

Dementia UK

A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society

SUMMARY OF KEY FINDINGS

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Introduction

Background

In 2006 the Alzheimer's Society commissioned the London School of Economics and the Institute of Psychiatry at King's College London to produce a report on dementia in the UK. The research team was commissioned to provide the most up-to-date evaluation of the numbers of people with dementia in the UK, projections on numbers of people in the future and to explain the financial cost of dementia.

This is a summary of key findings of the report.

What does the *Dementia UK* report cover?

- This report establishes an accurate estimate of the numbers of people in the UK who currently have dementia.
- It provides authoritative estimates for the numbers of people who will have dementia up to 2051.
- It includes a review of current evidence on the services and treatments currently provided to support people with dementia.
- The current costs of dementia are estimated.
- Recommendations for future dementia care are made.

1. What is dementia?

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease.

Dementia can affect people of any age, but is most common in older people. One in five people over 80 has a form of dementia and one in 20 people over 65 has a form of dementia.

Researchers are still working to find out more about the different types of dementia, and whether any have a genetic link. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia.

Dementia is a progressive condition. This means that the symptoms become more severe over time. Understanding how this progression happens can be useful in helping someone with dementia anticipate and plan for change.

The way each person experiences dementia, and the rate of their decline, will depend on many factors – not just on which type of dementia they have, but also on their physical

make-up, their emotional resilience and the support that is available to them. Typically symptoms will include:

- Loss of memory – for example, forgetting the way home from the shops, or being unable to remember names and places.
- Mood changes – these happen particularly when the parts of the brain which control emotion are affected by disease. People with dementia may feel sad, angry or frightened as a result.
- Communication problems – a decline in the ability to talk, read and write.

There are different types of dementia caused by different diseases of the brain. Because these diseases affect the brain in different ways, they produce different symptoms. Some of the most common forms of dementia are listed below:

Alzheimer's disease is the most common type of dementia. It changes the chemistry and structure of the brain, causing brain cells to die.

In the early stages of Alzheimer's, the person's behaviours may change in very small ways. They may start forgetting things or repeating themselves more often than usual, for example. At first people often attribute these symptoms to factors such as ageing, stress or bereavement.

In the middle stages of Alzheimer's, the person may need reminders to carry out activities of daily living such as eating, dressing or using the toilet. The person's memory will get worse, and they may have difficulty recognising familiar people or places.

Over time, the person will become increasingly dependent on others for help. They are likely to experience severe memory loss and become increasingly frail. They may have difficulty with eating, swallowing, incontinence and loss of communication skills such as speech.

Vascular dementia is caused by problems with the supply of oxygen to the brain following a stroke or small vessel disease. Conditions such as hypertension, which affect the heart, arteries or circulation of blood to the brain can cause vascular dementia. It is therefore very important these conditions are identified, monitored and treated. Symptoms can include problems concentrating and communicating, depression and physical frailty.

The symptoms that a person experiences as a result of a stroke depend on which part of the brain has been damaged. For example, if the damaged area is responsible for movement of a limb, paralysis might occur. If the part of the brain damaged is responsible for speech, the person might have problems communicating.

When vascular dementia is caused by a single stroke, it is called single-infarct dementia. Vascular dementia is more commonly caused by a series of small strokes. These can be so tiny that the person might not notice any symptoms or the symptoms may be only temporary. This is called multi-infarct dementia.

Vascular dementia progresses in a similar way to Alzheimer's disease, but progression is often 'stepped' rather than gradual, declining suddenly as the person has a new stroke. Progression of vascular dementia may be slowed through the control of underlying risk factors such as blood pressure.

Fronto-temporal dementia is a rare form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change.

In the early stages of fronto-temporal dementia, the person is less likely to become forgetful than in Alzheimer's disease. Instead their behaviour can change quite dramatically. For

example, they may seem more selfish or unfeeling than usual or sexually uninhibited. The later stages are very similar to Alzheimer's disease.

