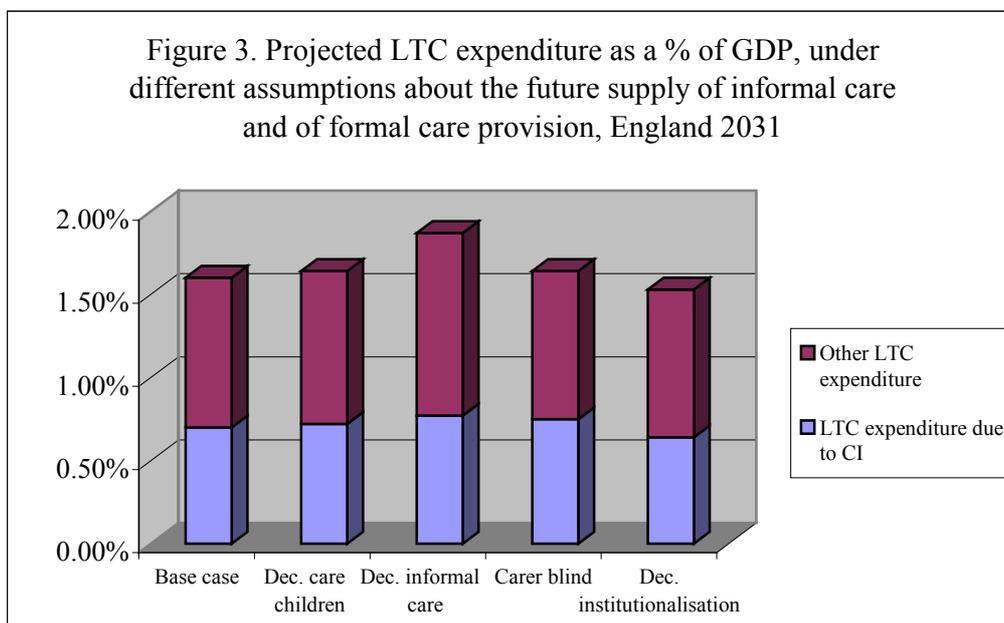
### Changes in the availability of informal care and in patterns of formal care

14. Demand for long-term care will depend partly on the availability of informal care by family and friends. Figure 3 below shows projected long-term care expenditure in England in 2031 as a % of GDP under different assumptions about informal

<sup>5</sup> Due to the relatively narrow range of life expectancy at birth assumptions explored in these variant population projections.

care, compared to the base case. It also shows projected expenditure under different patterns of formal care.

15. There is considerable uncertainty about the future supply of informal care. The model takes into account the effects of changes in marital status on informal care/household composition in the future. Whereas there is likely to be an increase in spouse carers of dependent older people in future years, there is much more uncertainty about the future provision of intensive informal care by children. The second column in figure 3 shows the impact of a hypothetical decline by one third in the proportion of single dependent older people living with others by 2031. It assumes that the older people who no longer move in with their children move into residential homes instead. The impact of this assumption is slight.
16. The third column shows a potential impact of a more substantial fall in the supply of informal care. In this case it is assumed that, as a result of a substantial fall in the supply of informal care, those who are currently living with others have the same probability of going into an institution as those who live alone. In other words, the probability of admissions to institutions increases not just for single dependent older people living with others but for married couples and married couples living with others as well. The impact of this assumption is more substantial. Expenditure on long-term care for those with cognitive impairment is projected to represent around 0.77% of GDP in 2031 under this scenario, compared with 0.70% under the base case.



17. There may also be changes affecting patterns of formal care in future years. The fourth column in figure 3 shows the impact of an increase in formal support provided to carers in future years, which would be in line with current policies. This assumption investigates the implications of giving to older people with moderate to severe cognitive impairment who live with others the same packages of non-residential services as received by those living alone (a 'carer-blind' assumption). The impact of this assumption is modest.

18. Finally, also in line with government policy, the fifth column shows the impact of a shift of the balance of care from institutional to domiciliary care. This assumption investigates the impact of reducing by 10%, between 2000 and 2020, the numbers of people with moderate to severe cognitive impairment in residential and nursing home care. Those in the community who would otherwise have been in an institution would receive 16 hours of home care and 3 district nurse visits per week. The impact of this assumption on projected long-term care expenditure is slight.

### **Changes in the future unit costs of care**

19. Expenditure projections over an extended period of time are inevitably sensitive to assumptions about real rises in the unit costs of care. The first variant assumption examined was that there would be no real rise in unit costs. This is an improbable assumption, but is a useful indicator of the projected rise in expenditure in pure volume terms. Under this assumption, by 2031, long-term care expenditure for people with cognitive impairment would represent 0.50% of GDP, compared to 0.70% under the base case (in which the unit costs of care rise broadly in line with rises in input pay and prices observed in the last 15 years).
20. The second assumption was that real unit costs would rise in line with the expected rise in earnings, by 2% per year. Under this assumption, by 2031, long-term care expenditure for people with cognitive impairment would represent 0.92% of GDP, compared to 0.70% under the base case. This shows that projected future expenditure on long-term care for older people with cognitive impairment is highly sensitive to the assumed rate of growth of real unit costs.

### **Conclusions**

21. The results of the model show that, unless more effective treatments for cognitive impairment are developed and made widely available, the numbers of older people with cognitive impairment will rise significantly over the next 30 years. This means that substantial rises in formal services will be required. The implication is that there is a need to develop, and make widely available, better treatments to slow down the progressive decline associated with dementia.
22. It should be stressed that *the PSSRU model does not make forecasts about the future*. It makes projections on the basis of specific assumptions about future trends. The approach involves simulating the impact on demand of specified changes in demand drivers, such as demographic pressures, changes in household composition, or specified changes in patterns of care, such as more support for informal carers. It does not involve forecasting future policies or future patterns of care.

## **1. Introduction:**

It is important, for purposes of planning services, to have projections of likely future service requirements for people with cognitive impairment. It is also important to have as good an understanding as possible of how future, or even current, changes in prevalence, treatment, or the provision of care will affect these future service requirements and expenditure. This study, commissioned by the Alzheimer's Research Trust, is concerned with such projections and with understanding their sensitivity to possible changes in the prevalence of cognitive impairment and other important drivers of demand.

Cognitive impairment has a substantial impact on the quality of life of people affected, their families and other caregivers. Around 450,000 older people in England are affected. Cognitive impairment also has major health service and social care implications, in turn generating high costs. The numbers of people reaching old age have increased substantially in recent years and are projected to keep growing in the coming decades. With the increase in the numbers of older people, the numbers of people with cognitive impairment is expected to rise as well, generating an increase in the future demand for services and, as a result, increased costs.

There are a number of additional factors apart from demographic trends that will affect future demand for services for people with cognitive impairment and associated expenditure. Future demand and expenditure on services will depend, among other factors, on the future prevalence of cognitive impairment, on its severity, on the availability of informal care, on future policies concerning services, and on the relative unit cost of services.

There have been important developments in recent years in the treatment of some of the causes of cognitive impairment. Drugs have been developed that may slow the progression of the symptoms of Alzheimer's disease and new psychosocial interventions have also been shown to be effective. In this context, the recent National Service Framework (NSF) for older people (Department of Health, 2001) proposes a service model for older people with dementia that stresses the importance of early diagnosis followed by a single assessment of the health and social care needs of the person and their carer. The model of treatment described in the NSF includes, as well as pharmaceutical treatment of Alzheimer's Disease when the person meets the criteria established by the National Institute for Clinical Excellence (NICE), 'non-pharmacological management strategies... (that) may be beneficial in reducing the impact or slowing down the progression of the disease' (Department of Health, 2001, p. 98).

### **1.2 Aims of the study**

The aim of the study was to make projections, for the next 30 years, of future numbers of older people with cognitive impairment, their demand for long-term care services and the future costs of their care under a range of specified assumptions. The study involved the development of a model to investigate the impact of cognitive impairment on long-term care demand and expenditure, and to explore systematically the factors that will affect future long-term care costs of cognitive impairment. These factors include, not only the future numbers of older people and future prevalence rates of cognitive impairment, but

also trends in household composition, provision of informal care, patterns of care services and the unit costs of care.

Long-term care includes help with domestic tasks, such as shopping and preparing meals, and assistance with personal care tasks, such as dressing and bathing. Most long-term care for older people living at home is currently provided by informal carers. Formal services are provided by a range of agencies including local authority social services, community health services and independent sector residential care, nursing homes and home care services. Long-term care services are financed by the National Health Service, local authorities and by older people themselves.

The model developed for this study builds on an earlier long-term care projections model constructed by the Personal Social Services Research Unit (PSSRU) and described in Wittenberg *et al* (1998 and 2001). The earlier model makes projections of the numbers of dependent older people, their demand for long-term care services and associated expenditure. It included all dependent older people and did not distinguish between those with cognitive impairment and those with other types of dependency. The new model developed for this study concentrates on cognitive impairment, using data from the Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS).

### 1.3 Outline of report

This report describes the methodology used to build the model and presents projections of long-term care expenditure in England to 2031 for people with cognitive impairment. Section 2 contains an overview of the literature on the implications of cognitive impairment for the demand for and costs of long-term care. Section 3 describes the sources of data used for this study, including the MRC CFAS Study. Section 4 describes the methodology used to build the PSSRU cognitive impairment long-term care model. Section 5 describes the base case assumptions of the model and the projections obtained using it. Section 6 investigates the sensitivity of the projections to alternative assumptions. Section 7 presents the conclusions of this study.

## **2. Literature review**

### **2.1 Definition and Prevalence of cognitive impairment**

Cognitive impairment is one of the manifestations of dementia. Others include behavioural problems and agitation. The most widely used definition of dementia is the definition in the ‘International Classification of Diseases (10<sup>th</sup> Revision) (ICD-10) Clinical Descriptions and Diagnostic Guidelines for Mental and Behavioural Disorders’, published by the World Health Organisation (WHO, 1992), and the more compact ‘Diagnostic Criteria for Research’ version (WHO, 1993). The summary of the ICD-10 Diagnostic Guidelines for Dementia published in Henderson and Jorm (2000, p.2) states that each of the following symptoms should be present for a diagnosis of dementia:

- ‘1. A decline in memory to an extent that interferes with everyday activities, or makes independent living either difficult or impossible.
2. A decline in thinking, planning and organising day-to-day things, again to the above extent.
3. Initially, preserved awareness of the environment, including orientation in space and time.
4. A decline in emotional control or motivation, or a change in social behaviour, as shown in one or more of the following: emotional lability, irritability, apathy or coarsening of social behaviour, as in eating, dressing and interacting with others.’

These diagnostic criteria are essentially similar to those in the Diagnostic and Statistical Manual (4<sup>th</sup> edition) of the American Psychiatric Association (1994) (DSM-IV).

There are various different scales used by epidemiologists and practitioners to assess the prevalence of dementia. The most frequently used are the Clinical Dementia Rating Scale (CDR), the Global Deterioration Scale (GDS) and the Mini-Mental State Examination (MMSE). These scales describe the development of dementia in terms of global functioning, from healthy ageing across mild cognitive changes to advanced dementia, in a number of stages or levels. Table 2.1 below presents a summary by Almkvist (2000) of these scales and stages of the disease.

