







The Dementia Epidemic

- where Scotland is now and the challenge ahead

Alzheimer Scotland
Action on Dementia

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4.1 There is an overall picture of insufficient services and great variability in provision between different areas. In many areas there is lack of provision, for example, of post-diagnostic services and of respite. On average, 11% of people with dementia living in the community receive home care and 12% receive day care, against a working target of 28%.

4.2 A vast amount of care for people with dementia is provided by informal carers, who compared with non-carers are more likely to take prescribed medication, visit their GP and report higher levels of stress and physical symptoms. Respite provision is a key issue for carers and people with dementia: only 27% of carers of people with dementia get a week's short break in a year.

4.3 Carers report a lack of services. In a survey only 37% felt that the services available were sufficient for their needs. 30% said day care was unavailable and 50% could not access home support. Information received at the point of diagnosis was inadequate and only 28% had access to training in how to cope with their caring role.

4.4 Around 6,500 people are diagnosed with dementia each year. They need appropriate post-diagnostic services including training and support for self-management. At present there are no self-management courses for people with dementia and only limited provision of support groups and one-to-one emotional support.

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1. Funding for a programme of self management courses for people with dementia jointly with carers as part of a strategy of saving future costs through anticipatory care.

2. Restoration of the availability of existing drug treatments to people with mild Alzheimer's disease.

3. Increased funding now for services such as home care, day care and short breaks and recognition that personalised care through specialist dementia services may be more cost effective in the long term by allowing people to remain in their own home for longer.

4. Increased future funding in line with demographic change and the increase in the number of people with dementia.

5. Improved training in dementia care.

6. A medical assessment for every person in a care home whom staff believe may have dementia and improved access to doctors and specialist services for care home residents.

7. Implementation of the recommendations of the report on free personal care, and allowances uprated in line with increases in care home fees.

8. Investment now in a major public health campaign to reduce people's risk of developing dementia in later life, by encouraging healthy eating, physical activity, mental exercise and social stimulation.

9. Support for research into better preventive treatments, better symptomatic treatments, causes and ways of preventing or delaying dementia.

10. Dementia to be made a national priority.

1 Introduction

Summary

- There will be 75% more people with dementia in Scotland by 2031.
- This report gives current and future numbers of people with dementia and looks at service provision and economic impact. It also sets out strategies for planning for the future increase in numbers.
- Dementia is a major cause of disability in people aged over 60.
- The estimated cost of dementia in Scotland in 2007 is between £1.5 and £1.7 billion.
- By 2031 the cost will be between £2.6 and £2.9 billion (at today's prices).

1.1 The dementia epidemic

Dementia is a key health issue facing Scotland over the coming decades as our population ages. It is vital that it is recognised as such. This report presents current and future numbers of people with dementia based on the best current evidence, outlines current service provision and issues of quality and adequacy, looks at the economic impact of dementia and sets out what strategies need to be put in place to manage the projected 75% increase in people with dementia as the baby-boom generation reaches old age.

Dementia is a global term used to describe a range of brain diseases characterised by a progressive decline in intellectual and other mental functions. The most common type of dementia is Alzheimer's disease, and other causes include vascular dementia and Lewy body dementia. At the early stages of dementia, memory is commonly affected but most people can be assisted to live an independent life. However, as the illness progresses people will need increasing assistance with personal care and the activities of daily living, and eventually will require constant support and supervision. People with dementia gradually lose their language skills and the ability to communicate. They become unable to make decisions about their own lives as the illness progresses, which means that others, such as family members, need to make these decisions for them. Dementia is a terminal condition.

Dementia is a major cause of disability in people aged over 60. It contributes 11.2% of all years lived with disability, more than stroke (9%), musculoskeletal disorders (8.9%), cardiovascular disease (5%) and all forms of cancer (2.4%)[1]. The estimated cost of dementia in Scotland in 2007 is between £1.5 and £1.7 billion. By 2031 we estimate the cost will be between £2.6 and £2.9 billion (at today's prices).

In order to cope effectively with this huge increase in the numbers of people with dementia and the associated cost, it is essential that Scotland has a forward-looking strategy for dementia that:

- seeks to minimise the numbers of people developing dementia through risk reduction measures; if the onset of dementia could be delayed by five years, the number affected would be approximately halved

- invests in anticipatory care and support for self management for people with dementia and carers to alleviate the impact of the illness
- provides sufficient good quality and cost-effective services
- increases resources in line with demographic growth and the increase in the number of people with dementia
- supports research into the causes, treatment and care of people with dementia.

In the face of this demographic change and in a context where services for people with dementia and carers are already inadequate, standing still is not an option.

1.2 Outline of report

This report draws on information from the Alzheimer Society's 2007 *Dementia UK* report[2], statistics provided by the Scottish Executive, *HDL (2004) 44 - The planning, organisation and delivery of joined up services for those with dementia and their carers*[3], and an earlier Alzheimer Scotland report, *Planning Signposts for Dementia Care Services*[4]. Detailed tables for local authorities and NHS boards are provided in the appendices.

Chapters 2 and 3 provide figures for the prevalence and demography of dementia based on the best current evidence. Chapter 2 looks critically at existing sets of prevalence rates. The prevalence rates from the *Dementia UK* report provide conservative estimates; rates from the Eurodem[5] study, which looked at twelve European prevalence studies, are also used to provide a range of the estimated numbers of people with dementia in Scotland now and over the next quarter of a century. Chapter 3 sets out the numbers of people with each type of dementia, the numbers at each level of need, the residential status of people with dementia, the number of people with dementia from black and minority ethnic groups and the number of people with dementia who die each year.

Chapter 4 looks at the provision and quality of dementia services, describing services for people with dementia along a journey of care, beginning with diagnosis of dementia. It sets out detailed dementia-specific data on the provision of day care, home care and care homes and compares provision of older people's services between UK countries. It also looks at issues of service quality.

Chapter 5 gives information on the costs of dementia in Scotland at present and in the future.

Finally, the report concludes with recommendations for action.

2 Prevalence of dementia

Summary

- There are three main studies which bring together and analyse the results of multiple studies into dementia prevalence.
- The studies differ slightly in their estimates of prevalence for each age group but all agree that dementia increase sharply with age.
- Eurodem is a systematic meta analysis of 12 European studies, and is in current use in Scotland. It provides the upper end of the range.
- The *Dementia UK* report used experts to come to a consensus agreement about estimated rates, and provides slightly lower prevalence rates.
- There are arguments for both sets of estimates and their validity for Scotland. This report uses both Eurodem and *Dementia UK* rates to provide a range of estimates based on the best evidence currently available.

Accurate estimates of the number of people with dementia in Scotland are needed to assess current and future service provision, to estimate costs and to assist local authorities and NHS boards to plan for the future.

There have been a number of studies of dementia prevalence. This report examines the relative merits of three over-arching studies, each of which brings together and analyses data from a number of single studies: the Eurodem study[6], Ferri et al[7] and the new rates from the *Dementia UK* report.

All the studies agree that the prevalence of dementia increases sharply with age, but they differ on exact prevalence rates for each age group. We have used the Eurodem estimates which are based on a larger and wider data set and are in current use in Scotland, and the more conservative estimates from the *Dementia UK* report, to provide a range for the numbers of people with dementia.

2.1 Eurodem and Harvey

To date, Alzheimer Scotland has used the Eurodem prevalence rates for people with dementia over 65. This study was a meta-analysis, and gathered together a large amount of data from 12 European population-based studies between 1980 and 1990 in Germany, Finland, Italy, the Netherlands, Norway, Spain, Sweden and the UK to yield overall age and gender-specific prevalence rates.

Some potential problems with the Eurodem prevalence rates are as follows.

- It does not include studies performed in the last 17 years.
- It includes studies from Europe, not just the UK - there may be subtle differences in the prevalence of dementia between Europe and the UK.
- None of the studies used neuroimaging for diagnosis.
- The data for people with dementia under 65 has limitations, which led Alzheimer Scotland to use a different estimate for this age group.

Despite these limitations, Melzer *et al*[8] stated that Eurodem has *"the most satisfactory compilation of prevalence data for dementia"*, and that, *"these studies all had sample sizes sufficiently large to enable stable age- and sex-specific estimates of prevalence to be calculated (at least 300 subjects aged 65 years and over). They all employed an individual examination of subjects and included both institutionalised and non-institutionalised cases."*

For people with dementia under 65, Alzheimer Scotland used prevalence rates from Harvey (1998)[9]. This was a study carried out in London over two and a half years, which identified 185 cases of young onset dementia. Harvey was used instead of Eurodem for the under 65 age group for five reasons.

- It was more recent than Eurodem (1998 as opposed to 1991).
- The lower limit in many of the Eurodem studies was 65 or older.
- It included prevalence rates for frontotemporal dementia.
- The Eurodem study was carried out prior to criteria for vascular dementia.
- None of the Eurodem studies used neuroimaging for diagnosis.

Table 1 shows the prevalence rates Alzheimer Scotland has used to date.

Age	Female %	Male %
30-64	0.0672	0.0672
65-69	1.1	2.2
70-74	3.9	4.6
75-79	6.7	5.0
80-84	13.5	12.1
85-89	22.8	18.5
90-94	32.2	32.1
95-99	36	31.6

Table 1: Prevalence rates (%) used by Alzheimer Scotland to calculate the number of people with dementia in Scotland. The 30-64 rate is from Harvey, and the 65-99 rates are from Eurodem.

The prevalence of dementia increases with age and is greater in men from 65 to 74; however, dementia is then more common in women at every subsequent age group.

2.2 Global prevalence of dementia

A Delphi consensus study was performed by Ferri et al (2005)[10] on behalf of Alzheimer's Disease International. The Delphi consensus is a method used to derive quantitative estimates through the qualitative assessment of evidence. Experts in the field were

provided with a systematic review of published population studies on dementia. The experts were then asked to provide prevalence estimates of dementia for the fourteen World Health Organisation world regions, for men and women combined in five year age bands from 60 to 84 years and for those age 85+. Each expert's estimates were fed back to the others anonymously. Each expert then reviewed his or her initial response in the light of group choices and the revised rates were averaged to yield a consensus rate. The consensus prevalence rates for the EURO A region (which includes the UK) are shown in table 2.

Age group	Prevalence rate %
60-64	0.9
65-69	1.5
70-74	3.6
75-79	6
80-84	12.2
85+	24.8

Table 2: Prevalence rates of dementia (%) in EURO A region from Ferri et al (2005)

These prevalence rates also show that dementia increases with age, doubling with almost every five year age band. Alzheimer Scotland has not adopted these prevalence rates for the following reasons.

- The rates are combined for men and women.
- The data is not specific to the UK or Scotland. The UK may have a slightly different prevalence of dementia to other countries in the region EURO A.
- No prevalence rates are given for people under the age of 60.
- There is one prevalence rate for people age 85+. As shown by other studies, the prevalence of dementia in the age groups above 85 continues to increase, and as more people are living longer into old age, it is more accurate to have separate 5 year age bands up to the age of at least 95+.

2.3 Dementia UK estimates

The *Dementia UK* report provides prevalence rates for dementia by age (in five year age bands from age 30 to 95+) and gender. The researchers came to these figures using the Delphi Consensus method, as in the Ferri *et al* study (section 2.2). Ten experts in the field reviewed all relevant UK epidemiological studies in dementia and came to a conclusion about prevalence rates individually. The group then reviewed their estimates in the light of the estimates of other members of the group and revised rates were averaged to yield a consensus rate.

2.3.1 Prevalence of dementia in people under 65

No population-based studies were found in the UK of people with dementia under the age of 65. This is because dementia in people under 65 is rare and in order to perform a population-based study, a large sample size is required. As an alternative, researchers mainly use the number of cases known to local service providers divided by the total local population. This clearly is not ideal, as not every person with dementia under 65 will be in contact with service providers. Two such studies were included in this Delphi consensus exercise. The estimates for the 30-64 age groups (table 3) are therefore likely to be under-estimates.