Dementia with Lewy bodies is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills.

This type of dementia has symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement. The person may also experience hallucinations. The progression of this condition can be confusing for carers, as the person's abilities may fluctuate.

2. New data on the prevalence of dementia

Health and social policy makers need accurate estimates of the numbers of people who currently have dementia and those who will develop it in the future in order to plan the services needed to support them.

The research that underpins this report has used a methodology known as the Expert Delphi Consensus to produce the best possible estimates using currently available research data. Ten leading UK and European experts systematically reviewed the evidence base and reached a consensus that:

- The prevalence of both early-onset and late-onset dementia increases with age, doubling with every five-year increase across the age range.

The consensus estimates of the population prevalence of late-onset dementia

Age (years)	F (%)	M (%)	Total (%)
65–69	1.0	1.5	1.3
70–74	2.4	3.1	2.9
75–79	6.5	5.1	5.9
80–84	13.3	10.2	12.2
85–89	22.2	16.7	20.3
90–94	29.6	27.5	28.6
95+	34.4	30.0	32.5

- The prevalence of early-onset dementia (under 65 years old) was adjudged to be higher in men than in women for those aged 50–65, while late-onset dementia was considered to be marginally more prevalent in women than in men.
- Alzheimer's disease was considered to be the dominant subtype, particularly among older people, and in women.
- Frontotemporal dementia was considered to account for a substantial proportion of early-onset cases among younger men.
- The report estimates that there are 11,392 people from black and minority ethnic groups with dementia. It is noteworthy that 6.1% of all people with dementia among

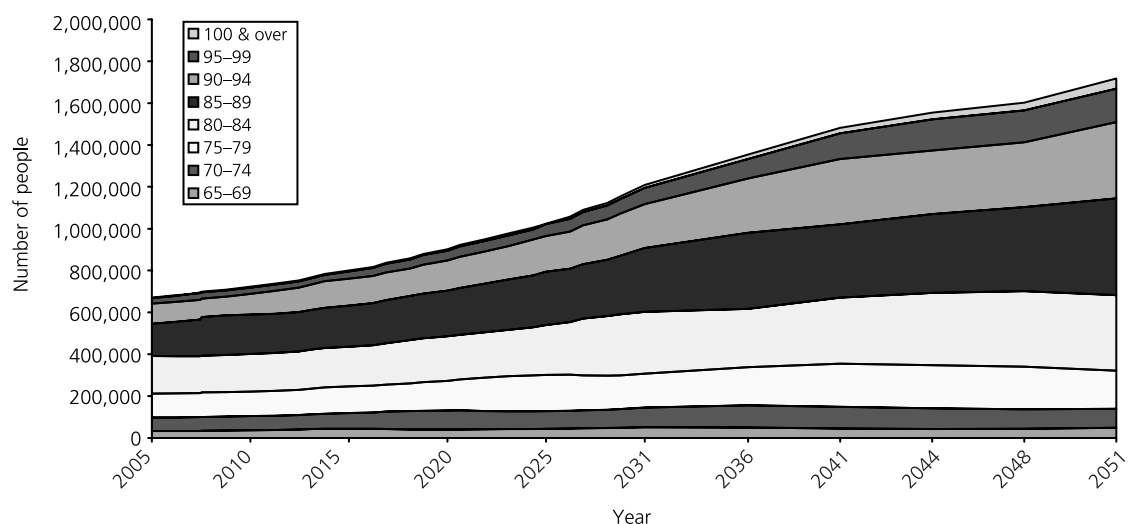
black and minority ethnic (BME) groups are early-onset, compared with only 2.2% for the UK population as a whole, reflecting the younger age profile of BME communities.