Table 2.1. Stages of decline in dementia

Stage	MMSE	CDR	GDS	ADAS-Cog	Typical features
None	30	0	1	0	No symptoms
MCI	24-30	0.5	2	0-12	Memory symptoms
Mild	21-23	1	3	13-20	Deficits in memory and cognition; depression
Marked	18-20	1	4	21-28	Clear cognitive deficits; compensatory coping
Moderate	15-17	2	5	29-36	Some assistance needed; psychiatric symptoms
Severe	12-16	2	6	37-44	Help with ADLs needed; psychotic symptoms; aggressiveness
Grave	0-11	3	7	45+	Institutional care needed

MMSE, Mini-Mental State Examination; CDR, Clinical Dementia Rating Scale; GDS, Global Deterioration Scale; ADAS-Cog, Alzheimer’s Disease Assessment Scale; MCI, mild cognitive impairment.

Source: Almkvist (2000, p. 149)

The most common dementia syndrome is Alzheimer’s Disease (AD), followed by vascular dementia, mixed dementia, Lewy body dementia and fronto-temporal dementias (Henderson and Jorm, 2000). A study by Ott *et al* (1995) in a suburb of Rotterdam found that 72% of dementias were due to Alzheimer’s Disease, 16% were vascular dementia, 6% Parkinson’s Disease and 5% were other dementias.

Alzheimer’s Disease is usually insidious in onset and develops slowly but steadily over a period of years. The onset can be “early” (in middle adult life or even earlier, with a more rapid course) or, more commonly, in later life, with a slower course. Dementia in AD is at present irreversible. Vascular dementia results from strokes destroying areas of the brain that subserve memory and intelligence. This dementia is distinguished from dementia in AD by its history of onset, clinical features and subsequent course.

It is quite common for feature of both AD and vascular dementia to be present in the same person at the same time. Lewy body dementia is thought to account for 10-15% of all dementias (Henderson and Jorm, 2000) and is characterised by a progressive course, in addition to variability in alertness, visual hallucinations and parkinsonism. Less common forms of dementia include Parkinson’s disease, severe alcohol abuse, Creutzfeldt-Jakob disease, Huntington’s disease, Pick’s disease and dementia from AIDS.

It is apparent from the descriptions of dementia that, at the advanced stages, cognitive impairment is accompanied by a requirement for help with activities of daily living. It is the combination of the cognitive symptoms and the help required with the activities of daily living that generates the need for long-term care. As dementia progresses to the more severe stages of the disease, so do the care needs of sufferers. Also, cognitive impairment is very often associated with co-morbidities, including depression (Banerjee and Macdonald, 1996, Mozley *et al.*, 2000 and Kavanagh and Knapp, 2002).

*Prevalence of cognitive impairment among older people*

There are over 100 studies from throughout the world that have estimated the prevalence of dementia in general population samples (Henderson and Jorm, 2000). Because the number of studies is so large, researchers have carried out meta-analyses in which the data from a group of studies is pooled to arrive at better estimates of prevalence. Table 2.2 below reports the prevalence rates for dementia found from three different meta-analyses, as reported by Henderson and Jorm (2000).

Table 2.2. Prevalence rates (%) for dementia estimated from three different meta-analyses.

Age-group	Jorm <i>et al.</i>	EURODEM Hofman <i>et al.</i>	Ritchie and Kildea
65-69	1.4	1.4	1.5
70-74	2.8	4.1	3.5
75-79	5.6	5.7	6.8
80-84	11.1	13.0	13.6
85-89	23.6*	24.5*	22.3
90-94			33.0
95-99			44.8

Source: Henderson and Jorm (2000, p.11).

Note: \* This is the prevalence rate for people aged 85 and over.

The EURODEM study consisted in the re-analysis of original data from European prevalence studies performed or published between 1980 and 1990. The measure used was a clinical diagnosis of dementia equivalent to DSM III. (Hofman *et al*, 1991). The study by Jorm *et al*, (1987) used data from 22 studies from throughout the world and that by Ritchie and Kildea (1995) was a meta-analysis of nine studies that used DSM-III criteria and included samples of people aged 80 and over.

Table 2.3 below presents prevalence estimates from a number of British studies that included both household and institutional populations. The studies include the MRC CFAS study, which is used for the research presented in this report. A brief description of each study is given in box 2.1.

Table 2.3 Comparison of prevalence rates in different UK and European studies.

	MRC CFAS 5 sites		MRC CFAS 4 sites		MRC ALPHA		OPCS 1985-6	
	Women	Men	Women	Men	Women	Men		
65-69	1.5	1.4	1.7	2.2	0.9	1.3		2.3
70-74	2.2	3.1			1.2	2.1		
75-79	7.1	5.6	6.6	6.7	5.1	2.9		7.2
80-84	14.1	10.2			10.2	7.3		
85-89	27.5	19.6	22.2	18.9	21.1	10.8		21.9
90-94					27.6	19.5		
95-99								
N	13,009		10,377		5,222		7,486	
	Agecat		Agecat		Agecat		OPCS measure	

Box 2.1: Description of the major prevalence studies:

MRC CFAS 5 centres: Study of 6 centres in England and Wales (prevalence reported for five centres: Cambridgeshire, North Wales, Newcastle, Nottingham and Oxford). Age-stratified random sample using Family Practitioner’s lists. Measures used: AGE CAT (03 and above). (MRC CFAS, 1998a).

MRC CFAS 4 centres: Same study as 5 centres, but reported for 4 centres in England: Cambridgeshire, Newcastle, Nottingham and Oxford. Age-stratified random sample using Family Practitioner’s lists. Measures used: AGE CAT (03 and above). (Melzer *et al*, 1999).

MRC ALPHA: Liverpool, age-stratified random sample using Family Practitioner’s lists. Data collected between 1989 and 1990. Measures used: AGE CAT (03 and above). (Saunders *et al*, 1993).

OPCS 1985-6 Survey of Disabilities in Great Britain, 1985-6: Population survey of adults living in private households and of adults living in communal establishments. Measure used: OPCS intellectual functioning scale. (Melzer *et al*, 1997).

*Prevalence rates of Alzheimer’s Disease:*

There have also been several meta-analyses focusing specifically on AD. In particular, Rocca *et al* re-analysed and compared prevalence estimates of AD in Europe. They did not find geographical differences. They estimated prevalences of 0.3% at 60-69 years, 3.2% at 70-79 years and 10.8% at 80-89 years. Cambridge Pharma Consulting and Bosanquet *et al* (1998) used those estimates, together with the assumption based on Jorm *et al* (1987) that dementia prevalence rates roughly double every five years, to produce

the prevalence rates of Alzheimer’s Disease by gender and five-year age bands reproduced in table 2.4. The table also includes broadly similar estimates obtained by the US General Accounting Office, which were estimated through analysis of data from 18 studies.

Table 2.4. Prevalence of Alzheimer’s Disease estimated by Bosanquet *et al* and Cambridge Pharma Consultancy, and the US General Accounting Office.

	Bosanquet and Cambridge Pharma Consultancy		US General Accounting Office	
	Male	Female	Male	Female
65-69	0.4	0.5	0.6	0.8
70-74	1.7	2.4	1.3	1.7
75-79	3.3	4.8	2.7	3.5
80-84	6.7	7.5	5.6	7.1
85-89	13.3	14.9	11.1	13.8
90-94	26.7	29.9	20.8	25.2
95-99	53.3	59.7	35.6	41.5

Source: Bosanquet *et al* (1998, appendix II, p.44) and Henderson and Jorm (2000, p.12)

## 2.2 Informal care

Most long-term care for older people living at home is currently provided by informal carers (Parker 1990), and this has considerable impact on the lives of the carers. Much of the literature relating to the impact of caring for someone with cognitive impairment is concerned with the stress of the carer. Until recently, relatively little was known about the relationship between the type of disability of the cared-for person and the costs and benefits of caregiving (RIS MRC CFAS 1998). Comparative studies have not consistently confirmed the commonly held view that supporting people with cognitive impairment is more stressful than supporting people who are physically frail (Gilleard 1984; Eagles *et al*, 1987; Draper *et al*, 1992; Yeatman *et al*, 1993; Wijerantne and Lovestone 1996). However, recent studies have suggested that the amount of informal care provided rises considerably with the severity of cognitive impairment of the person cared for (Langa *et al*, 2001 and Sou tre *et al*, 1999). Recent evidence also suggests that caring for someone with cognitive impairment, and particularly with moderate to severe cognitive impairment, has substantially greater costs and less benefits than caring for someone in the milder stages of dementia or with physical disability only (RIS MRC CFAS 1998 and Bauld *et al*, 2000).

Langa *et al*, (2001), in a study conducted in the United States, estimated the additional hours of care provided by informal carers of those with dementia, compared to the hours provided to individuals with normal cognition. They found that, after adjusting for sociodemographic characteristics, comorbidities and potential caregiving network, those with normal cognition received an average of 4.6 hours per week of informal care. Those with mild dementia received an additional 8.5 hours per week of informal care compared to those with normal cognition, while those with moderate and severe dementia received an additional 17.4 and 41.5 hours respectively.

As part of the RIS MRC CFAS study, the impact of caregiving on carers was studied (RIS MRC CFAS, 1998). It was found that, overall, the supporters of older people who were both mentally and functionally frail identified greater costs and fewer benefits of

caregiving than those who were supporting an older person who was either mentally or functionally frail. The costs reported were mainly opportunity costs, such as reduction in hours of employment, or withdrawal from work, loss of social interaction, and decline in well-being. The type of help given was also significantly associated with the type of frailty, with supporters of mentally and functionally frail subjects being most likely to provide personal and physical care.

In their analysis of publicly funded admissions to residential and nursing homes in Britain, Netten *et al*, (2001a) found that, at the time of admission, higher proportions of people with severe cognitive impairment were married and living with others, compared to those without cognitive impairment. They also found that carer-related reasons for admission, such as carer stress, were identified as reasons for admission significantly more often for people with severe impairment than for people with mild impairment or no impairment.

The evidence regarding the impact of caring on the health of carers is somewhat mixed. Some studies have failed to find evidence of a deleterious effect of caring on health (Parker and Lawton 1994; Taylor *et al*, 1995 and Sou tre *et al*, 1999), whereas other studies have found evidence of a relationship between caring and health, particularly when levels of caring responsibility and intensity of caring are taken into account (Evandrou 1996; Hirst 1998). Some studies have also reported an impact of caring for someone with cognitive impairment on the mental health of the carer (Morrissey *et al*, 1990 and Bauld *et al*, 2000). A study using the 1990 General Household Survey data on the provision of informal care found that caring for someone with both physical and mental impairments has a strong negative effect on the health of the carer (Evandrou 1996).

### 2.3 Formal services

In the United Kingdom, people with cognitive impairment tend to receive non-specialised long-term care services for their needs related to difficulties with activities of daily living and supervision needs. There is positive evidence that specialist interventions such as psychogeriatric inpatient units, consultation liaison interventions and outreach visits to nursing homes are effective (Burns *et al*, 2001), and psychological interventions for carers (Zarit and Leitsch, 2001), but these services are not widely available as yet.