Age	Female %	Male %
30-34	0.0095	0.0089
35-39	0.0093	0.0063
40-44	0.0196	0.0081
45-49	0.0273	0.0318
50-54	0.0551	0.0627
55-59	0.0971	0.1795
60-64	0.118	0.1989

Table 3: People with dementia under 65 (%) from the Dementia UK report

The consensus estimates show an approximately exponential increase in prevalence, doubling between most age bands. There is higher prevalence for men than women from 50-65.

Other evidence also points to significant underestimation in these figures. McGonigal *et al*[11] estimated Scottish incidence of Alzheimer's disease in people under 65. Multiplying the incidence by the survival rates from a Scottish study of survival in young-onset dementia[12] gives prevalence rates of 0.212% for men and 0.134% for women aged 60-64. This is marginally higher than *Dementia UK's* estimate for *all* types of dementia. McGonigal *et al* used a narrow definition of Alzheimer's disease, and also did not include people with Down's syndrome.

2.3.2 Prevalence of dementia in people over 65

The *Dementia UK* prevalence rates for people over 65 (table 4) also show dementia increasing exponentially, doubling with almost every age band in both men and women. As with Eurodem, dementia is more common in men than women under 75 and is more common in women at every subsequent age band.

Age	Female %	Male %
65-69	1.0	1.5
70-74	2.4	3.1
75-79	6.5	5.1
80-84	13.3	10.2
85-89	22.2	16.7
90-94	29.6	27.5
95+	34.4	30.0

Table 4: Consensus prevalence rates (%) of dementia in people age 65+ from the Dementia UK report

Despite the similar exponential increases in the estimated rates for those under 65 and those over 65, there is a very noticeable discontinuity between the 60-64 prevalence rates (0.118% for women, 0.1989% for men) and those for 65-69 (1% and 1.5% respectively). The rates for 65-69 are approximately eight times the 60-64 rates. This led the *Dementia UK* researchers to estimate that the extent of the underestimation of the under 65 age groups (section 2.3.1) may be as much as threefold.

2.3.3 Prevalence of dementia in care homes

The *Dementia UK* report produced separate dementia prevalence rates for people over 65 in Elderly Mentally Infirm (EMI) homes (79.9%), nursing homes (66.2%) and care homes (50.1%) (table 5). These categories do not apply in Scotland, where there are no EMI homes and former nursing homes and residential homes are now all classed as care homes. These rates were based on three studies, one of which did not involve a direct evaluation of the residents, thus the evidence base was limited. Overall, prevalence in care homes increases slightly at most age groups in both men and women.

Age	Female %	Male %
65-69	59.9	56.1
70-74	59.9	55.4
75-79	62.9	55.7
80-84	66.1	56.9
85-89	65.9	62.7
90-94	66.9	64.3
95+	67.6	62.9

Table 5: Prevalence of dementia in people over 65 among long-stay care residents (%)

2.4 Comparison between prevalence studies

Figures 1 and 2 compare the prevalence rates from the four studies discussed in sections 2.1-2.3.

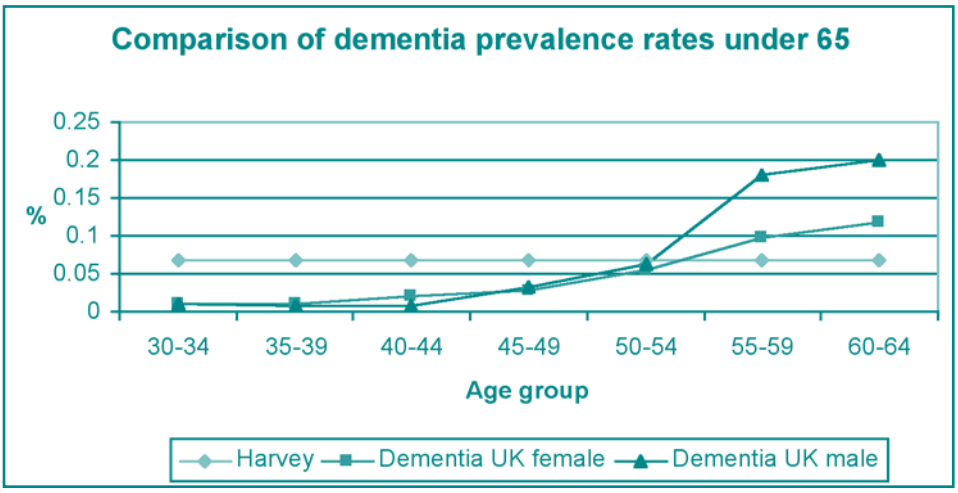

Figure 1: Comparison of dementia prevalence rates for people under 65

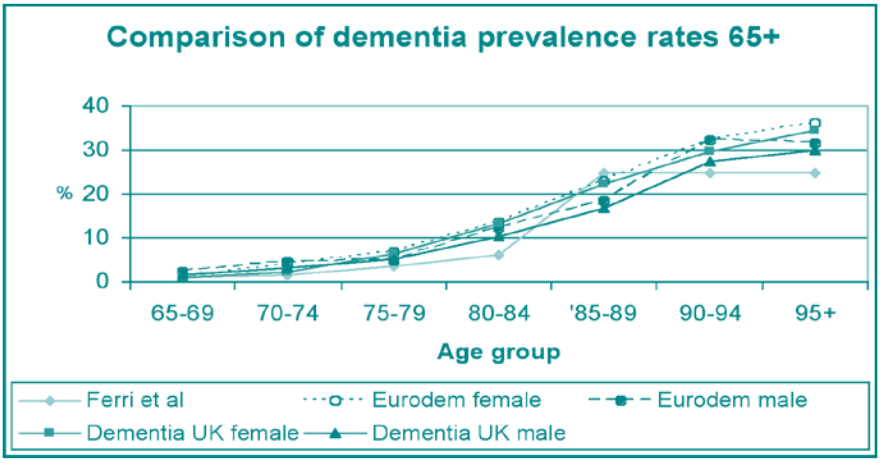

Figure 2: Comparison of dementia prevalence rates for people over 65

The estimates from the *Dementia UK* report are the most detailed for people under 65: the Ferri *et a*l rates do not give rates for people under 65 and the Harvey study has one rate for all age groups under 65. However, the *Dementia UK* rates are acknowledged to be an underestimate (section 2.3.1) and the higher number of people with dementia yielded by Harvey's single rate may be more accurate.

For the over 65 age groups, Eurodem and *Dementia UK* give the most detailed estimates. The Eurodem rates are higher than the *Dementia UK* rates for almost all age groups.

The most recent estimates of the prevalence of dementia for the UK are those generated by the *Dementia UK* report. However, they are a conservative estimate and may not accurately reflect the situation in Scotland because:

- they are an underestimate of prevalence of dementia under 65, for the reasons discussed in section 2.3.1
- they are based on a smaller and narrower data set than Eurodem
- all the studies used in the *Dementia UK* consensus are English and may not apply in Scotland; in particular Scotland's cardiovascular health is poorer, which could be expected to influence dementia prevalence.

For these reasons, throughout this report we give a range of the numbers of people with dementia in Scotland. The lower estimate is generated by the *Dementia UK* rates and the upper is generated by the Eurodem/Harvey rates.

2.5 Future work

The prevalence of dementia remains an area requiring further study, in particular for young-onset dementia, although accurate estimates for this group are difficult to obtain because it is a rare condition under 65.

Alzheimer Europe is currently undertaking a project called the European Collaboration on Dementia (EuroCoDe)[13]. This project will, among other work strands, compile a database of epidemiological studies in dementia. The studies will be analysed for their merits and shortcomings, and based on this analysis consensual prevalence rates will be established with a focus on a breakdown between the various forms of dementia and the different stages of the disease. The project is due to end in December 2008.

3 Demography

Summary

- There are approximately 58,000 to 65,000 people with dementia in Scotland in 2007, between 1,350 and 1,650 of whom are under 65.
- Dementia affects more women than men: between 19,500 and 23,000 men and between 38,500 and 42,000 women have dementia in Scotland. Alzheimer's disease is more common in women and vascular dementia more common in men.
- There is projected to be a 75% increase in the number of people with dementia in Scotland by 2031, to between approximately 102,000 and 114,000.
- This increase could be largely avoided if the onset of dementia could be delayed by five years.
- Alzheimer's disease is the most common form of dementia: between 10,000 to 12,000 men and 26,000-28,000 women have Alzheimer's disease.
- Around 60% of people with dementia live in the community (approximately 35,000-39,000) and 40% live in care homes or hospitals (approximately 23,000-26,000).
- There are an estimated 228 people with dementia from black and minority ethnic (BME) communities in Scotland.
- An estimated 4,722 deaths of people over 65 were theoretically attributable to dementia in 2005.

In 2007, there are approximately 58,000 to 65,000 people with dementia in Scotland, between 1,350 and 1,650 of whom are under 65. In 2031 there are projected to be between 102,000 and 114,000 people with dementia in Scotland.

These stark demographic figures underline the urgency of planning now for the coming generation of people with dementia, and of seeking ways to mitigate the impending epidemic and its impact on those with dementia, on their carers and on the provision of care services.

This chapter uses the prevalence range from chapter 2 to set out clearly the number of people with dementia; the number of people with each type of dementia; the numbers requiring different levels of services; their residential status and the number of people from BME communities. There are detailed breakdowns for local authority and heath board areas in the appendices.

This chapter also looks at the significant beneficial impact of delaying the onset of dementia by just five years. If an intervention could be found which would achieve this, the future increase in numbers could be largely alleviated.

3.1 Number of people with dementia in Scotland

The total number of people with dementia in Scotland in 2007 is between 57,946 and 65,031[a] (see appendix 1 for breakdowns by local authority and NHS board). Between 1,355 and 1,639 are under 65.

Due to Scotland's ageing population, the number of people with dementia will rise by around 75% in the next 24 years (table 6).

Year	Number of people with dementia in Scotland *(Dementia UK)*	Number of people with dementia in Scotland (Eurodem)	~ 5 year % increase	~ Cumulative increase over 2007
2007	57,946	65,031	-	
2012	63,718	71,460	10%	10%
2017	71,509	80,307	12%	23%
2022	81,196	90,856	13%	40%
2027	92,520	103,245	14%	60%
2031	101,650	113,501	10%	75%

Table 6: Projected increases of the numbers of people with in Scotland between 2007 and 2031

3.1.1 Types of dementia

The most common type of dementia is Alzheimer's disease (62%), followed by vascular dementia (17%) and mixed dementias (11%). Rarer forms include Lewy body dementia (4%), frontotemporal dementia (2%) and Parkinson's disease dementia (2%). Alzheimer's disease is more common in women and in men vascular dementia, Lewy body dementia, frontotemporal dementia and Parkinson's disease dementia are more common.

Table 7 shows the proportion of people with each type of dementia. These are from the *Dementia UK* report and can be considered as best current estimates. Table 8 shows the number of people with dementia in Scotland with each type of dementia.

[a] Calculated using 2007 population projections (2004 based) from the General Registrar's Office for Scotland for ages up to 89 and from the Government Actuary Department for 90-94, 95-99, 100+, as GROS projections use a single 90+ age category. These two sources are based on the same figures but GROS also gives breakdowns by local authority and NHS board.