- The prevalence of dementia among people in institutions varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over.
- The consensus group also generated estimates of the prevalence of dementia among all those aged 65 years and over living in EMI (elderly mentally infirm) homes (79.9%), nursing homes (66.9%) and residential care homes (52.2%).
- The proportion of deaths attributable to dementia increases steadily from 2% at age 65 to a peak of 18% at age 85–89 in men, and from 1% at age 65 to a peak of 23% at age 85–89 in women. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years may be attributable to dementia. Annually, 59,685 deaths among the over 65s might have been averted if dementia were not present in the population. The majority of these deaths occurred among those aged 80–95 years. Delaying the onset of dementia by five years would halve the number of UK deaths due to dementia to 30,000 a year.

3. Number of people with dementia in the UK

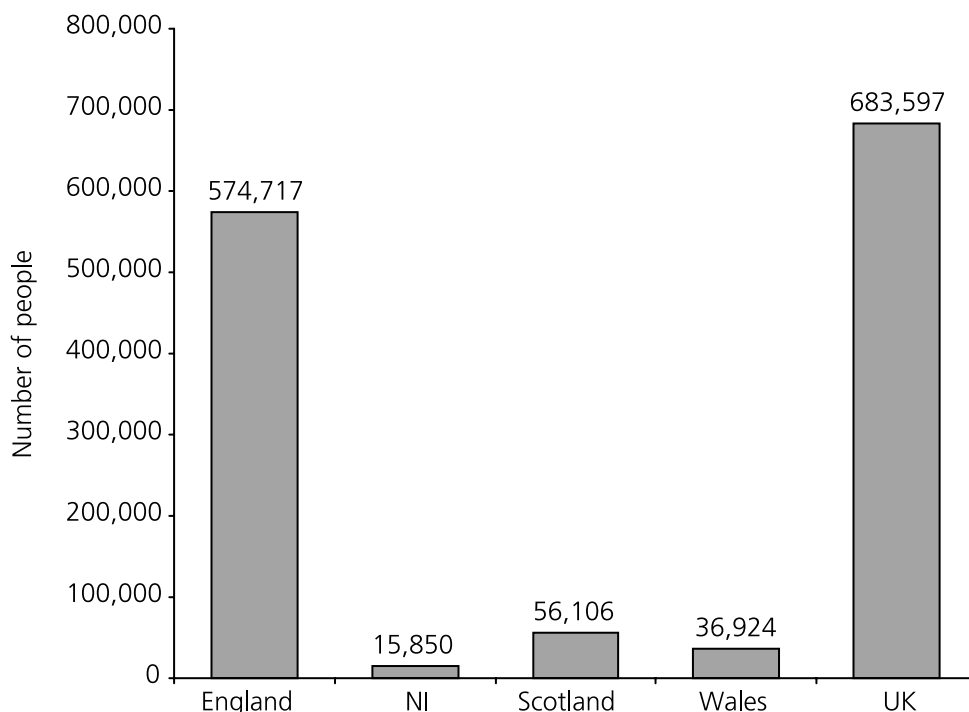
We estimate that there are now 683,597 people with dementia in the United Kingdom. This represents one person in every 88 (1.1%) of the entire UK population. For simplicity the Alzheimer's Society will be using the figure 700,000 for people with dementia in the UK in public messages.

The total number of people with dementia in the UK is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38% over the next 15 years and 154% over the next 45 years.



Projected number of people with late-onset dementia by age group (UK)

- Early-onset dementia is comparatively rare, accounting for 2.2% of all people with dementia in the UK. We estimate that there are now 15,034 people with early-onset dementia (onset before the age of 65 years) in the United Kingdom and 668,563 people with late-onset dementia (onset after the age of 65 years). However, given that data on the numbers of early-onset cases are based on referrals to services, this number is likely to be an underestimate. The true figure may be up to three times higher.
- The numbers of people with late-onset dementia continue to rise for each five-year age band up to the age of 80–84, and decline thereafter. Despite this, two-thirds (68%) of all people with dementia are aged 80 and over, and one sixth (17%) aged 90 or over.
- Overall we estimate that 222,925 men and 445,641 women have late-onset dementia, approximately two women for every man affected. Both the higher mortality among men and the higher age-specific dementia prevalence in women contribute to the preponderance of women among the oldest people with dementia.