Studies investigating factors associated with use of formal long-term care services by dependent people have shown that the lack of informal care is one of the main factors associated with use of formal services (Wittenberg *et al*, 1998; Kavanagh and Knapp 1999; Bauld *et al*, 2000). The literature on service receipt by people with cognitive impairment confirms that the lack of availability of informal care is an important predictor of the use of formal care for those with cognitive impairment, in particular for those at the milder stages (Boersma *et al*, 1997). However, as the severity of cognitive impairment increases and more intensive care is required, the severity of cognitive impairment becomes the most important factor explaining the use of formal services and institutionalisation in particular (Boersma *et al*, 1997, and Netten *et al*, 2001a). The link between the severity of cognitive impairment and the use of formal services is clearly established, especially for institutionalisation (Kavanagh and Knapp 1999, McNamee *et al*, 1999 and Sou tre *et al*, 1999).

Data from the 'Evaluating community care for elderly people' research project shows that older dependent people with cognitive impairment or behavioural disturbance tend to receive more social care services than people with the same level of dependency without cognitive or behavioural problems. However, the health care packages of services received by the two groups were broadly similar (Bauld *et al*, 2000).

These findings, together with the evidence on the effect on carers of providing informal care to those with cognitive impairment described before, point towards a clear distinction, in terms of formal care needs, between the milder stages of cognitive impairment and the more severe stages. In the mild stages care tends to be provided mainly by informal carers in the community, with some formal care support. At the more severe stages the balance of care shifts towards a greater importance of formal services, and in particular institutional care.

## 2.4 Costs and projections

There are many studies that have attempted to estimate the costs of dementia and, specially, the costs of Alzheimer's disease. It is difficult to make comparisons between the different studies, as most of them tend to incorporate different cost components. Whereas some of the studies set out to estimate the comprehensive costs of cognitive impairment or Alzheimer's disease to society (including valuations of the opportunity costs of informal care), others have concentrated on the costs of cognitive impairment to the health and social care services (as, for example, McNamee *et al*, 1999 and 2001).

There are some recent comprehensive reviews of the costs of cognitive impairment and Alzheimer's disease (Lowin *et al*, 2001, Stewart, 1998). As those reviews point out, it is difficult to make comparisons between the different studies as they tend to include different costs. One of the main differences between studies are the ways in which different studies have attempted to measure and put a monetary value on informal care (McDaid, 2001). Studies including the costs of informal care have produced wide differences in results and large funnels of doubt. For example, in the most recent study, Lowin *et al* (2001) estimate the gross annual costs of Alzheimer's Disease in the UK to be between £7.06 billion and £14.93 billion. This high level of uncertainty was generated primarily by using a number of different assumptions about the volume and value of informal care (Lowin *et al*, 2001).

It is important not to overestimate the effect of cognitive impairment on the overall costs of care. Co-morbidities and other manifestations of dementia also have an important impact on overall costs. An analysis of data from the OPCS Surveys of Disability by Kavanagh and Knapp (2002) is pertinent. They found that, whereas the marginal impact of a unit of change in the cognitive disability measure without taking into account other types of disability was £4.29, the marginal impact of this change when other types of disability were taken into account was only £1.44.

Future demand for services for people with cognitive impairment is expected to rise with the projected increase in the numbers of older people. A recently published study by McNamee *et al* (2001) has estimated that the costs of health and social care in England and Wales for people with cognitive impairment would rise from £6.30bn in 1994 to

£11.20bn in 2031, to keep pace with demographic changes. They produced these projections using a demographic model.

The research presented in this report does not aim to cover the total costs of cognitive impairment to society, unlike a “cost of illness” study. That would require the inclusion of the costs of a wider range of services to a wider range of public agencies and service users and the opportunity costs of informal care, with all the methodological difficulties described above. This study investigates the costs of cognitive impairment in terms of long-term care services, which includes long-term health and social care services but not acute health services.

### 2.5 Developments in the treatment of Alzheimer’s Disease:

In recent years a number of drugs (acetylcholine inhibitors) that can temporarily reduce the symptoms of AD and slow the progression of the disease have been licensed. In January 2001 the National Institute for Clinical Excellence (NICE) recommended that three of these drugs (donepezil, rivastimine and galantamine) should be made available in the NHS as ‘one component of the management of those people with mild and moderate Alzheimer’s Disease’ (NICE, 2001, p.1). A systematic review of the literature carried out to inform the NICE decision found that randomised controlled trials (RCT) of all three drugs had shown that they have some effect on cognitive function and functioning. However, not everyone treated appeared to benefit.

These drugs are potentially cost saving as delayed progression of the symptoms of the disease could result in delayed requirement for institutional care. In the absence of long term trials of these drugs, some the studies of their cost-effectiveness have extrapolated from current shorter term trials using techniques such as decision modelling (for example Stewart *et al*, 1998) and survival analysis (for example Fenn and Gray, 1999). The systematic review carried out for NICE concluded that the cost-effectiveness of the drugs could not be reliably estimated from the existing evidence (Clegg *et al*, 2001).

A new drug (memantine) for the treatment of the moderately severe to severe stages of Alzheimer’s Disease has recently become available in the United Kingdom. This new drug has been shown, in clinical trials, to slow down the symptoms of AD without significant side-effects. Patients showed improvements in daily living activities. The drug also helped memory and thought processes and reduced the amount of help a carer needed to give (Reisberg *et al*, 2002; Wimo and Poritis, 1999).

Progress is being made in the understanding of the molecular basis of Alzheimer’s Disease and other neurodegenerative conditions. This could lead to the development of effective therapeutic strategies in the next 10 years (Masters and Beyreuther, 1998). These authors envisage that future treatment will probably be based on combination therapies tailored to the genetic profile of an individual.

### **3. Data**

The study used data from a wide range of sources. These included:

- Department of Health, Government Actuary's Department and other official data;
- Data from the MRC Cognitive Function and Aging Study (CFAS);
- Data from the General Household Survey for 1998/9; and
- Data from a PSSRU survey of residential care for older people.

The main data sources are discussed briefly below.

#### **3.1 GAD population and marital status projections**

The study used the Government Actuary's Department's (GAD, 2001) projections of the numbers of older people in England to 2031 by age band and gender. The 2000-based principal projection is used as the base case and the 1998-based high and low life expectancy variants are used in the sensitivity analysis (Shaw 2002, Shaw 2000). The study also uses GAD's 1996-based marital status and cohabitation projections to 2020 (Shaw 1999, Shaw and Haskey 1999).

#### **3.2. The Medical Research Council's Cognitive Function and Ageing Study:**

The Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS) aimed to collect information about the incidence and prevalence of cognitive decline and dementia and the variation throughout the country (MRC CFAS, 1998a). It also aimed at identifying factors associated with the risk of dementia and to evaluate the degree of disability associated with cognitive decline and the service needs this disability generates.

The study was based in six areas: Liverpool, Newcastle, Nottingham, Oxford, Cambridgeshire and Gwynedd. Stratified random populations of people aged 65 and over, including those in institutions, were selected from Family Health Service Authority lists to achieve an interviewed sample of 2500 people in each centre. Respondents were screened with a basic interview covering socio-demographic details, activities of daily living, physical health measures, cognitive function and medication. The MRC CFAS study found no heterogeneity between the different sites, which leads their authors to suggest that their prevalence estimates can be generalised (MRC CFAS, 1998a).

In four of the sites (Cambridgeshire, Nottingham, Newcastle and Oxford) the resource implications of functional or cognitive frailty were investigated in the Resource Implication Study (RIS) (McNamee *et al*, 1999 and 2001). At the screening interview, individuals who were identified as functionally or cognitively frail were recruited. This study involved the formal and informal carers of those identified as frail in order to examine the way frail older people are cared for in the community.

The CI-LTC model uses data on the prevalence of cognitive and functional frailty from the four sites involved in the RI Study, as described in Melzer *et al*, (1999). The size of the sample for these four sites was of 10,377 people aged 65 and over. Of these, 1,446 were classified as disabled and, of these, the RIS collected service monitoring data on 1,391 people. People were classified as disabled if they were identified as functionally or cognitively frail. People were considered to be cognitively impaired as assessed by a

score of three or more on the Automated Geriatric Examination Computer Assisted Taxonomy (AGECAT) (Copeland et al. 1986). They were considered to have functional disability if they had a score of seven or less on the modified Townsend Disability Scale (MRC CFAS, 1998b).

### 3.3 General Household Survey 1998/9

The General Household Survey (GHS) is a continuous survey by the Office for National Statistics (ONS) of a sample of households in Great Britain. Every few years it contains a section of additional questions to older people about their ability to perform a range of domestic and personal care tasks, their receipt of help with tasks and their use of community care services. These questions were most recently asked in 1998/9 and 2001/2, but 2001/2 data are not yet available.

The 1998/9 GHS included a sample of around 3,082 people aged 65 and over living in private households in Great Britain. Of these, 3,073 provided information on their ability to perform tasks and on their use of community care services (Bridgwood, 2000). This study uses data on household type, housing tenure, functional dependency, receipt of informal help with domestic tasks and receipt of formal non-residential services.

### 3.4 Residential care data (DH and PSSRU)

#### *Department of Health data on older people in institutional care*

The Department of Health publishes data on the numbers of places in residential care homes for older people at 31 March each year and on the numbers of beds in general nursing homes on 31 March each year. Data for 31 March 1998 and 31 March 2000 are used in this study (Department of Health, 2000a). The Department also provides data from the Hospital Episode Statistics (HES) on finished and incomplete hospital inpatient consultant episodes. The study uses data on the numbers of incomplete episodes exceeding 55 days as at 31 March 1996, as an indicator of the numbers of older long-stay hospital patients.

#### *PSSRU Survey of Residential Care*

PSSRU conducted a survey of residential care for older people in autumn 1996 (Netten *et al.*, 1998 and 2001a). The sample consisted of almost 12,000 older residents in over 600 residential care and nursing homes in 21 English local authorities. The study uses data on the age, gender, cognitive impairment, previous household type and previous housing tenure of residents.

### 3.5 Unit costs data (PSSRU and Laing & Buisson)

The study used information from the PSSRU Study of Unit Costs (Netten *et al.*, 2001b) and from Laing and Buisson (2001), in order to cost each of the services.

## **4. Methodology and model design**

### **4.1. Overview of the model**

The PSSRU cognitive impairment projections model aims to make projections for England to 2031 of three key variables: the expected number of older people with cognitive impairment, their likely level of demand for long-term care services and the costs associated with meeting this demand. The construction of this model formed the core of this study.

The PSSRU cognitive impairment model is based on the PSSRU long-term care projections model. That earlier model was constructed as part of a project on long-term care finance funded by the Department of Health. A variant that could produce projections for the United Kingdom to 2051 was developed and used to provide projections for the Royal Commission on Long-Term Care (1999). More recently, new versions of the model have been used to provide projections for the HM Treasury Health Trends Review (Wanless, 2002) and for the Institute of Public Policy Research (Wittenberg *et al*, 2002). A full account of the long-term care projections model and of the data and assumptions used can be found in Wittenberg *et al* (1998, 2001, 2002).