Type of dementia	Proportion of females with dementia with each subtype	Proportion of males with dementia with each subtype	Proportion of all people with dementia with each subtype
Alzheimer's disease	67.1%	51.8%	62.2%
Vascular dementia	14%	22.3%	16.7%
Mixed dementia	10.3%	11.1%	10.6%
Lewy body dementia	3.3%	5.2%	3.9%
Frontotemporal dementia	1.6%	3.2%	2.1%
Parkinson's disease dementia	1.4%	2.6%	1.8%
Others	2.1%	3.8%	2.6%
Total	100%	100%	100%

Table 7: Proportion of people with dementia with each subtype

Subtype	Number of females: *Dementia UK*	Number of males: *Dementia UK*	Total people: *Dementia UK*	Number of females: Eurodem	Number of males: Eurodem	Total people: Eurodem
Alzheimer's disease	25,897	10032	**35,929**	28,153	11961	**40,114**
Vascular dementia	5,417	4320	**9,737**	5,889	5151	**11,040**
Mixed dementia	3,989	2150	**6,139**	4,336	2563	**6,899**
Lewy body dementia	1,288	1001	**2,289**	1,400	1194	**2,594**
Frontotemporal dementia	635	617	**1,252**	690	735	**1,425**
Parkinson's disease dementia	559	513	**1,072**	608	611	**1,219**
Other	800	729	**1,529**	870	870	**1,740**
Total	**38,585**	**19361**	**57,946**	**41,946**	**23085**	**65,031**

Table 8: Number of people with dementia in Scotland in 2007 with each subtype

3.1.2 Intervals of need for care

The frequency with which care or supervision may be required by older people was measured by Isaacs and Neville[14] and this was adapted by Melzer *et al*[15] to subdivide the group of people with dementia on the basis of the frequency with which care or supervision is needed. Applied to the statistics it is a useful indicator of the service levels which are likely to be required (table 9). Appendix 2 gives breakdowns by local authority and NHS board of the number of people with dementia in each category.

Interval of need for care	% of people with dementia (Melzer)	Number of people with dementia *(Dementia UK)*	Number of people with dementia (Eurodem)
Independent (not needing care)	6%	3,477	3,902
Long interval (care needed at some time during the week)	11%	6,374	7,153
Short interval (care needed at some time daily)	48%	27,814	31,215
Critical interval (constant care or supervision needed)	34%	19,702	22,111
Total[b]		57,367	64,381

Table 9: Interval of need for care for people with dementia and the number of people in each category

3.1.3 Residential status

The Dementia UK report estimates that 63.5% of people with dementia live in the community and 36.5% live in care homes. The proportion of people with dementia living in care homes is estimated to increase with age:

- 26.6% of people 65-74
- 27.8% of people 75-84
- 40.9% of people 85-89
- 60.8% of people 90+.

The proportions used in *Planning Signposts*[16] were similar, with 60% of people with dementia living in the community and 40% in care homes and hospitals. The *Planning*

[b] The totals do not add up to 57,946 and 65,031 as the intervals of need add up to 99%

Signposts proportions will be used in this report to calculate the number of people with dementia in the community receiving day and home care and to calculate the costs, because Scotland has proportionately more people in care homes and hospitals than England.

Between 34,767 and 39,017 people with dementia live in the community and between 23,178 and 26,012 people with dementia live in care homes (table 10).

Residential status	*Dementia UK* figures	Eurodem figures
Community	34,768	39,019
Care home	23,178	26,012
Total	57,946	65,031

Table 10: Number of people with dementia in 2007 in Scotland living in the community and in care homes

3.1.4 People with dementia in black and minority ethnic communities

The *Dementia UK* report included specific estimates of the prevalence of dementia in ethnic minority groups in the UK on the assumption that prevalence would be similar to the UK population as a whole. It estimated that in 2004 there were 11,392 people from BME communities with dementia. This represents 1.7% of all people with dementia in the UK. It also estimated that, due to differences in the age structure of BME communities, which have more younger people, 6.1% people with dementia from BME communities were under 65. This compares to a proportion of 2.2% of people with dementia as a whole under 65.

In 2001, there were 101,677 people in Scotland from BME communities[17]. This is equivalent to 2% of the population of Scotland at that time. *Dementia UK* gives figures for Scotland of 15 people with dementia under 65 and 213 people over 65 from black and minority ethnic communities in 2004, making a total of 228 people. These figures are equivalent to around 0.4% of people with dementia in Scotland.

There are no data on the projected numbers of people from BME communities by age and gender in the future. However, the *Dementia UK* report predicts that the increases will be relatively larger than for the UK population as a whole. This is due to the large numbers of middle aged people in the Black Caribbean, Indian, Black African and Chinese communities, who will become older.

3.1.5 Death rates and life expectancy

Dementia is a terminal condition; however, life expectancy varies between individuals. There is no direct means of counting deaths from dementia, since death certificates often

[c] This is a probabilistic approach based on empirical findings from epidemiological studies of the increased risk of mortality associated with dementia.

do not include dementia. In order to calculate the number of people who die from dementia each year, the *Dementia UK* report used a population attributable risk fraction[c] to determine the deaths that could be avoided if dementia was removed from the population. From this the number of deaths theoretically attributable to dementia can be calculated. The total figure for England, Scotland and Wales in 2005 was 59,685 deaths in people over 65.

The *Dementia UK* researchers[18] estimate that 4,722 deaths in people over 65 in Scotland were theoretically attributable to dementia in 2005.

A recent study estimated the median survival of people with Alzheimer's disease as 7.1 years, and 3.9 years for vascular dementia[19]. Other estimates of life expectancy for people with dementia in use include HDL (2004) 44[20], which predicts an average life expectancy of 5-6 years; Scottish Intercollegiate Guidelines Network (SIGN), which estimated a life expectancy of between 8-10 years[21]; and the National Institute for Health and Clinical Excellence (NICE), which states that the time from diagnosis to death can be between 5 and 20 years with a median time of 5 years for people aged 75-80[22].

Clearly it is not yet possible to estimate the duration of the illness with accuracy. Some of the variation in estimates will be caused by different methods of calculation and some by differences in practice, such as how early the illness is diagnosed.

3.2 The impact of delaying dementia

Although a cure for dementia in the near future seems not to be on the horizon, there are a number of ways in which the future number of people with dementia could feasibly be reduced. Because the prevalence of dementia doubles every five years, and because it is an illness predominately of old age, if the onset could be delayed by five years the number of people with dementia could be approximately halved. Alternatively, if the symptoms could be delayed, the impact of dementia on the individual and the family and the need for services could be dramatically alleviated.

Possible ways in which onset of the illness, or its symptoms, could be delayed or the prevalence reduced include:

- public health improvements through risk reduction campaigns and other interventions which reduce population risk of dementia; there is growing evidence that healthy eating, physical activity, mental exercise and social stimulation in middle age all contribute to reducing the risk of developing dementia in later life; Alzheimer Scotland has produced a publication setting out the evidence on risk reduction and dementia[23]
- better preventive treatments
- better treatments which are effective early in the disease.

The effect of delaying dementia by five years can be illustrated by calculating the number of people with dementia for each age group using the existing prevalence rates and by applying the prevalence rates to the next 5-year age band (figure 3). In this scenario the number of people over 65 with dementia in 2031 would be reduced from 100,337 to 56,372, which is very close to the 2007 figure of 56,592 people with dementia over 65 (using *Dementia UK* figures).

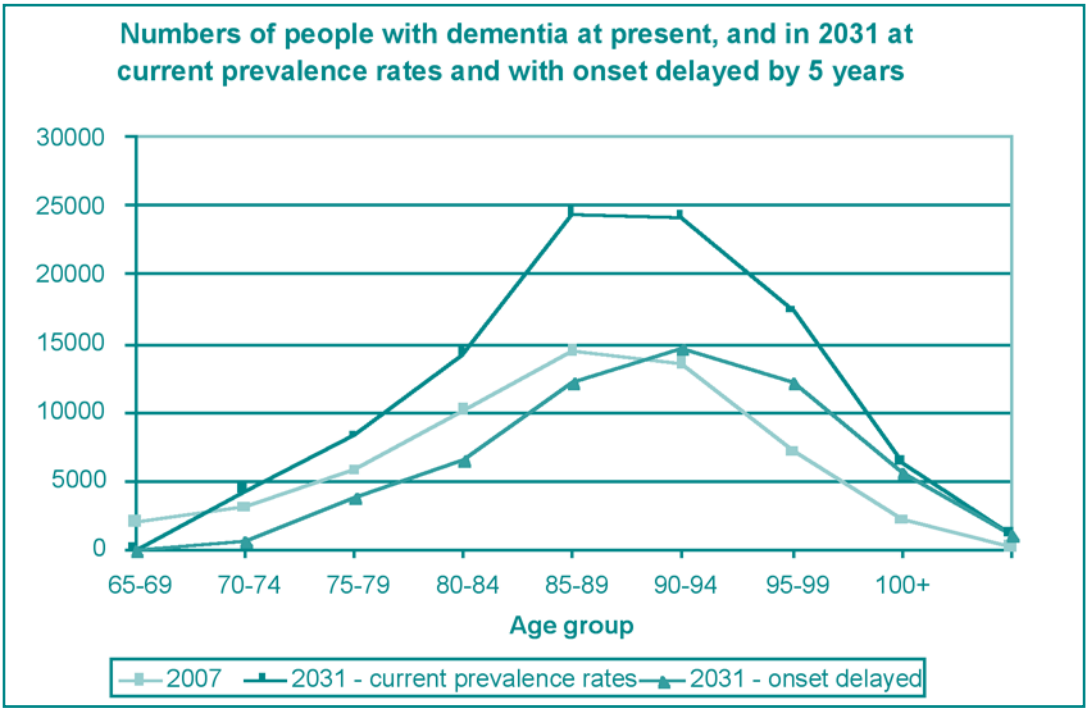

Figure 3: Number of people with dementia in 2007, 2031 at current prevalence rates and 2031 if the onset of dementia was delayed by 5 years (using *Dementia UK* rates).

In addition to the potential for reducing the number of people needing support services, Dementia UK calculates that, in principle, if the onset of dementia were delayed by 5 years the number of deaths theoretically attributable to dementia would be halved. This would save about 2,360 lives each year in Scotland.

4 Services for people with dementia in Scotland

Summary

- There is an overall picture of insufficient services, and great variability in provision between different areas.
- A survey of carers of people with dementia in Scotland found that only 37% felt that the services available were sufficient for their needs.
- Respite provision is a key issue for carers and people with dementia: only 27% of carers of people with dementia get a week's short break in a year.
- Around 6,500 people are currently diagnosed with dementia each year and need access to appropriate post-diagnostic services including training in self-management.
- On average, 11% of people with dementia living in the community receive home care and 12% receive day care, against a working target of 28%. Provision varies widely between local authorities.
- The quality of hospital care, both in specialist dementia wards and in acute wards, and the issue of delayed discharge are key concerns.
- Many people in care homes believed to have dementia have not had a diagnosis and are thus denied the opportunity to plan for the future and to receive appropriate treatments.
- There is serious concern about the quality of care for people with dementia living in care homes.

This chapter gives information and, where available, statistics on the services that people with dementia in Scotland will typically use along a journey of care, beginning with a diagnosis of the illness.

It paints a picture of a journey of care which is very different in different areas of Scotland. At present, the care a person receives depends on where he or she lives. In many areas there is lack of provision, for example of post-diagnostic services and of respite. Carers report a lack of services for them and for the people with dementia they care for. The quality of services is a continuing concern.

The 2007 Dementia Manifesto[24] called for better strategic planning for dementia and better funding for dementia care. It highlighted the inconsistent use of HDL (2004) 44[25], a report produced by a joint working group between Alzheimer Scotland and the Scottish Executive, which provided a template of the types and levels of dementia care services which local authorities and NHS boards should be providing.

> *We need a strategy to make sure that there is an equal level of service provision across the country. In 2004 the Scottish Executive published a template for dementia care - but 15% of local authorities aren't using it. And some local authorities are tightening eligibility criteria, limiting the services people receive.*
>
> *Dementia Manifesto*

Comprehensive statistics are available for the provision of home care and day care for people with dementia in Scotland, and we have used these to calculate the percentage of people with dementia living at home receiving these services. We have used the more conservative estimate of numbers of people with dementia from the Dementia UK report. This means that the percentages of people with dementia receiving services are generous estimates. We also separately analysed data for rural, urban and island local authorities[d] in order to examine differences[e] (see appendix 4).

We have compared these generous estimates with the targets set out in HDL (2004) 4426. The comparison reveals an overall picture of insufficient services, and great variability in provision between different areas.