Number of people in the UK with dementia (2005)

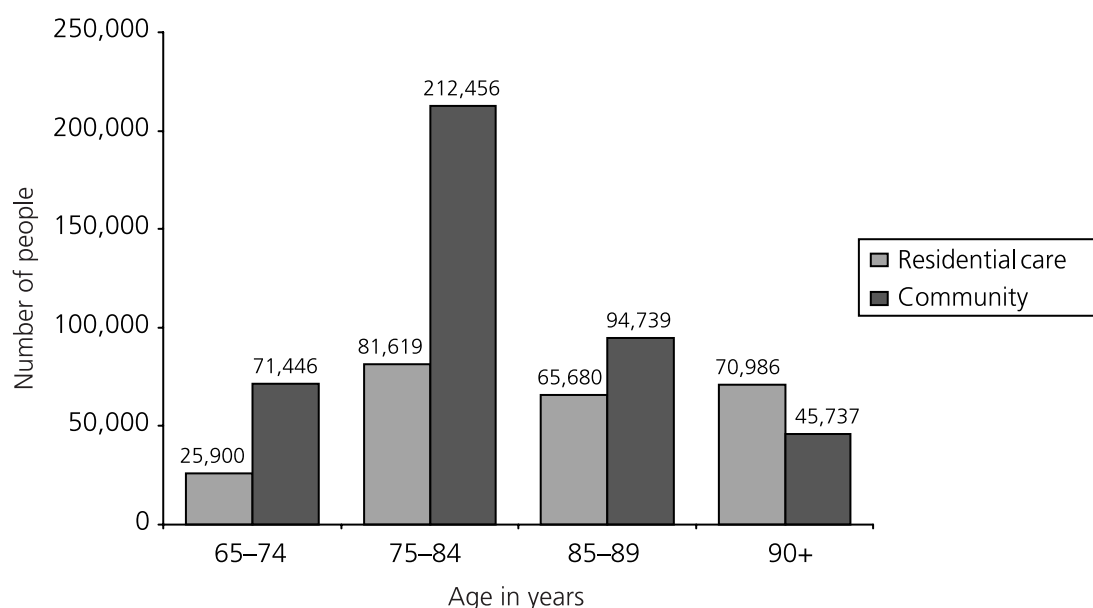
Dementia subtypes

- We estimate that 416,967 people with dementia (62%) have Alzheimer's disease, the most common form of dementia. The next most common subtypes are vascular dementia and mixed dementia, accounting for nearly one third (27%) of all cases.
- The distribution of subtypes is different in men and women. Alzheimer's disease is more common in women, while vascular dementia and mixed dementias are more common in men.

Institutional care

- We estimate that 424,378 people with late-onset dementia (63.5%) live in private households (the community), whereas 244,185 (36.5%) live in care homes.

- The proportion of those with dementia living in care homes rises steadily with age, from 26.6% of those aged 65–74, to 60.8% of those aged 90 and over.



Number of people in the UK with late-onset dementia living in residential care and in the community

Burden of disease

Dementia is one of the main causes of disability in later life. In a wide consensus consultation for the World Health Organization's Global Burden of Disease report, disability from dementia was accorded a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer. Of course, older people are particularly likely to have multiple health conditions – chronic physical diseases affecting different organ systems, coexisting with mental and cognitive disorders. Dementia, however, has a disproportionate impact on capacity for independent living. Still its global public health significance continues to be under appreciated, and misunderstood. According to the 2003 World Health Report Global Burden of Disease estimates, dementia contributed 11.2% of all years lived with disability among people aged 60 and over; more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of cancer (2.4%).

Research

There have been major advances in the field of dementia research. However, public funding for dementia research lags far behind that of other serious medical conditions.