The cognitive impairment model consists of three main parts. The first part divides the projected older population into sub-groups, or cells, by age, gender, cognitive impairment and/or functional dependency, household type and housing tenure. The second part of the model focuses on the receipt of long-term care services, by attaching a probability of receiving health and social care services to each cell. The last part of the model is concerned with long-term care expenditures on services for older people with cognitive impairment.

The model is a cell-based or macrosimulation model that has been developed to make projections of likely demand for long-term care for older people with cognitive impairment under different scenarios. It should be stressed that *the PSSRU model does not make forecasts about the future*. It makes projections on the basis of specific assumptions about future trends. The approach involves simulating the impact on demand of specified changes in demand drivers, such as demographic pressures, changes in household composition, or specified changes in patterns of care, such as more support for informal carers. It does not involve forecasting future policies or future patterns of care.

### **4.2. Projected numbers of older people with cognitive impairment**

The first part of the model classifies the projected numbers of older people into subgroups, according to age bands, gender, dependency and other key characteristics. The model uses the GAD 2000-based population projections as the basis for the numbers of people by three age bands and gender in each year under consideration until 2031.

Table 4.1 England population aged 65 and over: 1998 and projection for 2031

	1998	2031	% increase
Males			
65-74	1,913,000	3,244,000	61%
75-84	1,045,000	1,887,000	81%
85 & over	254,000	679,000	67%
Females			
65-74	2,214,000	3,366,000	52%
75-84	1,649,000	2,283,000	38%
85 & over	704,000	1,050,000	49%
All 65 & over	7,779,000	12,510,000	61%

Source: ONS mid-1998 population estimates and GAD 2000-based population projections

### Dependency

The numbers of older people by age and gender are split into those with cognitive impairment only, those with combined cognitive impairment and functional disability (defined as the ability to perform activities of daily living), those with functional disability only and those with neither cognitive impairment nor functional disability. The model uses for this purpose data on the prevalence of cognitive and functional frailty from the four sites involved in the CFAS Resource Implications Study, as described in Melzer *et al* (1999). People were classified as disabled in this study if they were identified as functionally<sup>6</sup> or cognitively frail. People were considered to be cognitively impaired as assessed by a score of three or more on the Automated Geriatric Examination Computer Assisted Taxonomy (AGECAT) (Copeland *et al* 1986). They were considered to have functional disability if they had a score of seven or less on the modified Townsend Disability Scale (MRC CFAS, 1998b). Table 4.2 presents the CFAS prevalence estimates used in the model.

Table 4.2 Estimated prevalence of cognitive impairment and/or functionally disability among older people in England and Wales, by age group, sex, and type of disability, in percentages:

	65-74		75-84		85 or more		All 65 and over	
	Men	Women	Men	Women	Men	Women	Men	Women
Functional only	3.3	5.0	7.7	14.8	17.3	32.2	5.7	12.5
Cognitive only	1.6	1.2	4.2	3.3	8.0	8.5	2.9	3.0
Combined	0.7	0.5	2.4	3.3	10.8	13.7	2.0	3.4
All with cognitive imp.	2.2	1.6	6.7	6.6	18.9	22.2	4.9	6.4

Source: Melzer *et al*, 1999 and personal communication from B. McWilliams, from the MRC CFAS team.

In some of the RIS CFAS studies (McNamee *et al*, 1999 and 2001), a group of people who, because of their advanced cognitive impairment were not able to answer the activities of daily living (ADL) questions were excluded. In the study by Melzer and others (1999) from which the prevalence rates used in this study were obtained these people were included in the group with combined dependency. As this group would have important care needs (see appendix 1), it seemed important to include them in the model, in the combined dependency group as in Melzer *et al* (1999).

<sup>6</sup> In the study of Melzer and others (1999), having difficulties with activities of daily living was referred to as having “physical” frailty. In this report we refer to “functional” dependency, as the difficulty or inability to perform activities of daily living can also be a consequence of severe cognitive impairment.

### *Household type and informal care*

The older population by age, gender and disability is then divided into household type/informal care groups. Household type is an important structural correlate of informal care (Pickard *et al*, 2000). Informal care is combined with household composition in a four-fold classification: living alone without informal help; living alone with informal help; single, widowed or divorced (*de facto* single) living with others; and married/cohabiting couple (including couples living with others). Household types where older people live with others have not been broken down between those with and without informal carers because all older people living with others have a potential carer and most of those who are dependent have an actual carer. In the 1998/9 General Household Survey (GHS), over 90% of dependent older people living with others received informal help with domestic tasks.

The 1998 population by age and gender was split into single (single, widowed or divorced) and living as a couple (married or cohabiting) using 1999 ONS data on marital status and, for those in institutions, 1991 Census data. For future years, the trends in marital status in the model are driven by the 1996-based GAD marital status and cohabitation projections (Shaw 1999, Shaw and Haskey 1999).

The *de facto* single group are broken down according to whether they were living alone or living with others. 1998 GHS data was used for those who had no cognitive or functional disability. Analysis of the RIS CFAS data set showed that, for those with cognitive or functional disability, the propensity to live alone was significantly different according to whether people had only one form of disability (74%) or had combined cognitive and functional dependency (61%). Although CFAS data was used for those with dependency, the CFAS proportions were adjusted so that the total proportion of older people living alone matched that observed in the 1998 GHS (as GHS data are more recent than CFAS data).

For those who lived alone and were dependent, analysis of the RIS CFAS dataset showed that the probability of receiving informal care also differs significantly according to the type of dependency. The proportion of people living alone who received informal care was 52% among those with cognitive impairment only, 64% among those with functional impairment only, and 77% among those with combined cognitive and functional impairment. These proportions from the RIS CFAS dataset are used to divide those with cognitive impairment and/or functional impairment who live alone by whether they receive informal care or not. For those not classified as having cognitive impairment or functional impairment, GHS data are used.

For future years, the projections assume that the proportion of single people living alone without informal help, living alone with informal help and living with others remains constant over time by age, gender and dependency group.

### *Housing tenure*

The model includes, for those living in private households, a simple breakdown by housing tenure, between those living in owner-occupied tenure and those living in rented accommodation. One reason for the inclusion of housing tenure is that it can be regarded as a simple proxy for socio-economic group. Another is that it is relevant, in the case of older people living alone, to the division between those who fund their own residential or nursing home care and those who are funded by their local authority or health authority.

The current means test for public support in residential or nursing home care generally takes account of the value of the person's home (unless it is occupied by their spouse or an older or disabled relative). This means that older home-owners who live alone generally need to fund their residential or nursing home care privately, while older tenants and older home-owners living with their spouse are often eligible for public funding.

The proportions of older people, by age band and household type, living in owner-occupier and in rented tenure were derived by analysis of 1998/9 GHS data. The use of this relatively recent GHS data seemed reasonable as an analysis of the RIS CFAS data showed no statistically significant difference in housing tenure between those with cognitive impairment and those with functional disability. The projections assume that the proportion of older people, by age band and household type, living in owner-occupier tenure rises in line with housing tenure projections by the Anchor Housing Trust (Forrest *et al*, 1996).

#### 4.3. Projected amounts of services demanded

The second part of the model is concerned with projections of the volumes of services demanded. The output of the first part of the model (the projected numbers of older people by dependency, household type/informal care and other characteristics) was combined with functions that assign receipt of services to each sub-group of the older population. The services covered include a range of services relevant to meeting the long-term care needs of older people with cognitive impairment and/or functional disability.

The model includes key formal non-residential social services, such as home care, day care and meals. It also includes key non-residential health services, such as day hospital care, community nursing and chiropody. Private domestic help is also included, though this should be treated with caution, as it may not be related to care needs. Residential care, nursing home care and long-stay hospital care are also included.

It did not seem appropriate to make direct use of the CFAS RIS data to investigate the proportion of older people with cognitive impairment and/or functional disability receiving different services. One reason was that the RIS data was collected in just four areas whose pattern of service receipt may not be typical of the national pattern. McNamee *et al* (1999) found that the costs of formal services differed by area. A further reason was that, since the period 1991 to 1995 when the RIS data was collected, there have been substantial changes in the patterns of service receipt (Pickard *et al*, 2001).

For non-residential services 1998/9 GHS data and RIS CFAS data were used. First, the probability of receipt of each of these services was estimated through multivariate (logistic regression) analysis of the GHS data. The independent variables were age, gender, level of functional dependency, household type/informal care and housing tenure. The fitted values from the analysis were then applied to the population in each cell by age, gender etc to produce an estimate of the overall numbers of older people receiving each service by age group, gender, functional dependency, household type/informal care and housing tenure.

RIS CFAS data were used to investigate, for the recipients of each service, the proportions of service recipients in each disability group (cognitive impairment and/or

functional dependency). This analysis was conducted by age and gender<sup>7</sup>. Table 4.3 shows, for each age group and gender, the proportion of recipients on non-residential services (except for chiropody) by type of dependency. Most of the recipients of services belong to the group with functional dependency only. This reflects the higher prevalence of functional dependency (see table 4.2).

Table 4.3 Percentage of users of non-residential services (except chiropody) by type of dependency.

	CI only	ADL only	Combined
Male			
65-74	13	72	15
75-84	22	58	20
85+	20	51	29
Female			
65-74	7	85	8
75-84	11	74	15
85+	10	69	21

Source: Analysis of the RIS-CFAS dataset

The overall estimated numbers of service recipients with functional dependency from the 1998 GHS were then divided between those with functional dependency only and those with both cognitive impairment and functional dependency using the analysis of the RIS data described above. Similarly, estimated overall numbers of service recipients without functional dependency were divided between those with cognitive impairment and those without cognitive impairment using RIS data.

The intensity with which services were received, i.e. hours or visits per client week, was also investigated using both GHS and RIS data. Analysis of RIS data showed that the average weekly receipt of each community-based service did not differ significantly between those with cognitive impairment only, those with cognitive impairment and functional disability, and those with functional disability only. The one exception was district nursing: it was found that those with functional impairment only were receiving significantly higher average number of weekly visits than those with cognitive impairment only. GHS data on intensity of service receipt was, therefore, used for all categories of service recipients, with an adjustment in the case of district nursing services.

For residential, nursing home and long-stay hospital care, the total numbers of older service recipients people were obtained from official national statistics (Department of Health, 2000a). The totals were broken down by gender, age band, household type before admission and housing tenure before admission, on the basis of information from PSSRU 1996 survey of residential care (Netten *et al*, 1998). They were also divided between those with cognitive impairment only, those with functional impairment only and those with both, using an analysis of the RIS data. Account was taken of the PSSRU survey finding that, at the time of admission to residential care, people with severe cognitive impairment were more likely to be still married and living with others compared to those with no cognitive impairment (Netten *et al*, 2001a). This approach enabled the proportion of older people in residential, nursing home and long-stay hospital care to be estimated by age band, gender,

<sup>7</sup> For the users of each service, logistic regression analysis was conducted using as the dependent variable whether the person had cognitive impairment. Explanatory variables were age, gender, household type/informal care and housing tenure. For most services the proportion of service recipients in the RIS data with cognitive impairment was found to vary with age and gender but not with the other variables.

type of disability and previous household type. The table 4.4 below shows, as an example, the probability for someone in the age group 75-84 to be in an institution, depending on their gender, household type and type of dependency.