4.1 Informal carers

A vast amount of care for people with dementia is provided by informal carers, such as a relative or friend. The census in 2001[27] found that there were 481,579 carers in Scotland. Of these people, 305,610 provided 1-19 hours per week of unpaid care, 60,294 provided 20-49 hours per week and 115,6745 provided 50 or more hours each week. The exact number of people caring for someone with dementia is not known.

Caring for people with dementia is different to caring for people with a solely physical illness due to the complex, unpredictable and progressive nature of the illness and its effect on the person's memory, understanding, judgement and personality. Complex care needs include intimate personal care as the ability for self care declines, increasing levels of supervision, emotional support, decision making, help relating to behaviour changes, coping with risks to safety, personality changes and changes within the relationship. These complexities contribute to the fact that carers of people with dementia suffer from high levels of stress and associated symptoms.

The Carer's Scotland manifesto[28] estimates that carers contribute £5.3 billion of care. However, only 1 in 1,000 carers have had their needs assessed and tens of thousands care without adequate breaks and support: 39% have not had a break from caring of more than 2 days. There is a long way to go to address the needs of Scotland's carers. In 2005 the Scottish Executive published a report on the future of unpaid care in Scotland[29]. The following were cited by unpaid carers as being the elements that would help to improve their quality of life.

- Giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options
- Increasing welfare benefits to people with support needs.
- Offering cash payments rather than services so that unpaid carers can arrange care according to needs and preferences.
- A greater emphasis on information and training, advocacy and guidance, including emotional support.

d Based on the commonly-used determinant of a local authority being defined as rural if it has a population density of less than one person per hectare.

e Both rural and island authorities face special challenges due to their geography and small and dispersed populations. Small numbers of people in island authorities in particular mean service unit costs are likely to be higher.

The Scottish Executive responded to this report by identifying four areas for early action: carers' health, young carers, carer training and respite.

In 2004[30], Alzheimer Scotland revealed that only 27% of carers of people with dementia get a week's short break in a year. The quantity, quality and flexibility of respite offered to carers and people with dementia can depend on where they live and on the age of the person with dementia. People reaching 65 may find that imaginative options, such as respite in a holiday setting, suddenly disappear and a care home becomes their only option. Some younger people with dementia may have to go into hospital because there are no suitable facilities. Respite allows carers to care for people with dementia at home for longer and is one of the main areas that people with dementia and carers flag up as an issue; it is imperative that action is taken to address this.

4.1.1 Carers' experience

A survey of 334 carers of people with dementia revealed major gaps in the provision of services for people with dementia and their carers in Scotland[31]. Two thirds (66%) of those caring for someone in the early stages and 81% caring for someone in the late stages spent more than ten hours every day caring. Yet only 37% felt that the services available were sufficient for their needs. 30% said day care was unavailable for the person with dementia they cared for and 50% could not access home support.

Almost all (99%) of the carers surveyed said they had to cope with stressful symptoms of dementia, such as no longer being able to leave the person with dementia alone, difficulties in showering and bathing and incontinence. In addition, 91% had to cope with severe behavioural symptoms such as aggression, personality changes and wandering.

Information received at the point of diagnosis was inadequate, with only half (54%) receiving information about dementia, and 75% given no information the likely progression of the illness. Only 37% were told about available services and 65% were given no information on the anti-dementia drugs. Only 28% had access to training on how to cope with their caring role.

4.2 Diagnosis and post diagnosis services

A diagnosis of dementia in Scotland is generally given by an old age psychiatrist and in some cases a neurologist (particularly if the person if under 65) or a geriatrician. In some cases a GP may diagnose dementia. In 2006 there were 150 old age psychiatrists in Scotland[32]. Around 6,500 people are currently diagnosed with dementia each year[f].

Following a diagnosis of dementia, the person with dementia and his or her carer or relatives should have access to:

- information about dementia and the likely course of the illness, welfare benefits, employment issues (where relevant), services available and how to plan for the future including financial and welfare power of attorney and advance statements

[f] This is a rough approximation based on the life expectancy of 6-8 years used in the SIGN report, which is around the middle of the wide range of life expectancy estimates - section 3.1.5.

- support or counselling to deal with the impact of the diagnosis, and peer support groups
- training and support for self-management of the illness and its symptoms and rehabilitative services
- appropriate treatments and therapies, including the cholinesterase inhibitor drugs currently unavailable to people with mild Alzheimer's disease under guidance from NICE and NHS Quality Improvement Scotland
- advocacy services.

Provision of these services is patchy, as is evidenced by the lack of information and support reported by carers (section 4.1). At present there are no self-management courses for people with dementia and only limited provision of support groups and one-to-one emotional support. The majority of carers have no access to carer education courses. NHS Quality Improvement Scotland disallows drug treatment for people with early Alzheimer's disease. Many mental health advocacy services do not support people with dementia.

People with dementia who need practical support to remain in their home should receive a community care assessment to allow them to receive appropriate services. In light of the recent decision by NHS QIS to allow the cholinesterase inhibitors only for people with moderate Alzheimer's disease, close contact should be kept between the person and his or her GP, so that the GP can assess when a moderate stage has been reached and refer him or her to a consultant who can prescribe the drugs where appropriate.

A diagnosis of dementia also has great implications for the person's family, who may become 'informal' carers. Carers should receive education on dementia to allow them to develop the skills they need to care for the person with dementia and themselves. They should also be provided with information on legal issues, welfare benefits and how to access services. Some carers may need counselling to assist them to come to terms with the impact of the illness on the person they care for and themselves. There is a significant body of research which indicates that carers of people with dementia suffer less stress if they have timely information, counselling and training and as a result are enabled to continue caring for the person with dementia at home for longer than they otherwise would[33].

Anticipatory care includes a focus on early dementia services and advance planning for the future. It places an emphasis on ameliorating the impact of dementia for the person with dementia and their carers. This includes making decisions about future medical treatments, and putting legal arrangements into place through powers of attorney. It also includes support for self management; that is, furnishing people with dementia and their carers with the tools they need to manage dementia. Examples are information on understanding the illness, maintaining independence, stimulating activities, things that can be done to preserve mental capacity, nutrition, exercise, and good general health care, thus helping people with dementia and their carers to cope for longer in the community.

Anticipatory care also includes more access to services such as home care, day care and innovative short break services to allow respite for the carer and a positive and enhancing experience for the person with dementia.

The *National Framework for Service Change*[34] assessed the changing needs for health care in Scotland. It highlighted the combination of an ageing population and the growth in long term conditions; the trend of rising emergency admissions to hospital among older people and the growing divergence in life expectancy, despite the general improvement for Scotland as a whole. It concluded that that there needs to be a shift towards preventive medicine and more continuous care in the community, with targeting of resources and anticipatory care to reach out to those at greatest risk. *Delivering for health*[35] takes the recommendations of the *National Framework for Service Change* and describes how these recommendations will be implemented. It calls for a *"wider effort on improving health and well-being, through preventive medicine, through support for self care, and through greater targeting of resources on those at greatest risk, with a more proactive approach in the form of anticipatory care services"*.

Improved anticipatory care and self-management for dementia are an essential part of a strategy to invest in approaches which allow people with dementia and carers to cope better and for longer in the community.

4.3 Home care

On average, 11% of people with dementia living in the community receive home care (appendix 4). HDL (2004) 44 set a working target of 28% of people with dementia living in the community needing services. Current provision of home care falls far short of this level.

Alzheimer Scotland reported on short breaks in 2004, and highlighted the fact that only 10% of people with dementia received home care in 2002-3. There has been no significant increase in the last four years; using the Eurodem population figures there has been a decrease (9%).

Overall, 3,679 people with dementia received a home care service in 2006. There is wide diversity between different areas, from 3% in Perth & Kinross and the Scottish Borders[g] to 27% in Dundee (appendix 4). Analysis of rural, urban and island local authorities (figures 4 to 6) shows that these differences in provision are not accounted for by differing local conditions, although on average more people with dementia living at home in urban local authorities receive home care (12%) than in rural local authorities (7%) or in the islands (9%).

The *Dementia UK* report compares data for older people in general between Scotland and England. Slightly more people over 65 in Scotland (6.9%) receive home care than in England (6.1%).

Expenditure on home care per head of the population over 65 is very different. In England it is £214.40, whereas in Scotland it is £437.50. This difference is due to free personal care in Scotland and the fact that the £17 per hour average home care cost is 21% higher than in England. This may be because in England there is much greater use of private

[g] Statistics for East Lothian show zero people with dementia receiving home care; however, following discussion with the Scottish Executive it appears this may be due to a difference in classification, whereby East Lothian put people with dementia into a different category (eg older people) from other local authorities.

sector providers and they have lower costs. However, travel costs in Scotland's rural areas add significantly to the costs of providing services in people's own homes.

The local authorities in Scotland which spent most on home care per head of the over 65 population in 2004-5 were Glasgow (£811), North Lanarkshire (£779) and the Western Isles (£680). The lowest spending were East Renfrewshire (£107), Highland (£223) and Stirling (£252). There was an almost eight-fold difference between the highest and lowest spending local authorities.

The lowest spending local authorities per unit of home care for people over 65 were East Renfrewshire (£4.40), Midlothian (£7.70), and Clackmannanshire (£9). The highest spending were West Lothian (£27), Angus (£27) and Argyll (£32).

The average weekly home care package for older people in England in 2005 was 8.1 hours, compared with 7.4 hours in Scotland. The average number of hours provided per week in Scotland was around 10 in Midlothian, South Ayrshire and Lanarkshire to 3.6 in Angus, 4.7 in Dundee and 4.8 in Fife.

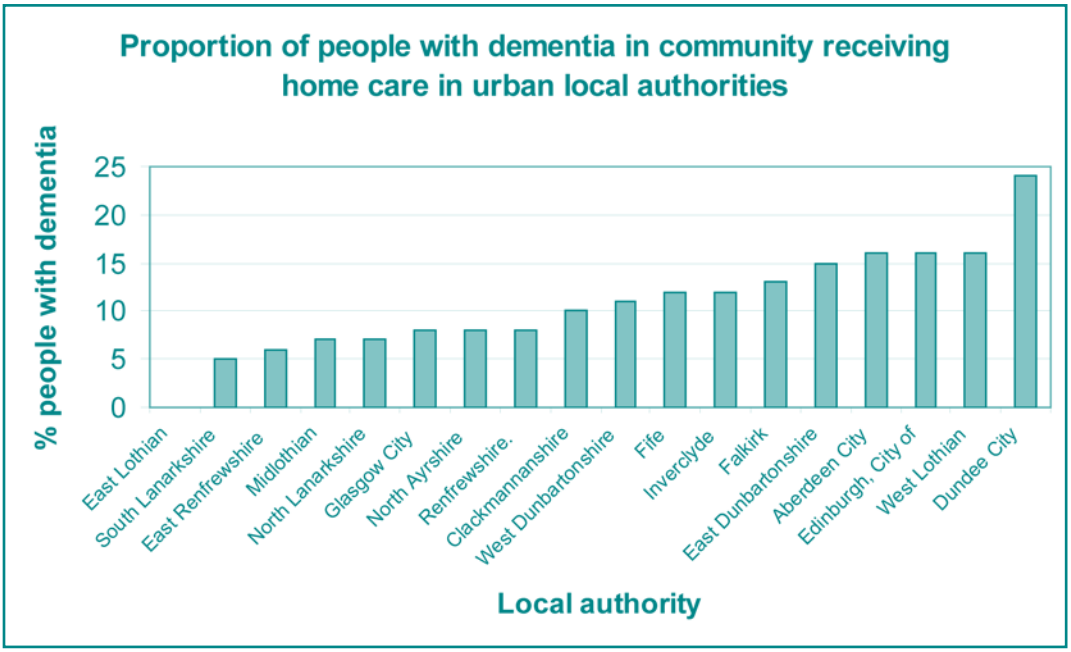

Figure 4: Proportion of people with dementia living in the community in urban local authorities receiving home care