The proportion of research papers (since 2002) devoted to these chronic disorders reveals a starkly different ordering of priorities: cancer 23.5%, cardiovascular disease 17.6%, musculoskeletal disorders 6.9%, stroke 3.1% and dementia 1.4%.

4. Development of services for people with dementia

The role of the health and social care systems in meeting the multiple needs of people with dementia and their families is a key policy issue in the UK. However, the evidence base on the range of services supplied for people with dementia is very limited and needs significant work. In the full report this chapter concentrates on:

- Informal care – unpaid care provided by family members and friends, the mainstay of dementia care in the UK.
- Financing health and social care – demographic challenges, charges, choices and independence.
- Specialist health services for people with dementia – including the role of old age psychiatry.
- Dementia assessment and care – considering diagnosis and referrals.
- Social care provision – residential and nursing care, extra care housing, community based support and mental health services.
- The state of current dementia commissioning, care and policy – services are not available for a large majority of the population to deliver the memory assessment and care services that are stipulated in government policy, yet demand is predicted to grow.

5. Mapping social service provision

Mapping local levels of social care support for people with dementia in the UK is difficult as there are no available local authority level data on service provision specific to older people with mental health problems.

This study gathered information on local levels of provision of residential and nursing care, home care and day care services to *all* older people in England, Scotland, Wales and Northern Ireland.

There were very marked variations in levels of provision, expenditure and (to a lesser extent) in unit costs across all services and in all UK countries. Variability was smallest for residential care services.

Residential care services:

<i>UK country</i>	<i>% of people over 65 supported in residential or nursing care homes</i>
England	2.5
Scotland	4.0
Wales	2.8
Northern Ireland	4.0

- Significantly higher proportions of older people were supported in institutions in Scotland and Northern Ireland than in England and Wales.

Home care services:

<i>UK country</i>	<i>% of people over 65 in receipt of home care services</i>
England	3.9
Scotland	6.9
Wales	4.3
Northern Ireland	2.4 (NB, not directly comparable figure)

Possibly as a result of the introduction of free personal care there in 2003, older people in Scotland show the highest take-up of home care services in the UK, followed by older people in Wales, England and Northern Ireland.

The highest rates of home care provision (and home care expenditure) per head of older population are concentrated in high-population urban areas, such as metropolitan districts and London boroughs.

Day care services:

<i>UK country</i>	<i>% of people over 65 in receipt of day care services</i>
England	1.7
Scotland	1.3
Wales	1.6
Northern Ireland	1.1

The levels of day care provided within each country vary widely, much more than for either of the other services explored.

6. The financial cost of dementia in the UK

Using the new prevalence estimates from this report, together with other data, we calculated the overall costs of dementia in the UK. Costs to be included were those provided by formal care agencies as well as the financial value of unpaid informal care provided by family and friends.

Costs were not available for the 2% of people with dementia under the age of 65.

Total costs amounted to £17.03 billion, or an average of £25,472 per person with late-onset dementia.

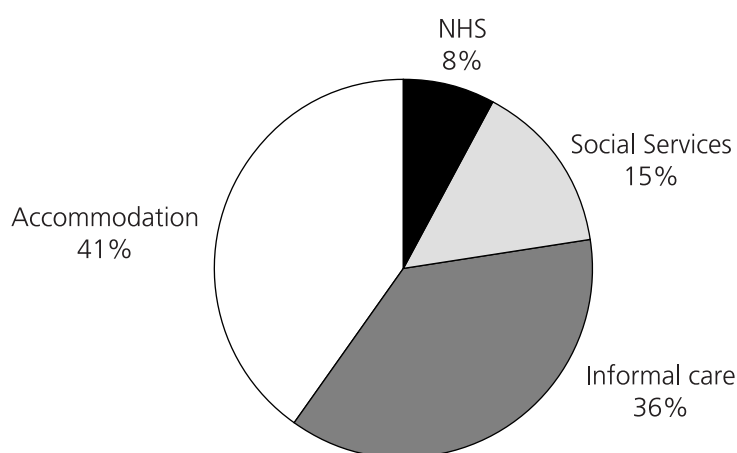
The total annual cost per person with dementia in different settings is estimated as follows:

- people in the community with mild dementia – £16,689
- people in the community with moderate dementia – £25,877
- people in the community with severe dementia – £37,473
- people in care homes – £31,296.