Table 4.4. Probability of being in an institution for people aged 75 to 84, by gender, household type and dependency group.

		Probability of being in an institution		
		CI only	ADL only	Combined
75-84 male	Alone	27	38	73
	With others	37	49	72
	Married	8	7	38
75-84 female	Alone	9	26	87
	With others	13	36	86
	Married	4	3	74

Source: PSSRU CI LTC model estimates (using MRC CFAS data).

Table 4.5 shows the estimated proportions of older people in different forms of institutional care and in different household types in the community, by type of disability. Of those with cognitive impairment only, 88% live in the community, compared to 75% of the functional impairment only group, and 15% of the group with combined dependency.

Table 4.5. Distribution of the population 65 and over by dependency and household type, 1998

	No dep.	CI only	ADL 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
All by dependency	6,547,795	234,480	769,715	227,009

Source: derived from analyses of 1998 GHS, Department of Health, PSSRU and CFAS RIS data

The estimated proportion of each sub-group of the older population by age, gender, household type, type of disability and housing tenure who received each service was then held constant for future years<sup>8</sup>. This means that the projections are based on recent patterns of care for older people, except where changes in the pattern of care are specifically investigated.

#### 4.4. Projected aggregate expenditure on long-term care services

The third part of the model projects the total expenditure on the formal services demanded. It covers the costs to the health service, social services and users of services, for those long-

<sup>8</sup> As there has been a decline in the number of people in institutions between 1998 and 2000, the model has reflected this change.

term care services included in the model. However, this does not comprise the total costs of long-term care to society. That would require the inclusion of the costs of a wider range of services to a wider range of public agencies and to service users and the opportunity costs of informal care.

A key input is the unit costs of care, for which information has been drawn from a PSSRU study (Netten *et al*, 2001b) and from Laing and Buisson (2001). The other input is the projected levels of services demanded as estimated in the second part of the model. Estimated expenditure on home care and community nursing services has been grossed up broadly to match official data. Separate expenditure projections can be produced for services for older people with cognitive impairment and services for older people without cognitive impairment.

Projections for future years need to take account of expected rises in the real unit costs of care, such as the cost of an hour's home care. Real unit costs are likely to be affected by a number of factors, including future real wages and other input prices, efficiency and quality of care. As long-term care services are highly labour-intensive, future real wages are probably the key factor. It is assumed, as a base case, that real unit costs of health care will rise by 1.5% per year and of social care by 1% per year. This reflects trend rises in real input prices, i.e. health care and social care pay and prices.

## **5. Base case projections**

### **5.1 Base case assumptions**

The PSSRU CI-LTC model does not make forecasts about the future. Rather it makes projections on the basis of specific assumptions about future trends. There are a wide range of factors that impact on future long-term care expenditure for people with cognitive impairment. This section presents some projections under a set of base case assumptions about the key factors.

The main assumptions that form the base case of the model are summarised in box 5.1.

#### **Box 5.1.**

##### **MAIN BASE CASE ASSUMPTIONS**

###### Numbers of older people

- *Older population changes in line with GAD 2000-based population projections*
- *Age/gender specific prevalence rates of cognitive impairment and of problems with ADLs remain unchanged.*
- *Marital status rates change in line with GAD 1996-based marital status and cohabitation projections.*
- *There is a constant ratio of single people living alone to single people living with others.*
- *Housing tenure changes in line with Anchor Housing Trust projections.*

###### Demand for services

- *Proportion of older people receiving informal care, formal community care services and residential and nursing home care remains constant for each sub-group by age, dependency, household type and other needs-related circumstances.*

###### Expenditure

- *Social care unit costs rise by 1% per year and health care unit costs by 1.5% per year in real terms.*

The base case attempts to approximate what may happen if no changes are made in the quality of long-term care services, the patterns of care provided for different needs and the system of funding long-term care. It aims to take account only of external pressures exogenous to policy. This base case should be treated as a starting point for examination of the assumptions used in the model, not as a prediction of the future. The base case is a point of comparison when these assumptions are subsequently varied in alternative scenarios.

## 5.2 Base case key results

The model estimates that between 1998 and 2031, the numbers of people with cognitive impairment will rise from 461,000 to 765,000 (an increase of 66%). Of these 765,000 people, 376,000 would also have problems with activities of daily living. In most cases, having both cognitive impairment and problems with ADLs is a marker for severe cognitive impairment (see appendix 2). These projections are based on GAD 2000-based population projections and assume unchanged age-specific rates of cognitive impairment and functional disability.

The model projects that between 1998 and 2031, the numbers of hours of home care arranged by local authorities for older people with cognitive impairment would need to rise by 67%, to keep pace with demographic projections. The numbers of people with cognitive impairment receiving any home-based services (excluding chiropody) would need to rise by 62%, from 131,000 to 211,000. The numbers of people with cognitive impairment in institutions would need to rise by 63%, from 224,000 in 1998, to 365,000 in 2031 (table 5.1).

Table 5.1. Projected numbers of people and future service requirements, England.

	1998	2031	% increase between 1998 and 2031
Numbers aged 65 or more	7,779,000	12,510,000	60.8%
Numbers aged 85 or more	958,000	1,730,000	80.5%
Numbers with CI only	234,000	389,000	65.8%
Numbers with ADL only	770,000	1,215,000	57.9%
Numbers with combined	227,000	376,000	65.8%
All with CI	461,000	765,000	65.8%
Numbers with informal care <sup>9</sup>	934,000	1,532,000	63.9%
of which with CI	191,000	324,000	69.8%
Numbers with home-based services <sup>10</sup>	1,495,000	2,387,000	59.7%
of which with CI	131,000	211,000	61.7%
Numbers in institutions	416,000	631,000	51.6%
of which with CI	224,000	365,000	63.2%

Source: PSSRU CI LTC model estimates (using MRC CFAS data).

The numbers of people with cognitive impairment are projected to increase faster between 1998 and 2031 than the numbers of people with functional disability only (66% and 58% respectively). This implies that demand for long-term care will rise at a faster rate among those with cognitive impairment than would be suggested by projections of the overall demand for long-term care. For example, between 1998 and 2031, the number of recipients of home-based services is projected to rise by 62% among those with cognitive impairment, but by only 60% among the total dependent older population. Similarly, the number of people with cognitive impairment in institutional care is projected to increase by 63%, compared to a projected 52% increase in the total number of older people in institutional care.

<sup>9</sup> Includes all the older people with dependency who either reported to have a carer or had a potential carer as a result of their household circumstances.

<sup>10</sup> Except chiropody

Expenditure on long-term care services for older people with cognitive impairment in England (in 2000/1 prices, i.e. with expected real increases but not nominal changes in care costs) is projected to rise from around £4.6 billion in 1998 to around £10.9 billion in 2031. As shown in table 5.2, this amounts to a rise from around 0.61% of GDP in 1998 to around 0.70% of GDP in 2031 (if real GDP grows by 2.25% per year). It is important to recognise that this figure does not comprise the total costs of cognitive impairment to society. That would require the inclusion of the costs of a wider range of services to a wider range of public agencies and service users and the opportunity costs of informal care.

Under the base case assumptions, the projected increase in long-term care expenditure for older people between 1998 and 2031 would be 131%. However, the increase in long-term care expenditure for those with cognitive impairment would be 139%. This differential shows that long-term care expenditure on older people with cognitive impairment is projected to rise faster than long-term care expenditure on older people as a whole. This demonstrates the value of developing separate projections for cognitive impairment.

Table 5.2. Base case projected long-term care expenditure (in £ billions) for England, to 2031.

	1998	2000	2010	2020	2031
LTC expenditure for people with CI	4.55	4.74	5.77	7.50	10.68
Total LTC expenditure	10.68	11.14	13.33	17.21	24.65
Long-term care expenditure as % of Gross Domestic Product <sup>11</sup>					
LTC expenditure for people with CI	0.61%	0.61%	0.60%	0.62%	0.70%
Total LTC expenditure	1.44%	1.44%	1.38%	1.43%	1.60%

Source: PSSRU CI LTC model estimates (using MRC CFAS data).

It has been estimated that people with Alzheimer's Disease represent 72% of the total number of people with cognitive impairment (Ott *et al*, 1995). Assuming that the distribution of the severity of the disease and use of resources was the same for those with AD as those with other types of dementia, it could be extrapolated that the long-term care costs of AD would be £3.3 billion in 1998 and would rise to £7.9 billion by 2031.

<sup>11</sup> Assuming Gross Domestic Product increases by 2.25% per year in real terms.

## 6. Sensitivity analysis

There are a number of factors to which future demand for long-term care services for people with cognitive impairment and associated expenditure are sensitive. This section explores the impact of changes in assumptions about future numbers of people with cognitive impairment, by looking at variant population projections and changes in prevalence rates of cognitive impairment. It then examines the potential impact of changes in informal care and in patterns of formal services. Finally, it explores the impact of different assumptions about future rises in the real unit costs of care.

### 6.1 Changes in the future numbers of older people

The first area of uncertainty in making projections is the future numbers of older people. The key factor affecting the projected number of older people are mortality rates in old age (Murphy, 1995). In order to explore the impact of alternative assumptions about future mortality in old age, the GAD's lower and higher life expectancy variants to the *1998-based* principal population projections have been used<sup>12</sup>.

Table 6.1 shows the impact of a higher life expectancy (or lower mortality in old age) assumption on the projections of long-term care for older people with cognitive impairment.

Table 6.1. Projections using GAD's high life expectancy population projection, England.

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031, base case
Numbers aged 65 or more	7,779,000	12,836,000	65.0%	60.8%
Numbers aged 85 or more	958,000	1,892,000	97.5%	80.5%
Numbers with CI only	234,000	407,000	73.8%	65.8%
Numbers with CI and ADL	227,000	400,000	76.3%	57.9%
Numbers with ADL only	770,000	1,270,000	65.0%	65.8%
All with CI	461,000	808,000	75.0%	65.8%
Numbers with informal care of which with CI	934,000 191,000	1,603,000 333,000	71.6% 77.3%	63.9% 69.8%
Numbers with home-based services of which with CI	1,495,000 131,000	2,483,000 222,000	66.1% 69.9%	59.7% 61.7%
Numbers in institutions of which with CI	416,000 224,000	668,000 389,000	60.4% 74.0%	51.6% 63.2%
Total LTC expenditure of which by people with CI	10.68 4.55	25.90 11.51	142.5% 153.0%	130.8% 138.6%
LTC expenditure as % of GDP of which due to CI	1.44% 0.61%	1.68% 0.75%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

Under GAD's high life expectancy variant, the numbers of people aged 65 and over are projected to increase by 65% between 1998 and 2031, compared to a rise of 61% under the principal population projections. More importantly, the numbers of people aged 85 and over

<sup>12</sup> The variants to the 2000-based projections are not expected until later in 2002.