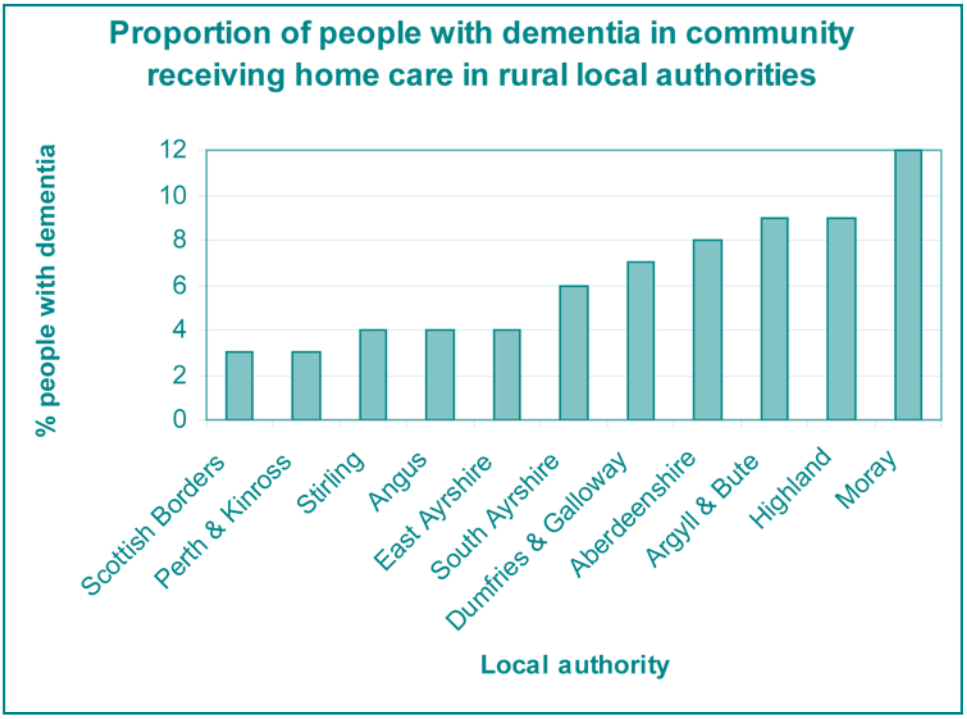

Figure 5: Proportion of people with dementia living in the community in rural local authorities receiving home care

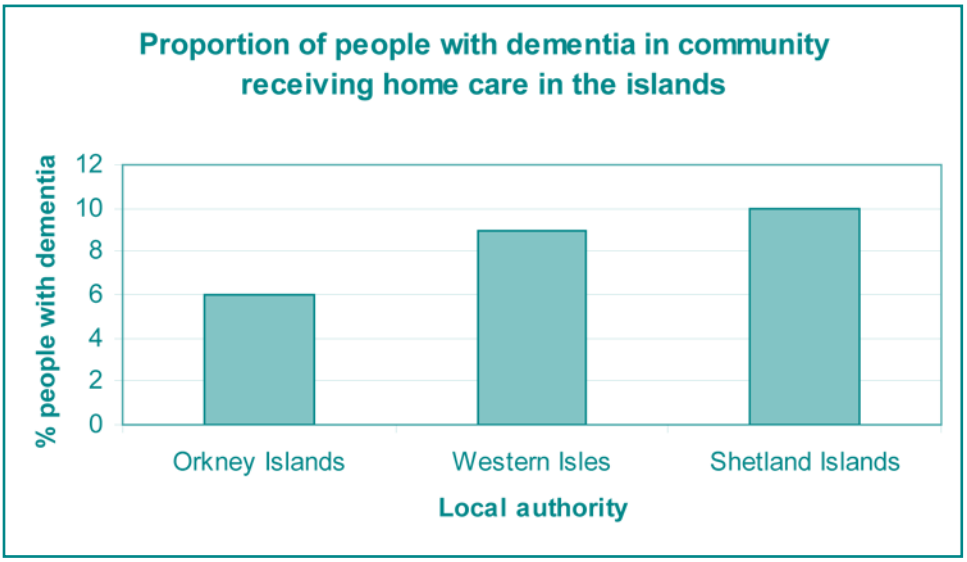

Figure 6: Proportion of people with dementia living in the community in island local authorities receiving home care

4.3.1 Quality of home care

In 2006, the rate of upheld complaints to the Care Commission about home care services was 5.5%, which is around the average for all care services. Almost 30% had a requirement[h] against them. In order to improve the quality of home care services, the Care Commission will look at services' internal quality assurance systems and the ways in

[h] Made when a service is not complying with a regulation

which they get feedback from service users. It is also looking at recruitment practice, how well services protect people at risk and how services meet their obligations as employers[36].

4.4 Day care for people with dementia

On average, only 12% of people with dementia living in the community receive day care (appendix 4). HDL (2004) 44 set a working target of 28% of people with dementia living in the community needing services. As with home care (section 4.3), current provision of day care falls far short of this level.

However, Alzheimer Scotland reported on short breaks in 2004 and highlighted the fact that in 2001-2 only 7% of people with dementia living in the community received day care, so there has been an increase since then.

Overall, 4,232 people with dementia received a day care service in 2006. There is a wide range between areas, from 35% in Glasgow to 3% in Midlothian. Analysis of rural, urban and island local authorities (figures 7 to 9) show that, as with home care, these differences in provision are not accounted for by differing local conditions. On average more people with dementia living at home in urban local authorities receive day care services (14%), than in rural local authorities (9%) or in the islands (11%).

The *Dementia UK* report compared data for older people between England and Scotland. Slightly fewer older people over 65 in Scotland received day care (1.3%) than in England (1.7%).

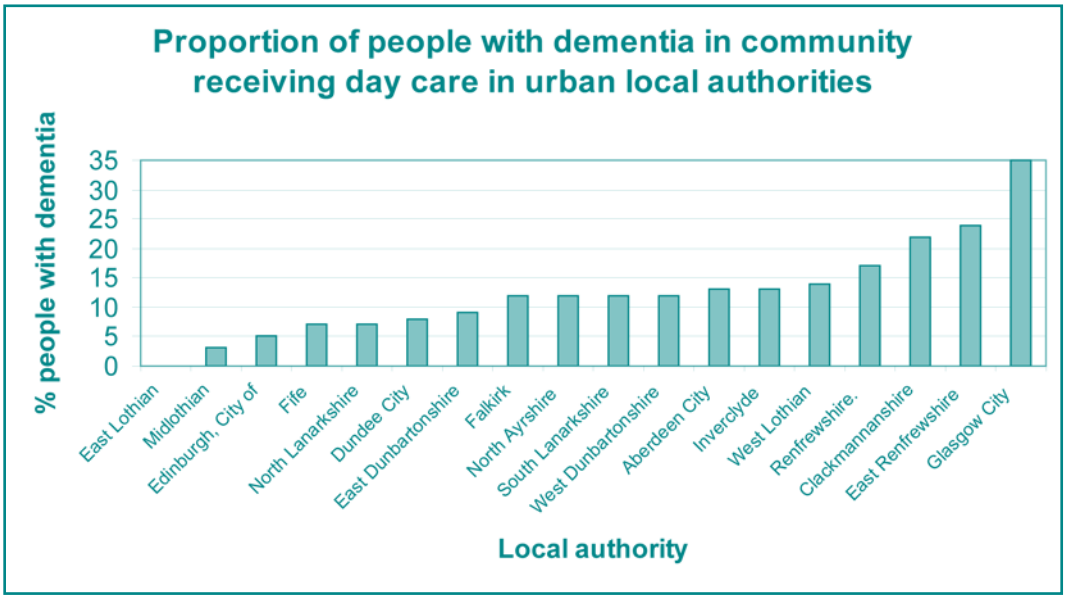

Figure 7: Proportion of people with dementia living in the community in urban local authorities receiving day care

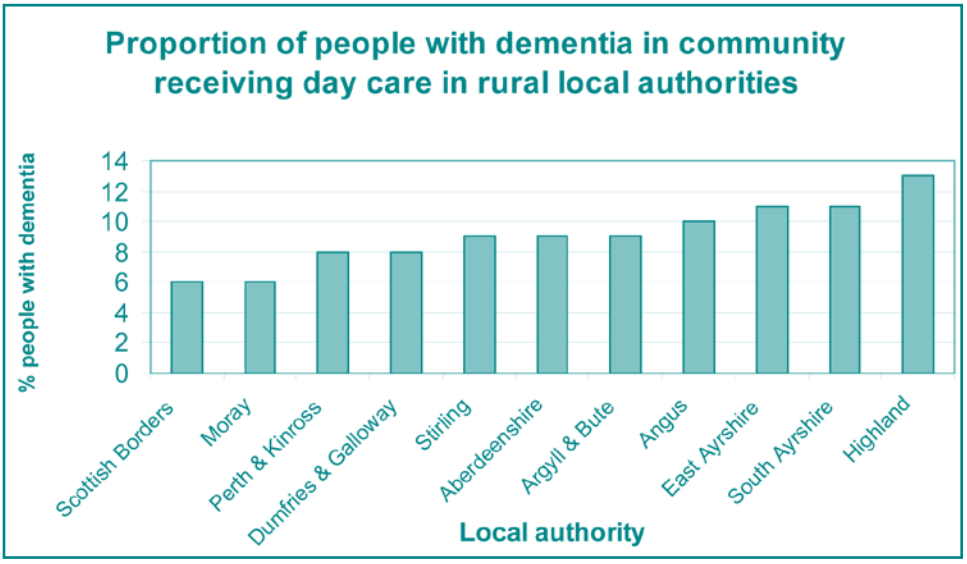

Figure 8: Proportion of people with dementia living in the community in rural local authorities receiving day care

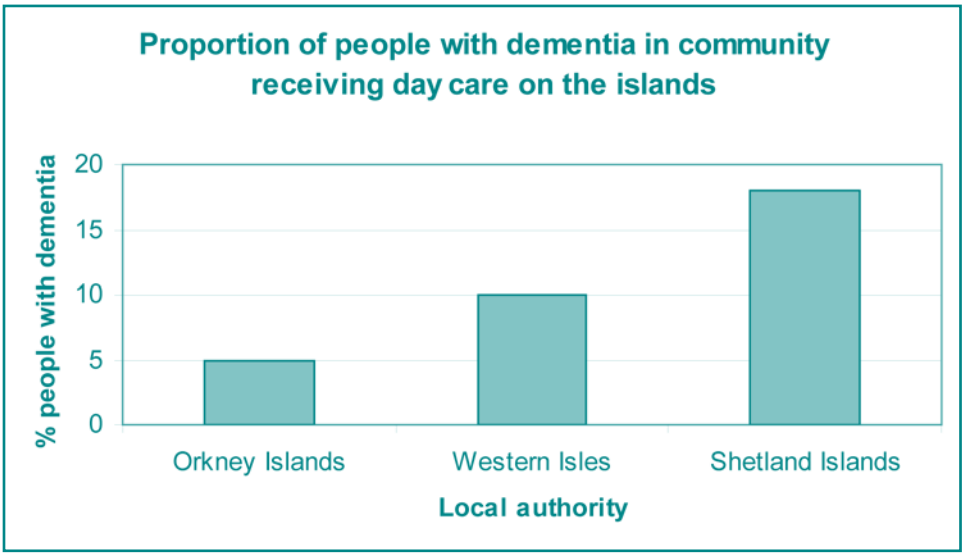

Figure 9: Proportion of people with dementia living in the community on the islands receiving day care

4.4.1 Quality of day care services

Short breaks, such as day and home care, provide many advantages for carers and people with dementia. However, those that are of a poor quality or are inappropriate for the person's needs can adversely affect him or her, which can increase the stress and burden on the carer and ultimately may lead to the person with dementia entering long-term care earlier than he or she otherwise would. The quality of the care received is of the utmost importance.

A report by Alzheimer Scotland[37] highlighted that short breaks such as day care are often seen as a benefit for carers rather than also for people with dementia. More attention could be given to maintaining the skills of the person with dementia and to giving him or her opportunities to experience enjoyable activities. This emphasises the importance of a person-centred approach. It was also reported that younger people with dementia, people from BME communities and people with challenging behaviour find it more difficult to access appropriate short break services.

In 2005/6, the percentage of day care services with complaints to the Care Commission against them was low: 1.5% of 692 services. Areas for improvement were identified as being an increased awareness of the National Care Standards[i] and person-centred planning[38].

To improve the quality of care, in 2006/7 the Care Commission examined how day care services help people to eat well. In 2007/8 it will investigate how services protect people at risk and help staff to deal with people who exhibit challenging behaviour, and will examine how services take account of the Codes of Practice from the Scottish Social Services Council.

4.5 Free personal care and direct payments

A major difference between Scotland and the rest of the UK is that personal and nursing care are provided free to people who are assessed as needing it, both in their own homes and in care homes. As substantial users of personal care, people with dementia have benefited from this policy.

Direct payments are also available in Scotland, although their use by people with dementia is not widespread. A survey of local authorities by Alzheimer Scotland in January 2006 showed that a total of 82 people with dementia in 19 local authorities were receiving direct payments. Direct payments can increase choice and the personalisation of services, but more work is necessary to increase access by people with dementia and to support them and their carers to manage direct payments.

In 2007 an evaluation of the operation and impact of free personal care (FPC) was published by the Scottish Executive[39]. It found that overall FPC has helped to support unpaid carers in their caring role and has made a positive difference to the lives of carers and the people they care for.

The report found that around 9,000 self-funders receive £145 per week to meet their care home costs without being means-tested. Around 6,000 of these also receive £65 per week towards their nursing care costs. Over 42,000 people are receiving FPC at home. The review found that the vast majority of these people receive their care without delay or complication. However, around half of all local authorities had waiting lists for assessments, mainly due to a lack of staff. In addition, two thirds of local authorities had people waiting for a care home place and FPC payments due to a lack of vacancies in

[i] The National Care Standards are centred around 5 themes: dignity, privacy, choice, safety, realising potential and equality and diversity.

care homes or people waiting for a vacancy in the home of their choice. Around a third of authorities had people waiting for all or part of their care package at home due to problems with purchasing or providing services. Four local authorities attributed the delays in service provision and payments to a lack of funding. Only five authorities had no-one waiting for services or FPC payments.

The report found that differences in the interpretation of guidance on assistance with the preparation of food and with medication had led to local authorities adopting different policies. However, a survey by Alzheimer Scotland in 2007 found that almost all local authorities are no longer charging for assistance with the preparation of food. The overwhelming majority of local authorities are not now charging for services such as heating up a frozen meal or cutting up sandwiches. Only a handful of the local authorities who responded to our survey would charge for any of the seven different scenarios we asked about, and even they would only charge in some of the situations. We have called on the Scottish Executive to make the rules absolutely clear in these remaining cases.

A matter of concern is that very few local authorities have attempted to measure unmet need for FPC and the report suggests that there may be some hidden unmet need for FPC among older people who receive support from unpaid carers; a large proportion of older people were found to rely solely on unpaid carers for their personal care, rather than receiving FPC.

Detailed recommendations were given in the Scottish Executive report in order to improve the situation, including the creation of a short life working group to review and clarify the guidance on FPC on issues such as assistance with preparation of food and with medication.

An uprating of free personal and nursing care allowances towards care home fees is overdue: the allowances have not increased since the policy's inception in 2002, during which time fees have increased by more than 20%.

4.6 Hospital care

The quality of hospital care, both in specialist dementia wards and in acute wards, and the issue of delayed discharge, are key concerns.

People with dementia may have to receive care and treatment in a hospital at points throughout their illness. This may be due to symptoms related to the dementia or may be unrelated to dementia: as most people with dementia are older they are at higher risk of a wide range of conditions. The care of people with dementia in acute wards is of continuing concern. Lack of staff knowledge about dementia can mean that patients with dementia are not given the support they need, for example to eat and drink, and they may risk malnutrition[40] or dehydration, to the severe detriment of their health. In 2006, Alzheimer Scotland funded the first specialist dementia nurse post in Scotland, at the Royal Alexandra Hospital in Paisley, to work with nurses, doctors and other health professionals to improve their understanding of the needs of people with dementia in hospital.

In 2006 there were 2,520 occupied psychiatry of old age beds and 2,364 occupied geriatric medicine long stay beds[41]. Following treatment in hospital, the discharge of people with dementia from hospital either back home or to a care home can be delayed for a number of reasons. This can mean that they are receiving inappropriate care and can become de-skilled as a result of remaining in hospital where they may not get the rehabilitative attention they need. In January 2007 there were 1,182 people of all ages waiting to be discharged from hospital[42], which is a decrease from the same time last year (1,488). These figures are a snapshot of all NHS inpatients in January 2007. Of these, 378 were delayed for community care assessment reasons, 86 were awaiting funding for a care home place and 426 were waiting for a care home place. 74% of those outwith the six week discharge planning period (a total of 606) were aged over 75.

In November 2006, the Mental Welfare Commission made unannounced visits to 16 hospital wards for people with dementia[43]. Some positive results were found, such as dedicated staff and the provision of person-centred care. However, there were many areas of concern. Many of the environments were found to be poor, with long corridors and poor lighting which could disorientate someone with dementia. This was compounded by there not being adequate signage and visual cues to assist navigation. There were insufficient staff available at mealtimes, which could result in people with dementia not eating enough. In addition, there was not enough water readily available, and people could become dehydrated. There was a lack of activities provided: 14 out of 30 people had no evidence of activities in their care plan and nine had never been outside the ward since they were admitted. Factors like this could lead to people with dementia losing skills and any independence they had prior to entering hospital. Finally, there was a lack of knowledge in the staff questioned on current guidance on the management of people with dementia.

4.7 Long stay care

In 2006 there were a total of 15,321 people with dementia reported to be living in care homes in Scotland[j]. 10,994 people had received a medical diagnosis of dementia and 4,327 had not, but were believed to have dementia by care home staff.

The fact that there are over 4,000 people in care homes with suspected dementia who have not received a medical diagnosis is unacceptable for a number of reasons. It could be that rather than dementia they have an illness that can result in similar symptoms, such as a urinary tract infection or depression, which can be treated. Lack of a proper diagnosis does not allow the person with dementia and their family to access dementia treatments and to plan for the future with regard to legal matters and expressing wishes about future treatment. It denies the person and his or her family an understanding through information about what is happening to them and what the likely course of the illness is. Every person in a care home whom staff believe may have dementia should be given a medical diagnosis and assessment.

There is likely to be a further group of between 8,000-11,000 people with dementia in care homes who have not received even a non-medical label of dementia. There is consensus from research studies that around 40% of people with dementia live in care homes; yet

[j] This data involves some estimation by the Scottish Executive, as they receive details only for around 75% of residents.

the number reported to the Scottish Executive is only 15,321, which is 26%. The missing 14% is likely to be people whose dementia is unrecognised. This may be due to under-diagnosis, mis-categorisation or underestimation.

The *Dementia UK* report compares data for older people in general between Scotland and England. More older people were in residential care in Scotland (4%) than in England (2.5%). In March 2005 there were 980 care homes for older people in Scotland, 20 of which were specifically for people with dementia[44].

Expenditure on care homes per head of the population over 65 per year is very different. In Scotland in 2004-5 it was £777.60, whereas in England it was £578.30. There is approximately a threefold difference between the local authority with the highest expenditure in 2004-5, Western Isles, who spent £1,171, and the local authority with the lowest expenditure, South Ayrshire, who spent £374.

In Scotland, the average weekly charge in care homes person in 2004-5 was £448.30, whereas in England it was lower at £410.50. The range in Scotland is between Dumfries and Galloway (£390) and Orkney (£621).

4.7.1 Quality of care homes

There is serious concern about the quality of care for the 40% of people with dementia living in care homes. Scandals are reported in the media on *"a depressingly regular basis"* yet *"although these enter the public consciousness, none provokes the outcry caused by reports of abuse of vulnerable people at the opposite end of the age range - children"*[45].

Recent examples of abuse by care home staff include a care worker in care home in Falkirk who bullied and tormented residents with dementia[46]; a nurse in a care home in Edinburgh who was found guilty of tormenting people with dementia[47]; and a nurse who admitted disconnecting panic alarms in a care home in Aberdeenshire, which left a person with dementia lying on a toilet floor with a broken thigh bone, unable to raise the alarm[48].

There are also institutionalised examples of poor care practice, including the misuse of sedative medication, an issue which the Care Commission is due to investigate in 2007.

In adult services, care homes for older people gave the Care Commission *"the most significant cause for concern"*[49]. The report by the Care Commission highlights evidence that the contribution of doctors, other professionals and specialist services for older people is limited in some homes. This is a concern, given that Bowman *et al*[50] found that over 50% of care home residents have dementia, stroke or other neurodegenerative illness or diseases and thus have complex needs, and the *Dementia UK* estimates of 50.1% - 79.9% of care home residents having dementia (section 2.3.3).

Most of the complaints that the Care Commission uphold or partially uphold are about care homes for older people - 57% of upheld complaints in 2005-6. There were 792 complaints in 2005/6 about care homes for older people, 76% of which were upheld or partially upheld. Most complaints were about general health and welfare and there were also many complaints on staffing levels and communication. In 2005/6 more than one in four care

homes had a complaint upheld against them and two thirds had a requirement, meaning that they were not meeting their legal obligations. Improvements can be slow: of a sample of 401 care homes for older people, 37% had a requirement against them in 2004/5 which they had not met in 2005/6.

The Care Commission found that the larger the home, the more likely it was to have a complaint upheld against it, an enforcement issued or a requirement made. The biggest care home in Scotland has 240 places, the smallest has 1 place and the average is 39 places. The Care Commission also found that smaller homes are more likely to offer a more personalised service.

The private sector provides 68% of care homes for older people, local authorities 19% and 13% are provided by the voluntary sector. Private sector homes have the highest level of upheld complaints: 37%, compared with 11% of local authority homes and 8% of voluntary sector homes. Despite these issues, 92% of respondents to a survey of care home residents by the Care Commission said they were happy or very happy with the quality of the service they receive in their care home.

Areas for improvement in care homes were identified as being general health and welfare matters, and there were problems with staffing in some care homes. Some homes did not supply the minimum number of staff required to meet the needs of the residents and staffing levels were not adjusted in response to changing needs. Some services were found to be appointing staff without the relevant qualifications and training and some were not aware of the National Care Standards.

Some care homes have not shown a commitment to making more single rooms available. There are nearly 6,000 older people sharing rooms in care homes, denying them the privacy and dignity they deserve.

Healthcare issues exist, such as infection control and problems with medication: medicines being stored inappropriately and unqualified staff with inadequate training on administering medication. There are also issues with nutrition in care homes, such as a lack of awareness of some care home staff of the help some residents need to eat and drink. Finally, tissue viability was identified as an issue; there is poor care planning for preventing pressure sores.

In order to address some of these issues, a nurse consultant for care homes has been appointed by the Care Commission. Alzheimer Scotland is working in partnership with the Care Commission on 'Beyond Barriers', a project developing a palliative care approach to dementia in care homes. The project will support care home staff to meet the palliative care needs of people with dementia and an educational programme including both staff and relatives will be developed to influence palliative care practice.

In order to improve the quality of care, the Care Commission intends to: focus its inspections on areas that matter most e.g. privacy; work more closely with the care homes with the most complaints and requirements; and follow up on Scottish Executive policies that impact on practice in care homes, such as nutrition.

5 Costs of dementia in Scotland

Summary

- The cost of dementia in Scotland in 2007 is between £1.5 and £1.7 billion.
- The cost in 2031 is projected to be £2.6 - £2.9 billion (at today's prices).

The cost of dementia in Scotland in 2007 is between **£1.5 and £1.7 billion**. Dementia has a major impact on our economy. Rising numbers mean that by 2031 the cost - at today's prices - could rise to £2.6 - £2.9 billion.