(for whom the prevalence of cognitive impairment is much higher) are projected to rise by 98% under the high life expectancy variant, much faster than the 81% increase under the base case. The numbers of people with cognitive impairment are projected by the model to rise to 808,000 in 2031, compared to 765,000 under the base case. The numbers of people with combined cognitive impairment and functional dependency are projected to rise to 400,000, compared to 376,000 under the base case. Under this assumption, total long-term care expenditure for those with cognitive impairment would be around £11.5 billion in 2031, which would represent 0.75% of GDP, compared to 0.70% under the base case.

Under GAD's low life expectancy variant, the number of older people are projected to rise more slowly than under the base case (54% for those 65 and over and 61% for those 85 and over). The numbers of people with cognitive impairment in 2031 would increase to 713,000, compared to 765,000 under the base case. Total long-term care expenditure for those with cognitive impairment is projected to be around £10.1 billion in 2031, which would represent 0.66% of GDP, compared to 0.70% under the base case (table 6.2).

**Table 6.2. Projection using GAD's low life expectancy population projection, England.**

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031, base case
Numbers aged 65 or more	7,779,000	12,013,000	54.4%	60.8%
Numbers aged 85 or more	958,000	1,543,000	61.1%	80.5%
Numbers with CI only	234,000	365,000	55.5%	65.8%
Numbers with CI and ADL	227,000	348,000	53.3%	57.9%
Numbers with ADL only	770,000	1,146,000	48.9%	65.8%
All with CI	461,000	713,000	54.4%	65.8%
Numbers with informal care of which with CI	934,000 191,000	1,441,000 304,000	54.2% 59.9%	63.9% 69.8%
Numbers with home-based services of which with CI	1,495,000 131,000	2,255,000 197,000	50.9% 50.6%	59.7% 61.7%
Numbers in institutions of which with CI	416,000 224,000	588,000 337,000	41.3% 50.7%	51.6% 63.2%
Total LTC expenditure	10.68	23.12	116.5%	130.8%
of which by people with CI	4.55	10.06	121.1%	138.6%
LTC expenditure as % of GDP	1.44%	1.50%		
of which due to CI	0.61%	0.65%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

In the next assumption the numbers of people aged 85 and over are assumed to rise by 1% per year faster than under the GAD principal population projection. This assumption has been chosen because it corresponds roughly to the extent of past under-estimation of the numbers of very elderly people in past population projections (Shaw 1994). It is debatable whether the most recent projections, based on a changed approach (Shaw 2000), will still prove to be under-estimates. This assumption is included, however, because the assumptions underlying the GAD high and low variants produce a range in

life expectancy at birth which is somewhat narrow compared with variants produced by other organisations<sup>13</sup>.

An increase in numbers of very elderly people of this magnitude would have a substantial impact on future numbers of people with cognitive impairment and on demand for long-term care. Under this assumption, the numbers of people aged 85 and over would rise by 151%, much faster than the 81% increase projected under the principal GAD population projections. The numbers of people with cognitive impairment would rise to 906,000 in 2031, compared to 765,000 under the base case. The numbers of people with combined cognitive impairment and functional dependency would rise to 461,000, compared to 376,000 under the base case. The numbers of people with cognitive impairment receiving informal care would rise by 91%. The numbers of people with cognitive impairment receiving home-based services (except for chiropody) would need to rise by 87% and the numbers with cognitive impairment receiving institutional care by 102% to keep pace with demographic pressures (table 6.3). Total long-term care expenditure for those with cognitive impairment is projected to be around £13.2 billion in 2031, which would represent 0.85% of GDP, compared to 0.70% under the base case.

Table 6.3. Projection where the numbers of people aged 85 and over increase 1% per year faster than projected by the GAD's principal population projections.

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031, base case
Numbers aged 65 or more	7,779,000	13,182,000	69.5%	60.8%
Numbers aged 85 or more	958,000	2,402,000	150.7%	80.5%
Numbers with CI only	234,000	445,000	89.6%	65.8%
Numbers with CI and ADL	227,000	461,000	103.1%	57.9%
Numbers with ADL only	770,000	1,392,000	80.9%	65.8%
All with CI	461,000	906,000	82.9%	65.8%
Numbers with informal care	934,000	1,761,000	88.5%	63.9%
of which with CI	191,000	364,000	91.0%	69.8%
Numbers with home-based services	1,495,000	2,663,000	78.1%	59.7%
of which with CI	131,000	245,000	87.2%	61.7%
Numbers in institutions	416,000	761,000	82.6%	51.6%
of which with CI	224,000	452,000	102.0%	63.2%
Total LTC expenditure	10.68	28.80	169.62%	130.8%
of which by people with CI	4.55	13.18	189.67%	138.6%
LTC expenditure as % of GDP	1.44%	1.87%		
of which due to CI	0.61%	0.85%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

## 6.2 Changes in prevalence rates

<sup>13</sup> Personal correspondence with GAD.

The development of treatments for Alzheimer's disease could be expected to have an impact on future prevalence rates of cognitive impairment. It may be possible to develop drugs which can slow the rate of progression of Alzheimer's disease. This could have the effect of reducing future prevalence rates of the severe stages of the disease.

In order to illustrate how changes in the prevalence of cognitive impairment may affect projected expenditure on long-term care, two prevalence assumptions are investigated. In the first one, the age-specific rates of cognitive impairment only fall by 1% per year while age-specific rates of functional dependency only and combined dependency remain constant. This would have the effect of decreasing mainly the prevalence of mild to moderate cognitive impairment (see appendix 2). In the second assumption, the age-specific prevalence of combined cognitive impairment and functional dependency declines by 1% per year. This second assumption aims at illustrating the possible impact of a delay in the progression of cognitive impairment to the more severe stages.

If the prevalence rates of cognitive impairment only declined by 1% per year, the model estimates that in 2031 there would be 279,000 people aged 65 and over with cognitive impairment only, compared to 389,000 under the base case. The numbers of people with cognitive impairment receiving informal care in 2031 are projected to rise by 30%, to 246,000 people, compared to an increase of 70% under the base case. Between 1998 and 2031 the number of cognitively impaired users of home-based services (except for chiropody) would rise by 42%, compared to 62% under the base case, and the number of cognitively impaired people in institutions would rise by 58% compared to 63%. Table 6.4 shows the impact on long-term care expenditure of this assumption.

Table 6.4. Projection with a decrease of 1% per year in prevalence rates of cognitive impairment only.

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031, base case
Numbers with CI only	234,480	279,000	19.0%	65.8%
Numbers with CI and ADL	227,010	376,000	65.8%	57.9%
Numbers with ADL only	770,000	1,215,000	57.9%	65.8%
All with CI	1,004,195	655,000	42.0%	65.8%
Numbers with informal care of which with CI	934,000 191,000	1,429,000 246,000	53.0% 29.2%	63.9% 69.8%
Numbers with home-based services of which with CI	1,495,000 131,000	2,394,000 185,000	60.1% 41.8%	59.7% 61.7%
Numbers in institutions of which with CI	416,000 224,000	619,000 353,000	48.6% 57.7%	51.6% 63.2%
Total LTC expenditure of which by people with CI	10.68 4.55	24.30 10.42	127.5% 128.9%	130.8% 138.6%
LTC expenditure as % of GDP of which due to CI	1.44% 0.61%	1.58% 0.68%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

A reduction of 1% per year in the prevalence of cognitive impairment only has an important impact on the numbers of future recipients of informal care. However, it has only a limited

impact on the future numbers of recipients of formal services and on expenditure. This reflects the current patterns of service receipt, with relatively low levels of service use observed for those with cognitive impairment only.

The table 6.5 below shows the impact of a 1% decline per year in the prevalence of combined cognitive impairment and functional dependency. This scenario aims at illustrating the possible impact of a delay in the progression of cognitive impairment to the more severe stages. Three quarters of the decline has been allocated to the cognitive impairment only group and one quarter to the functionally dependent only group. This takes into account the finding that 20% of those with combined impairment in the sample had only mild cognitive impairment (based on a classification of severity according to the MMSE scores, see appendix 2) and that their combination of cognitive and functional impairment could be due to a coincidence of mild cognitive impairment and physical disability.

Table 6.5. Projection with a decrease of 1% per year in the prevalence rates of combined frailty

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031, base case
Numbers with CI only	234,000	492,000	109.8%	65.8%
Numbers with CI and ADL	227,000	239,000	5.2%	57.9%
Numbers with ADL only	770,000	1,250,000	62.3%	65.8%
All with CI	1,004,000	1,741,000	58.4%	65.8%
Numbers with informal care of which with CI	934,000 191,000	1,626,000 369,000	74.1% 96.4%	63.9% 69.8%
Numbers with home-based services of which with CI	1,495,000 131,000	2,380,000 190,000	62.3% 86.1%	59.7% 61.7%
Numbers in institutions of which with CI	416,000 224,000	542,000 269,000	31.3% 17.4%	51.6% 63.2%
Total LTC expenditure of which by people with CI	10.68 4.55	22.19 8.10	107.8% 77.9%	130.8% 138.6%
LTC expenditure as % of GDP of which due to CI	1.44% 0.61%	1.44% 0.52%		

Source: PSSRU CI LTC model estimates (using MRC CFAS data).

As the table shows, a decrease in the prevalence of combined impairment of 1% per year would have a substantial impact on future long-term care expenditure. The proportion of GDP spent on long-term care services is projected to remain broadly constant under this scenario.

### 6.3 Changes in the availability of informal care

There is considerable uncertainty about the future supply of informal care. The model takes into account the effects of changes in marital status on informal care/household composition in the future. One of the central findings of the research carried out using the main PSSRU model has been that there is likely to be an increase in spouse carers of

dependent older people in future years (Pickard *et al*, 2000). However, the future provision of intensive informal care by children is much more uncertain.

The next assumption investigates the possible consequences of a decline in households in which children care for their older parents. The proportion of older people living with an adult child has declined from 42 per cent in 1962 to 14 per cent in 1986, with a further decline during the late 1980s (Grundy 1995, Grundy and Glaser 1997). The assumption using information from the 1998/9 GHS) allows for a decline by one third in the proportion of single dependent older people living with others by 2031 (see Wittenberg *et al*, 2002 for more details). It assumes that the older people who no longer move in with their children move into residential homes instead.

Under this assumption, in 2031 there would be 312,000 people with cognitive impairment living at home who receive informal care, compared to 324,000 under the base case, and there would be 377,000 people with cognitive impairment in institutions, compared to 365,000 under the base case. Expenditure on long-term care for people with cognitive impairment is projected to be approximately 0.72% of GDP in 2031 under the scenario in which co-resident care declines, which is similar to the 0.70% projection under the base case (Table 6.6).

Table 6.6 Projection with a decline in the provision of informal care by children.

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031 under base case
Numbers with informal care	934,000	1,494,000	59.9%	63.9%
of which with CI	191,000	312,000	63.6%	69.8%
Numbers with home-based services	1,495,000	2,367,000	58.4%	59.7%
of which with CI	131,000	204,000	46.3%	61.7%
Numbers in institutions	416,000	669,000	60.7%	51.6%
of which with CI	224,000	377,000	68.5%	63.2%
Total LTC expenditure	10.68	25.3	137.0%	130.8%
of which by people with CI	4.55	11.1	143.2%	138.6%
LTC expenditure as % of GDP	1.44%	1.64%		
of which due to CI	0.61%	0.72%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

The next assumption allows for a more wholesale fall in the supply of informal care. As in the previous assumption, it is assumed that a fall in the supply of informal care would have the effect of increasing admissions to institutional care. However, in this assumption, it is assumed that the greater probability of admission to institutions affects all older people with dependency needs who live with others. In other words, it increases the probability of admissions to institutions not just for single dependent older people living with others but for married couples and married couples living with others as well.