These figures are based on estimates in the *Dementia UK* report, and include the cost of accommodation (41% of total), informal care (i.e. the costs to family of caring) (36%), social work services (15%) and NHS care (8%). The *Dementia UK* report estimated that the average cost per annum of a person with dementia is £25,472.

Using the *Dementia UK* prevalence rates, the cost of dementia in 2007 is £1.5 billion. Using the Eurodem prevalence rates, the cost of dementia in 2007 is £1.7 billion.

5.1 Future costs

The predicted 75% rise in the numbers of people with dementia in Scotland over the next 24 years mean a cost of dementia in Scotland in 2031 of between £2.6 billion (using *Dementia UK* prevalence rates) and £2.9 billion (using Eurodem prevalence rates) at today's prices (table 11).

Year	Number of people with dementia in Scotland *(Dementia UK)*	Cost (*Dementia UK* figures)	Number of people with dementia in Scotland (Eurodem)	Cost (Eurodem figures)
2007	57,946	-	65,031	-
2012	63,718	£1.6 billion	71,460	£1.8 billion
2017	71,509	£1.8 billion	80,307	£2 billion
2022	81,196	£2.1 billion	90,856	£2.3 billion
2027	92,520	£2.4 billion	103,245	£2.6 billion
2031	101,650	£2.6 billion	113,501	£2.9 billion

Table 11: Future costs of dementia

6 Conclusion

This report has brought together a wealth of information to give a comprehensive picture of dementia in Scotland, current service provision and the economic impact now and in the future.

The picture painted is a dramatic one, highlighting:

- large and rapidly-growing numbers of people with dementia
- inadequate current levels of service provision
- significant differences in provision between different areas
- serious concerns about the quality of some services
- the very significant economic impact of dementia.

The World Health Organization estimates that dementia contributes more years lived with disability among people over 60[51] than stroke, musculoskeletal disorders, cardiovascular disease and cancer.

Alzheimer Scotland makes ten recommendations for immediate action.

6.1 Services

The importance of anticipatory care is well-recognised, but provision of post-diagnostic services in dementia is weak, with carers reporting a lack of support and information at precisely the time when they and the person with dementia need to come to terms with the illness, learn to manage the symptoms and plan ahead. Self-management of long term conditions is a key element of the strategy set out in *Delivering for Health*[52], and has the potential to save health and social service costs by equipping people with the skills they need to cope with the condition. Yet there are no self-management courses for people with dementia and carers, and only limited availability of courses to assist carers to cope.

We have shown that only around 11% of people with dementia living at home receive home care and 12% receive day care, some way off the working target of 28% set by HDL (2004) 44[53], and with large variations between local authorities. There is a severe lack of respite, with only 27% of carers of people with dementia receiving a week's short break in a year.

For care homes the concern is quality rather than quantity, with the care home sector for older people causing the most concern to the Care Commission of all types of adult care services. Many cases of dementia in care homes go undiagnosed or even unrecognised. Free personal care is by and large working well, but there remain concerns about waiting lists and the interpretation of guidance on assistance with food preparation and medication.

Recommendations

1. **Funding for a programme of self management courses for people with dementia jointly with carers as part of a strategy of saving future costs through anticipatory care.**

2. **Restoration of the availability of existing drug treatments to people with mild Alzheimer's disease.**
3. **Increased funding now for services such as home care, day care and short breaks and recognition that personalised care through specialist dementia services may be more cost effective in the long term by allowing people to remain in their own home for longer.**
4. **Increased future funding in line with demographic change and the increase in the number of people with dementia.**
5. **Improved training in dementia care.**
6. **A medical assessment for every person in a care home whom staff believe may have dementia and improved access to doctors and specialist services for care home residents.**
7. **Implementation of the recommendations of the report on free personal care, and allowances uprated in line with increases in care home fees.**

6.2 Preventing the epidemic

The projected rise in numbers of people with dementia of 75% by 2031 is truly an epidemic, and urgent action is required if we are to forestall it.

Urgent efforts must be made to reduce this rise. Barring the emergence of a cure, the most feasible option is to find ways of delaying the onset of dementia. If the onset of dementia were delayed by 5 years, the number of people with dementia in 2031 would be almost exactly the same as it is today. Possible strategies include public health improvements to facilitate risk reduction and research into prevention and better treatments. A study commissioned by the Alzheimer's Research Trust[54] showed that £11 is spent on UK research into Alzheimer's disease for every person affected by the disease, compared with £289 for each cancer patient.

Recommendations

8. **Investment now in a major public health campaign to reduce people's risk of developing dementia in later life, by encouraging healthy eating, physical activity, mental exercise and social stimulation.**
9. **Support for research into better preventive treatments, better symptomatic treatments, causes and ways of preventing or delaying dementia.**

6.3 Making dementia a priority

In conclusion, the picture that has been painted for 2007 is of serious concern; and if this is the situation now, what will the picture look like in 24 years' time, when Scotland has 75% more people with dementia?

With careful planning and investment now, the impending dementia epidemic can be managed better, to the benefit of people with dementia, their carers and Scotland as a whole. With that in mind, we conclude with a final, overarching recommendation.

10. **Dementia to be made a national priority.**

7 Appendices

Appendix 1 - Numbers of people with dementia by local authority and NHS board

Local authority	Number of people with dementia (*Dementia UK* prevalence rates)			Number of people with dementia (Eurodem prevalence rates)		
	Under 65	**Over 65**	**Total**	**Under 65**	**Over 65**	**Total**
Aberdeen City	50	2227	**2277**	62	2486	**2548**
Aberdeenshire	70	2508	**2578**	81	2816	**2897**
Angus	32	1387	**1419**	36	1554	**1590**
Argyll & Bute	27	1176	**1203**	30	1321	**1351**
Clackmannanshire	14	516	**529**	16	578	**595**
Dumfries & Galloway	45	2012	**2058**	48	2262	**2311**
Dundee City	34	1727	**1761**	40	1927	**1967**
East Ayrshire	33	1323	**1356**	39	1487	**1526**
East Dunbartonshire	30	1240	**1270**	34	1391	**1425**
East Lothian	25	1129	**1154**	31	1262	**1292**
East Renfrewshire	24	1056	**1080**	29	1179	**1208**
Edinburgh, City of	106	4953	**5059**	143	5504	**5647**
Western Isles	8	357	**365**	9	399	**408**
Falkirk	40	1577	**1617**	49	1770	**1819**
Fife	98	4102	**4200**	115	4593	**4708**
Glasgow City	126	5708	**5834**	176	6374	**6550**
Highland	65	2525	**2590**	72	2833	**2905**
Inverclyde	22	918	**940**	26	1028	**1054**
Midlothian	22	836	**858**	26	940	**966**
Moray	24	1023	**1048**	29	1151	**1179**
North Ayrshire	38	1553	**1591**	43	1745	**1788**
North Lanarkshire	83	3068	**3150**	104	3458	**3562**
Orkney Islands	6	238	**244**	7	267	**273**
Perth & Kinross	41	1839	**1880**	46	2056	**2102**
Renfrewshire	45	1778	**1823**	55	1998	**2053**
Scottish Borders	33	1441	**1474**	37	1615	**1652**
Shetland Islands	6	237	**243**	7	264	**272**
South Ayrshire	33	1502	**1534**	36	1684	**1719**
South Lanarkshire	82	3319	**3401**	101	3723	**3823**
Stirling	24	967	**990**	27	1084	**1111**
West Dunbartonshire	24	971	**995**	29	1086	**1115**
West Lothian	43	1380	**1423**	56	1559	**1615**
Total	1355	56,592	**57,946**	1639	63,393	**65,031**

Table 12: Number of people with dementia in each local authority in Scotland in 2007 as calculated using Eurodem and Dementia UK report prevalence rates

NHS Board	Number of people with dementia (*Dementia UK* prevalence rates)			Number of people with dementia (Eurodem prevalence rates)		
	Under 65	**Over 65**	**Total**	**Under 65**	**Over 65**	**Total**
Argyll and Clyde	114	4579	**4693**	134	5143	**5277**
Ayrshire & Arran	104	4378	**4482**	118	4916	**5034**
Borders	33	1441	**1474**	37	1615	**1652**
Dumfries & Galloway	45	2012	**2058**	48	2262	**2311**
Fife	98	4102	**4200**	115	4592	**4707**
Forth Valley	77	3055	**3131**	93	3427	**3519**
Grampian	144	5758	**5902**	172	6452	**6624**
Greater Glasgow	204	9058	**9262**	267	10117	**10385**
Highland	65	2525	**2590**	72	2833	**2905**
Lanarkshire	145	5605	**5750**	181	6307	**6487**
Lothian	197	8298	**8495**	256	9265	**9521**
Orkney	6	238	**244**	7	267	**273**
Shetland	6	237	**243**	7	264	**272**
Tayside	108	4949	**5056**	121	5533	**5655**
Western Isles	8	357	**365**	9	399	**408**
Total	1355	56592	**57946**	1636	63393	**65029**[k]

Table 13: Number of people with dementia in each NHS Board in Scotland in 2007 as calculated using Eurodem and Dementia UK report prevalence rates

[k] Difference due to rounding errors

Appendix 2 - Intervals of need for care of people with dementia by local authority and NHS board

These tables use the measures of intervals of need described in section 3.1.2 to yield an indication of the numbers of people in each local authority or NHS board requiring different levels of service[I]. Separate tables are provided using *Dementia UK* and Eurodem prevalence figures.

Local authority	Independent	Long interval	Short interval	Critical interval	Total
Aberdeen City	137	250	1093	774	2254
Aberdeenshire	155	284	1237	877	2552
Angus	85	156	681	482	1405
Argyll & Bute	72	132	577	409	1191
Clackmannanshire	32	58	254	180	524
Dumfries & Galloway	123	226	988	700	2037
Dundee City	106	194	845	599	1743
East Ayrshire	81	149	651	461	1342
East Dunbartonshire	76	140	610	432	1257
East Lothian	69	127	554	392	1142
East Renfrewshire	65	119	518	367	1069
Edinburgh, City of	304	556	2428	1720	5008
Western Isles	22	40	175	124	361
Falkirk	97	178	776	550	1601
Fife	252	462	2016	1428	4158
Glasgow City	350	642	2800	1984	5776
Highland	155	285	1243	881	2564
Inverclyde	56	103	451	320	931
Midlothian	51	94	412	292	849
Moray	63	115	503	356	1038
North Ayrshire	95	175	764	541	1575
North Lanarkshire	189	347	1512	1071	3119
Orkney Islands	15	27	117	83	242
Perth & Kinross	113	207	902	639	1861
Renfrewshire	109	201	875	620	1805
Scottish Borders	88	162	708	501	1459
Shetland Islands	15	27	117	83	241
South Ayrshire	92	169	736	522	1519
South Lanarkshire	204	374	1632	1156	3367
Stirling	59	109	475	337	980
West Dunbartonshire	60	109	478	338	985
West Lothian	85	157	683	484	1409
Total	3477	6374	27814	19702	57367

Table 14: Intervals of need for care of people with dementia in each local authority (2007) using *Dementia UK* prevalence rates

[I] Totals do not match the tables in Appendix 1 as the intervals of need total 99%

Local authority	Independent	Long interval	Short interval	Critical interval	Total
Aberdeen City	153	280	1223	866	2523
Aberdeenshire	174	319	1391	985	2868
Angus	95	175	763	541	1574
Argyll & Bute	81	149	648	459	1337
Clackmannanshire	36	65	286	202	589
Dumfries & Galloway	139	254	1109	786	2288
Dundee City	118	216	944	669	1947
East Ayrshire	92	168	732	519	1511
East Dunbartonshire	86	157	684	485	1411
East Lothian	78	142	620	439	1279
East Renfrewshire	72	133	580	411	1196
Edinburgh, City of	339	621	2711	1920	5591
Western Isles	24	45	196	139	404
Falkirk	109	200	873	618	1801
Fife	282	518	2260	1601	4661
Glasgow City	393	721	3144	2227	6485
Highland	174	320	1394	988	2876
Inverclyde	63	116	506	358	1043
Midlothian	58	106	464	328	956
Moray	71	130	566	401	1167
North Ayrshire	107	197	858	608	1770
North Lanarkshire	214	392	1710	1211	3526
Orkney Islands	16	30	131	93	270
Perth & Kinross	126	231	1009	715	2081
Renfrewshire	123	226	985	698	2032
Scottish Border	99	182	793	562	1635
Shetland Islands	16	30	131	92	269
South Ayrshire	103	189	825	584	1702
South Lanarkshire	229	421	1835	1300	3785
Stirling	67	122	533	378	1100
West Dunbartonshire	67	123	535	379	1104
West Lothian	97	178	775	549	1599
Total	3902	7153	31215	22111	64381

Table 15: Intervals of need for care of people with dementia in each local authority (2007) using Eurodem prevalence rates

NHS Board	Independent	Long interval	Short interval	Critical interval	Total
Aberdeen City	153	280	1223	866	2523
Argyll and Clyde	282	516	2253	1596	4646
Ayrshire & Arran	269	493	2151	1524	4437
Borders	88	162	708	501	1459
Dumfries & Galloway	123	226	988	700	2037
Fife	252	462	2016	1428	4158
Forth Valley	188	344	1503	1065	3100
Grampian	354	649	2833	2007	5843
Greater Glasgow	556	1019	4446	3149	9169
Highland	155	285	1243	881	2564
Lanarkshire	345	633	2760	1955	5693
Lothian	510	934	4078	2888	8410
Orkney	15	27	117	83	242
Shetland	15	27 117	83	241	
Tayside	303	556	2427	1719	5005
Western Isles	22	40	175	124	361
Total	3477	6374	27814	19701	57366

Table 16: Intervals of need for care of people with dementia in each NHS Board (2007) using *Dementia UK* prevalence rates

NHS Board	Independent	Long interval	Short interval	Critical interval	Total
Argyll and Clyde	317	580	2533	1794	5224
Ayrshire & Arran	302	554 2416	1712	4984	
Borders	99	182	793	562	1635
Dumfries & Galloway	139	254	1109	786	2288
Fife	282	518	2259	1600	4660
Forth Valley	211	387	1689	1196	3484
Grampian	397	729	3180	2252	6558
Greater Glasgow	623	1142	4985	3531	10281
Highland	174	320	1394	988	2876
Lanarkshire	389	714	3114	2206	6422
Lothian	571	1047	4570	3237	9426
Orkney	16	30	131	93	270
Shetland	16	30	131	92	269
Tayside	339	622	2714	1923	5598
Western Isles	24	45	196	139	404
Total	3902	7153	31214	22110	64380

Table 17: Intervals of need of people with dementia in each NHS Board (2007) using Eurodem prevalence rates

Appendix 3 - Projections for 2024 by local authority and NHS board

Local authority	Number of people with dementia (*Dementia UK* prevalence rates)			Number of people with dementia (Eurodem prevalence rates)		
	Under 65	**Over 65**	**Total**	**Under 65**	**Over 65**	**Total**
Aberdeen City	47	2925	**2972**	4	3147	**3193**
Aberdeenshire	77	4481	**4558**	76	5046	**5123**
Angus	31	2185	**2216**	30	2420	**2450**
Argyll & Bute	26	1810	**1836**	29	2020	**2049**
Clackmannanshire	14	847	**861**	14	943	**957**
Dumfries & Galloway	45	3176	**3221**	42	3542	**3584**
Dundee City	32	2113	**2145**	34	2300	**2334**
East Ayrshire	35	2000	**2035**	36	2223	**2259**
East Dunbartonshire	27	1875	**1902**	29	2049	**2078**
East Lothian	30	1689	**1718**	31	1918	**1949**
East Renfrewshire	26	1590	**1616**	28	1767	**1795**
Edinburgh, City of	125	6494	**6619**	161	7355	**7515**
Western Isles	8	492	**500**	7	538	**545**
Falkirk	46	2432	**2478**	50	2743	**2793**
Fife	106	6343	**6449**	116	7173	**7289**
Glasgow City	147	6772	**6919**	181	7455	**7636**
Highland	68	4147	**4215**	66	4665	**4731**
Inverclyde	22	1276	**1298**	22	1397	**1419**
Midlothian	22	1278	**1300**	23	1428	**1452**
Moray	25	1611	**1636**	27	1800	**1826**
North Ayrshire	38	2488	**2526**	38	2760	**2798**
North Lanarkshire	92	4872	**4964**	99	5441	**5540**
Orkney Islands	7	402	**409**	6	449	**455**
Perth & Kinross	44	2829	**2873**	43	3170	**3213**
Renfrewshire	48	2641	**2689**	47	2907	**2955**
Scottish Borders	37	2308	**2345**	36	2640	**2676**
Shetland Islands	6	386	**392**	6	423	**429**
South Ayrshire	31	2213	**2244**	32	2454	**2485**
South Lanarkshire	93	5141	**5234**	100	5750	**5849**
Stirling	25	1502	**1526**	26	1691	**1718**
West Dunbartonshire	25	1329	**1354**	26	1464	**1491**
West Lothian	56	2600	**2656**	63	2995	**3058**
Total	1461	84247	**85708**	1571	94072	**95643**

Table 18: Number of people with dementia in each local authority in Scotland in 2024 as calculated using Eurodem and *Dementia UK* report prevalence rates

NHS Board	Number of people with dementia (*Dementia UK* prevalence rates)			Number of people with dementia (Eurodem prevalence rates)		
	Under 65	**Over 65**	**Total**	**Under 65**	**Over 65**	**Total**
Argyll and Clyde	116	6737	**6853**	119	7529	**7647**
Ayrshire & Arran	104	6669	**6773**	105	7437	**7542**
Borders	37	2365	**2402**	36	2640	**2676**
Dumfries & Galloway	45	3174	**3219**	42	3542	**3584**
Fife	106	6435	**6541**	116	7172	**7288**
Forth Valley	85	4814	**4899**	91	5370	**5461**
Grampian	149	8922	**9071**	149	9993	**10142**
Greater Glasgow	227	11485	**11712**	267	12826	**13093**
Highland	68	4170	**4239**	66	4665	**4731**
Lanarkshire	163	8872	**9034**	174	9907	**10081**
Lothian	232	12276	**12508**	278	13696	**13974**
Orkney	7	402	**409**	6	449	**455**
Shetland	6	377	**383**	6	423	**429**
Tayside	107	7069	**7176**	106	7886	**7993**
Western Isles	8	482	**489**	7	538	**545**
Total	1461	84247	**85708**	1569	94072	**95641**

Table 19: Number of people with dementia in each NHS Board in Scotland in 2024 as calculated using Eurodem and *Dementia UK* report prevalence rates

Appendix 4 - Current service provision by local authority

People with dementia living in care homes

Local authority	People with dementia in care homes (all ages): medically diagnosed	People with dementia in care homes (all ages): not medically diagnosed	Total people with dementia in care homes	Local authority classification
Aberdeen City	438	216	**654**	Urban
Aberdeenshire	611	251	**862**	Rural
Angus	275	90	**365**	Rural
Argyll & Bute	202	78	**280**	Rural
Clackmannanshire	90	20	**110**	Urban
Dumfries & Galloway	321	127	**448**	Rural
Dundee City	359	143	**502**	Urban
East Ayrshire	284	102	**386**	Rural
East Dunbartonshire	143	33	**176**	Urban
East Lothian	247	69	**316**	Urban
East Renfrewshire	122	79	**201**	Urban
Edinburgh, City of	862	438	**1,300**	Urban
Western Isles	48	17	**65**	Island (Rural)
Falkirk	321	84	**405**	Urban
Fife	777	324	**1,101**	Urban
Glasgow City	1,303	345	**1,648**	Urban
Highland	506	212	**718**	Rural
Inverclyde	196	53	**249**	Urban
Midlothian	152	74	**226**	Urban
Moray	238	42	**280**	Rural
North Ayrshire	342	156	**498**	Urban
North Lanarkshire	559	317	**876**	Urban
Orkney Islands	36	21	**57**	Island (Rural)
Perth & Kinross	312	130	**442**	Rural
Renfrewshire	451	109	**560**	Urban
Scottish Borders	185	94	**279**	Rural
Shetland Islands	48	12	**60**	Island (Rural)
South Ayrshire	305	100	**405**	Rural
South Lanarkshire	631	381	**1,012**	Urban
Stirling	251	48	**299**	Rural
West Dunbartonshire	137	53	**190**	Urban
West Lothian	242	109	**351**	Urban
Total	**10,994**	**4,327**	**15,321**	

Table 20: Numbers of people with dementia living in care homes in Scotland (medically and not medically diagnosed). ***Note: the data involves some estimation as the Scottish Executive only receives details for around 75% of residents.***

Home care

Local authority	Home care clients with dementia (all ages)	% people with dementia at home receiving home care (using *Dementia UK* figures)	Classification of local authority
Aberdeen City	238	17	Urban
Aberdeenshire	132	9	Rural
Angus	37	4	Rural
Argyll & Bute	70	10	Rural
Clackmannanshire	34	11	Urban
Dumfries & Galloway	91	7	Rural
Dundee City	288	27	Urban
East Ayrshire	40	5	Rural
East Dunbartonshire	126	17	Urban
East Lothian	0	0	Urban
East Renfrewshire	44	7	Urban
Edinburgh, City of	544	18	Urban
Western Isles	21	10	Island
Falkirk	137	14	Urban
Fife	339	13	Urban
Glasgow City	320	9	Urban
Highland	160	10	Rural
Inverclyde	76	13	Urban
Midlothian	38	7	Urban
Moray	88	14	Rural
North Ayrshire	86	9	Urban
North Lanarkshire	141	7	Urban
Orkney Islands	10	7	Island
Perth & Kinross	35	3	Rural
Renfrewshire	96	9	Urban
Scottish Borders	26	3	Rural
Shetland Islands	17	12	Island
South Ayrshire	60	7	Rural
South Lanarkshire	125	6	Urban
Stirling	29	5	Rural
West Dunbartonshire	74	12	Urban
West Lothian	157	18	Urban
Total	**3679**	**Average = 11%**	

Table 21: Number of people with dementia receiving home care by local authority in March 2006

Day care

Local authority	Day care attendees with dementia (all ages)	% people with dementia at home receiving day care (using *Dementia UK* figures)	Classification of local authority
Aberdeen City	175	13	Urban
Aberdeenshire	135	9	Rural
Angus	85	10	Rural
Argyll & Bute	66	9	Rural
Clackmannanshire	69	22	Urban
Dumfries & Galloway	103	8	Rural
Dundee City	85	8	Urban
East Ayrshire	87	11	Rural
East Dunbartonshire	72	9	Urban
East Lothian	2	0	Urban
East Renfrewshire	153	24	Urban
Edinburgh, City of	158	5	Urban
Western Isles	22	10	Island
Falkirk	112	12	Urban
Fife	177	7	Urban
Glasgow City	1210	35	Urban
Highland	196	13	Rural
Inverclyde	75	13	Urban
Midlothian	14	3	Urban
Moray	39	6	Rural
North Ayrshire	117	12	Urban
North Lanarkshire	141	7	Urban
Orkney Islands	8	5	Island
Perth & Kinross	91	8	Rural
Renfrewshire	187	17	Urban
Scottish Borders	52	6	Rural
Shetland Islands	26	18	Island
South Ayrshire	98	11	Rural
South Lanarkshire	238	12	Urban
Stirling	51	9	Rural
West Dunbartonshire	71	12	Urban
West Lothian	117	14	Urban
Total	**4232**	**Average = 12%**	

Table 22: Numbers of people with dementia living at home receiving day care

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Notes









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Dementia is a key health issue facing Scotland as our population ages. In less than 25 years, the number of people with dementia in Scotland is projected to increase by 75%, as the baby-boom generation reaches old age.

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This report sets out ten key recommendations.

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