This assumption is explored by assuming that older people who live with others have the same likelihood of admission to residential care as those who live alone. In this way it allows for a substantial fall in the supply of informal care. The increased probability of

admission to institutions of people who currently receive informal care is assumed to have occurred fully by the year 2031.

Under this assumption, the numbers of people with cognitive impairment receiving informal care in 2031 would be 286,000 (compared to 324,000 under the base case), and the numbers in institutional care (residential, nursing and hospital care) would be around 403,000 in 2031, compared with 365,000 under the base case. This assumption has a substantial impact on future long-term care expenditure. Expenditure on long-term care for those with cognitive impairment is projected to represent around 0.77% of GDP in 2031 under this scenario, compared with 0.70% under the base case (Table 6.7).

**Table 6.7. Projection with a wholesale decline in the provision of informal care.**

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031 under base case
Numbers with informal care	934,000	1,382,000	48.0%	63.9%
of which with CI	191,000	286,000	50.2%	69.8%
Numbers with home-based services	1,495,000	2,312,000	54.6%	59.7%
of which with CI	131,000	187,000	43.2%	61.7%
Numbers in institutions	416,000	780,000	87.4%	51.6%
of which with CI	224,000	403,000	79.9%	63.2%
Total LTC expenditure	10.68	28.9	170.2%	130.8%
of which by people with CI	4.55	11.9	161.3%	138.6%
LTC expenditure as % of GDP	1.44%	1.87%		
of which due to CI	0.61%	0.77%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

The financial implications of the assumption in which there is a decline in co-resident care by children are relatively close to the base case of the model, compared to the implications of the assumption in which there is a more wholesale increase in institutionalisation as a result of a decline in informal care. The relatively small effect of the assumption in which there is a decline in co-resident care by children may arise because the numbers of older people who are co-resident with their children is already very small. The results suggest, however, that a wider decline in the supply of informal care, resulting in admissions to residential, nursing and hospital care for a larger group of older people, is likely to have much greater financial consequences.

#### 6.4. Change in the patterns of formal care

As well as changes in the provision of informal care, there may be changes affecting the patterns of formal care in future years. The implications of two assumptions are explored here. In the first, the policy aim is to provide more formal support to carers in future years, with potential effects on the balance between domiciliary and institutional care.

The results of the main PSSRU model, using the GAD marital status and cohabitation projections, have suggested that there is likely to be an increase in spouse carers of dependent older people in the future (Pickard *et al* 2000). Many spouse carers are themselves elderly, many are in poor health and, as carers, many are themselves in need

of support from formal services. An increase in spouse carers therefore raises issues about the need for support for carers. Carers of people with cognitive impairment are in particular need of support from formal services because of their long hours of caring and the greater costs of caring that they incur (Langa *et al.* 2001, RIS MRC CFAS 1998). Current policies, in particular the National Strategy for Carers (1999), are intended to increase the amount of service support received by carers.

An assumption has therefore been developed which looks at the implications of increasing support for carers of people with cognitive impairment. The assumption focuses on providing more support to the most heavily burdened carers. These have been identified as carers providing personal care to older people living in the same household (Parker 1992). The assumption investigates the implications of giving to older people with combined cognitive impairment and functional disability who live with others the same packages of non-residential services as received by those living alone (a ‘carer-blind’ assumption, cf. Pickard *et al.*, 2000).

Table 6.8 below shows the results of running the model under the ‘carer-blind’ assumption for carers of people with combined frailty. Between 1998 and 2031, the numbers of older cognitively impaired recipients of home-based services (except for chiropody) are projected to rise by around 144%, compared to around 62% under the central base case of the model. Home care hours for people with cognitive impairment are projected to rise, under the carer-blind assumption, by about 242% between 1998 and 2031, compared to 67% under the base case. Community nursing visits are projected to rise by 202% between 1998 and 2031 under the ‘carer blind’ assumption, compared to around 59% under the central base case. Expenditure on long-term care for people with cognitive impairment is projected to represent around 0.75% of GDP in 2031 under the ‘carer-blind’ assumption, compared with 0.70% under the base case.

Table 6.8. Projection with increased support for carers of people with combined frailty.

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031 under base case
Numbers with informal care	934,000	1,531,000	63.9%	63.9%
of which with CI	191,000	324,000	69.8%	69.8%
Numbers with home-based services	1,495,000	2,495,000	66.9%	59.7%
of which with CI	131,000	319,000	144.3%	61.7%
Numbers in institutions	416,000	631,000	51.6%	51.6%
of which with CI	224,000	365,000	63.2%	63.2%
Total LTC expenditure	10.68	25.3	137.3%	130.8%
of which by people with CI	4.55	11.55	153.7%	138.6%
LTC expenditure as % of GDP	1.44%	1.64%		
of which due to CI	0.61%	0.75%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

It is important to point out that the introduction of substantial support to carers, as described in the carer-blind assumption could have the effect of enabling informal carers to continue to care for long, thus delaying admission into institutions, which could make

the introduction of such a policy less expensive than projected. Such an effect was not taken into account here.

The second formal care assumption investigates the possible impact of a shift in the balance of care from institutional to domiciliary care. It has been the policy of successive governments to emphasise caring for older people in the community rather than in residential settings. The assumption used draws on the National Beds Inquiry (NBI), which was an inquiry established within the Department of Health in 1998 to review the growth of hospital services over the next 10 to 20 years (Department of Health 2000b).

The NBI assumed that the number of people in residential and nursing homes would rise in line with demographic pressures. However, it also assumed that there would be “a shift from institutional to domiciliary settings for long term care in line with current social care policy” (Department of Health 2000b: 66). It assumed that, by 2019, there would be a shift of between 5% and 15% to non-residential care, with a central assumption of 10%. It further assumed that those “shifted” from residential or nursing homes would receive between 6 and 10 hours home care per week (with a central assumption of 8 hours of home care a week) and that those “shifted” from nursing homes would receive 1 to 2 community nursing visits per week (with a central assumption of 1.5 community nursing visits per week) (Department of Health 2000b: 72).

A similar assumption is projected here to 2031, although the shift is assumed to be complete by 2020, as in the NBI. It is assumed here that, between the years 2000 and 2020, there will be a 10% reduction in the numbers of people with combined cognitive and functional dependency who will be in institutions. Those in the community who would otherwise been in an institution would receive 16 hours of home care and 3 district nurse visits per week. This is a more intensive care package than that used by the NBI, but it aims to take account of the more intensive care needs of those with combined cognitive impairment and functional disability.

Table 6.9. Projection with a 10% reduction in the numbers of people in institutions with combined dependency.

	1998	2031	% increase between 1998 and 2031	% increase between 1998 and 2031 under base case
Numbers with informal care <sup>14</sup>	934,000	1,632,000	74.7%	63.9%
of which with CI	191,000	368,000	93.1%	69.8%
Numbers with home-based services	1,495,000	2,487,000	66.4%	59.7%
of which with CI	131,000	256,000	95.9%	61.7%
Numbers in institutions	416,000	549,000	31.8%	51.6%
of which with CI	224,000	283,000	26.4%	63.2%
Total LTC expenditure	10.68	23.6	121.0%	130.8%
of which by people with CI	4.55	9.7	116.0%	138.6%
LTC expenditure as % of GDP	1.44%	1.53%		
of which due to CI	0.61%	0.64%		

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

<sup>14</sup> It has also been assumed that they would all receive informal care.

Under this assumption, projected overall expenditure on long-term care for people with cognitive impairment in 2031 would be somewhat lower than under the base case (£9.7 billion compared to £10.9). A policy change of this sort would have additional costs to carers that have not been quantified here. A slightly more comprehensive care package that, in addition to the 16 hours of home care and 3 district nurse visits per week, included two sessions of day care per week and 4 weeks of respite care per year would bring projected long-term care expenditure for those with cognitive impairment to £10.1 billion in 2031, which would still be slightly lower than projected expenditure under the base case (£10.9 billion).

#### 6.5. Assumptions on Unit Costs of health and social care

Expenditure projections over an extended period are inevitably sensitive to assumptions about real rises in the unit costs of care, such as the cost of an hour's home care or a community nurse visit. Yet, there is inevitable uncertainty about future rises in the unit costs of care. As long-term care services are labour-intensive, a key factor is future rises in the real wages of care staff. If demographic trends lead to a shortage of care staff, real wages in this sector may rise considerably. Another important factor is future changes in the technical efficiency of service provision. This could potentially offset part of the upward pressure from real wage increases.

The base case of the model assumes that health care costs rise by 1.5% per year and that social care costs rise by 1% per year. The base case assumptions about unit costs reflect the extent to which health and social care input pay and prices have risen in real terms on average over the last 15 years. Two additional assumptions are examined here. The first assumes that there will be no real rise in costs. The second assumes that unit costs will rise by 2% per year in real terms, in line with the expected rise in average earnings. The assumption of a rise of 2% per year in real terms was used by the Care Development Group for its projections of costs of long-term care services for older people to 2022 (Care Development Group, 2001, # 5.21).

If care costs remained constant in real terms, projected long-term care expenditure for people with cognitive impairment in 2031 would be only around 69% higher than in 1998, (63% higher for total long-term care expenditure). This is a significantly lower increase than under the base case, which assumes increases in real terms of 1% per year for social care and 1.5% for health care<sup>15</sup>. If, however, real unit costs increased by 2% per year in line with real earnings, projected long-term care expenditure for people with cognitive impairment in 2031 would be over 211% higher than in 1998. Long-term care expenditure for people with cognitive impairment would represent 0.50% of GDP in 2031 with constant unit costs, 0.70% of GDP under the base case assumption and 0.92% of GDP with unit costs rising 2% per year in real terms (Tables 6.10 and 6.11). This suggests that expenditure projections are arguably even more sensitive to assumptions about rises in real care costs than to assumptions about future mortality, prevalence rates, availability of informal care and patterns of care.

Table 6.10. No increase in real care costs projection of long-term care expenditure (in £ billions) for England, to 2031.

	1998	2000	2010	2020	2031
LTC expenditure by people with CI	4.55	4.74	5.17	5.99	7.66
Total LTC expenditure	10.68	11.14	11.92	13.74	17.37
Long-term care expenditure as % of Gross Domestic Product					
LTC expenditure by people with CI	0.61%	0.61%	0.53%	0.50%	0.50%
Total LTC expenditure	1.44%	1.44%	1.23%	1.14%	1.13%

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

Table 6.11. 2% per year increase in real care costs projection of long-term care expenditure (in £ billions) for England, to 2031.

	1998	2000	2010	2020	2031
LTC expenditure by people with CI	4.55	4.74	6.30	8.90	14.15
Total LTC expenditure	10.68	11.14	14.52	20.41	32.09
Long-term care expenditure as % of Gross Domestic Product					
LTC expenditure by people with CI	0.61%	0.61%	0.65%	0.74%	0.92%
Total LTC expenditure	1.44%	1.46%	1.50%	1.69%	2.08%

Source: PSSRU CI LTC model estimates (using MRC CFAS and GHS data).

## **7. Conclusions**

### **7.1 Key results**

The model estimates that between 1998 and 2031, the numbers of people with cognitive impairment will rise from 461,000 to 765,000 (an increase of 66%). Of these 765,000 people, 376,000 will also have problems with activities of daily living. Expenditure on long-term care services for older people with cognitive impairment is projected to rise from around £4.6 billion in 1998 to around £11 billion in 2031. This amounts to a rise from around 0.61% of GDP in 1998 to around 0.70% of GDP in 2031 (if real GDP grows by 2.25% per year). These projections are on the base case assumptions, including unchanged rates of prevalence of cognitive impairment by age and gender.

The costs of long-term care expenditure for people with cognitive impairment for England in 2031 estimated using the model are comparable to the projections produced by McNamee *et al* (2001). Their demographic model estimates the projected costs of formal care for people with cognitive impairment to be £11.2 billion. The study by McNamee *et al*, however, included the costs of acute health services, as well using a different methodology.

One of the findings of this study is that the numbers of older people with cognitive impairment are projected to increase faster between 1998 and 2031 than the numbers of older people with functional disability only (66% and 58% respectively). Long-term care expenditure on older people with cognitive impairment is projected to rise faster than long-term care expenditure on older people as a whole. Under the base case assumptions, the projected increase in long-term care expenditure for older people generally between 1998 and 2031 is 131%. The projected increase in long-term care expenditure for those with cognitive impairment is 139% over the same period. Demand for long-term care can be expected to rise at a faster rate among those with cognitive impairment than would be suggested by projections of the overall demand for long-term care. This demonstrates the value of developing separate projections for cognitive impairment.

The sensitivity analysis carried out using the model has produced some important results. It shows that projected future demand for long-term care services for older people with cognitive impairment is sensitive to assumptions about future numbers of older people and about future prevalence rates of cognitive impairment and functional dependency. Projected future expenditure on long term-care for older people with cognitive impairment is also sensitive to assumptions about future rises in the real unit costs of services, such as the cost of an hour's home care.

### **7.2 Key limitations**

As no single recent source of data contained all the necessary information for this study, it has used data from a number of different sources. As some of the data used covered different populations and were collected at different points of time, there are issues of comparability. An important part of this study has been devoted to investigating how best to use each available source of data and to combine the information available from each of them.

The CFAS RIS Study provides a very valuable source of information about the characteristics and service utilisation of dependent older people. In comparison with the General Household Survey and other available surveys, it provides a larger sample of dependent older people. It uses a well-recognised measure of cognitive impairment, records the use of services in detail and covers older people living in households and older people in institutions. A more up-to-date survey of the same quality would be a valuable tool for further research on the implications of cognitive impairment for demand for services and associated expenditure.

It is important to note that the expenditure projections produced by this study do not constitute the total costs of cognitive impairment to society. That would require inclusion of the costs of a wider range of services to a wider range of public agencies and service users and the opportunity costs of informal care. Inclusion of the latter would present considerable problems, as there is much scope for debate about the best method for estimating the opportunity costs of informal care.

It should also be stressed that no allowance has been made here for changes in public expectations about the quality, range or level of care. The base case projections presented here assume an unchanged relationship between age, gender, dependency, household type and housing tenure and receipt of care. Rising expectations, associated with rising real pensioner incomes, could clearly have a substantial impact on future demand for long-term care. Indeed, they could have a larger impact than demographic changes. Yet, it would be difficult to speculate usefully on their potential impact.

### 7.3 Social and policy implications

The results of the model show that, unless more effective treatments for cognitive impairment are developed and made widely available, the numbers of older people with cognitive impairment will rise significantly over the next 30 years. This means that substantial rises in formal services will be required. The model also shows that, if current or future treatments were to have the effect of reducing prevalence rates of the more severe stages of cognitive impairment by 1% per year, this would broadly offset expected demographic pressures from rising numbers of older people. The implication is that there is a need to develop, and make widely available, better treatments to slow down the progressive decline of dementia.

Much of the care for older people with cognitive impairment living at home is provided by their families and other informal carers. No attempt has been made here to make an estimate of the value of informal care provided to older people with cognitive impairment nor to make projections of the value of informal care in future years. The model does, however, allow for projections to be made of the expenditure implications of a possible decline in informal care in the future. Such a decline has been anticipated for a number of reasons, including changes in the structure and size of the family, increased geographical mobility in the working population, retirement migration and increased economic activity by women (RIS MRC CFAS 1998). Projections presented here suggest that a decline in the supply of informal care provided to older people with cognitive impairment, resulting in increased admissions to residential, nursing and hospital care, could have very great financial consequences. A decline in informal care provided to older people living with others, so that their probability of admission to residential care was the same as that of

older people living alone, would add around a billion pounds to long-term care expenditure on older people with cognitive impairment by 2031.

The provision of informal care to older people with cognitive impairment could be positively affected by more effective treatments for cognitive impairment. Treatments that delay the progression of the disease could result in a delay in the need for institutional care and enable older people to be cared for at home, by both informal and formal supports, for longer. The need for support for informal carers in these circumstances would be essential. The recent National Service Framework for older people recognises the importance of providing support to informal carers of people with dementia, stressing the need for information, advice and practical help to support them in caring for the older person (Department of Health, 2001).

The results reported here have looked at the future financial consequences of providing more support for carers of older people with cognitive impairment, in the form of domiciliary services provided on a 'carer-blind' basis. These results suggest that the financial consequences of providing support for carers on this basis would be lower than the costs of a decline in informal care that resulted in increased institutionalisation. The delay or prevention of institutional care for older people with cognitive impairment may be the consequence not just of improved treatments for dementia but also of the successful implementation of long-standing government policies. It has been the policy of successive governments to shift the balance of care from institutional to domiciliary care. The projections presented here suggest that a 10% reduction in the numbers of people with combined cognitive and functional dependency in institutions, and a concomitant increase in domiciliary care packages, would mean that long-term care expenditure on older people with cognitive impairment would be about a billion pounds less by 2031 than it would have otherwise been. The financial savings associated with a reduction in institutionalisation is an important reason for continuing to develop service arrangements that substitute for 'expensive' placements such as those in residential and nursing homes.

The importance of the results of the sensitivity analysis lies in the fact that it is beyond the present state of knowledge to set probabilities for future trends in the factors examined here. Yet it is important for policy and planning purposes to demonstrate the extent of sensitivity of future long-term care expenditures to assumptions about these trends. The findings suggest that policy-makers need to plan for uncertainty in future demand for long-term care for people with cognitive impairment. Future mortality and prevalence rates and rises in unit care costs, which are inevitably uncertain, have substantial implications for future demand for long-term care and associated expenditure.

## **8. Acknowledgments**

The research on which this report is based was financed by the Alzheimer's Research Trust. It builds on the PSSRU long-term care projections model, which forms part of the Personal Social Services Research Unit's long-term programme, financed by the Department of Health.

This research has used data from the Medical Research Council's Cognitive Function and Ageing Study. The MRC CFAS study is supported by major awards from the Medical Research Council and the Department of Health. We would like to acknowledge the essential contribution of Family Health Authorities, local general practitioners, interviewers and interviewees for their participation in the CFAS study.

Responsibility for any errors and all views in this article lies with the authors. The article does not purport to represent the views of the Department of Health, the Alzheimer's Research Trust or the Medical Research Council.

The assistance of the Government Actuary's Department in providing the population projections is gratefully acknowledged.

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### ***Appendix 1: Dependency classification***

In some of the RIS CFA Studies (McNamee *et al*, 1999 and 2001), a group of people who, because of their advanced cognitive impairment were not able to answer the ADL questions were excluded. In the study by Melzer and others (1999) from which we obtained the prevalence rates used in the model these people were included in the group with combined dependency. As this group of people would have very important care needs, we included them in the model, in the combined dependency group. Comparing the MMSE scores by the people in the “ADL missing” group with the stages of the disease identified by Almkvist (2000, see table 2.1) showed that, according to his classification, almost of the people in that group would have been in the “grave” category, which would require institutionalisation, with no ability to perform activities of daily living. The table 4.3 shows the numbers of people from the “ADL missing” group that would be in each of the groups described in Almkvist (2000).

Numbers of people from the “ADL missing” group that would be in each of the groups described in Almkvist (2000).

	Numbers of people from the ADL missing group	Typical features as described by Almkvist
None	0	No symptoms or memory symptoms
Mild	1	Deficits in memory and cognition; depression
Marked	5	Clear cognitive deficits; compensatory coping
Moderate	9	Some assistance needed; psychiatric symptoms
Severe	18	Help with ADLs needed; psychotic symptoms; aggressiveness
Grave	115	Institutional care needed
All	148	

Source: analysis of RIS MRC CFAS and Almkvist (2000, p.149)

## ***Appendix 2: Severity of cognitive impairment***

It is apparent from the literature, both from CFAS and from other studies, that the “combined dependency” group tend to have much more severe cognitive impairment than those in the “cognitive impairment” group. This suggests that, for most people in the combined group, having both types of dependency is likely to be a result of advanced cognitive impairment, rather than the coincidence of mild cognitive impairment and functional dependency resulting from physical disability. A similar finding was reported by Banerjee and Macdonald (1996) in their study of users of home care services. They found that, for each additional area of ADL dependence, the odds of being having cognitive impairment increased by one and a half. In their studies of people in nursing homes and residential homes, Mozley *et al* (2000) also found a very close correlation between cognitive impairment and functional dependency. The table below shows the degree of severity of cognitive impairment of those in each of the dependency groups used in the model. The table gives the percentages of people in each dependency group that, according to their MMSE scores, would fall into each of the stages of the severity classification proposed by Almkvist.

Percentage of people, in each of the dependency groups, in each of the stages of severity proposed by Almkvist (based on MMSE scores).

	Cognitive impairment only	Functional dependency only	Combined dependency	Typical features as described by Almkvist
None	13	57	1	No symptoms or memory symptoms
Mild	22	23	8	Deficits in memory and cognition; depression
Marked	27	14	11	Clear cognitive deficits; compensatory coping
Moderate	16	4	17	Some assistance needed; psychiatric symptoms
Severe	16	1	19	Help with ADLs needed; psychotic symptoms; aggressiveness
Grave	7	1	45	Institutional care needed
All	226	857	305	

Source: analysis of RIS MRC CFAS and Almkvist (2000, p.149)

It is clear from the table above that the combined dependency group has substantially more severe cognitive impairment than the cognitive impairment only group or the functional dependency only group. Whereas 80% of people in the combined dependency group would be classified as having severity in the range moderate to grave, only 39% of those with cognitive impairment only and 6% of those in the functional dependency only group<sup>16</sup> have severity in this range.

<sup>16</sup> The cognitive impairment classification in the MRC CFA Study was obtained using the Automated Geriatric Examination Computer Assisted Taxonomy (AGECAT) (Copeland et al. 1986). The outcomes of classifying according to AGECAT or the MMSE (as used in the table) are not always the same.