Accommodation accounted for 41% of the total.

Over a third of the total (36%) was due to informal care inputs by family members and other unpaid carers. Included in this amount is the estimated £690 million in lost income for those carers who have to give up employment or cut back their work hours. This lost employment means a loss of £123 million in taxes paid to the Exchequer.

Benefit payments are not strictly a cost (since they are transfer payments), but they are an expense to the government. Receipt of Attendance Allowance or DLA amounted to around £919 million per year, increasing to total cost of about £18 billion.



7. Recommendations

- 1 Make dementia a national priority**
- 2 Increase funding for dementia research**
- 3 Improve dementia care skills**
- 4 Develop community support**
- 5 Guarantee carer support packages**
- 6 Hold a national debate on who pays for care**
- 7 Develop comprehensive dementia care models**

Historically, a lack of attention from policy makers and service commissioners to the needs of people with dementia has led to dementia care being delivered piecemeal and in an inefficient fashion. More investment accompanied by careful planning will be needed in the

years ahead in order to ensure that not only do we maximise quality of life for people with dementia and their families, but also that we do so in an efficient way with the resources available.

Despite areas of good practice, the UK's current health and social care system is characterised by a widespread failure to support people with dementia and their families. These findings have been demonstrated most recently in evidence from the Wanless report into social care (2006) and CSCI state of social care report (2007). This failure to develop services which meet the needs of people with dementia is perplexing given that dementia is a significant driver of demand for health and social care.

This *Dementia UK* report identifies:

- 1 People with dementia are substantial users of health and social care services.
- 2 The number of people with dementia and families affected by dementia is set to increase rapidly and we will therefore see increasing demand for support services.
- 3 Increased demand for support services will be driven both by the increases in the numbers affected and the shift in the age distribution towards a preponderance of the oldest people, who tend to be frailer and to have more limited informal support networks.

Dementia care is characterised by a significant lack of evidence on outcomes and the current state of service delivery. The recommendations that follow therefore contain both a series of proposals for policy development, and proposals on improving the evidence base.

Recommendation 1: Make dementia a national priority

Dementia must be made a publicly stated national health and social care priority. This must be reflected in plans for service development and public spending.

- A cross-government strategy for dementia must be developed to respond to the growing need for care from early diagnosis to end of life care.
- Dementia care and research must be prioritised in the 2007 Comprehensive Spending Review.
- Health and social care commissioners must develop local plans to support increasing numbers of people with dementia and their families.

Current government policies, including the National Service Framework for Older People, Carers Strategy, NICE care guideline and Everybody's Business provide a starting point. Although mental health is a national clinical priority along with cancer and heart disease, dementia has not received the attention it requires. A co-ordinated national dementia plan with political commitments is now a necessity. This will require planning between the public, private and independent sectors.

Recommendation 2: Increase funding for dementia research

As a matter of urgency there must be a review of UK medical research funding to establish a more ambitious funding programme into the causes, prevention, cure and care of dementia.

Increasing the amount of dementia research is an urgent priority if we are to improve the treatment of people with dementia in the future, and make evidence based plans to provide high quality care to meet the evolving needs.

Recommendation 3: Improve dementia care skills

Dementia care training should be made a core and substantial part of the training curriculum for nurses and social care staff. National Minimum Standards must be developed to include dementia specific requirements on dementia care training.

Poor understanding of dementia and its consequences is currently leading to under diagnosis, late diagnosis and an inadequate care response. This all creates an inefficient use of resources. For example, people who go in for similar procedures can stay twice as long in hospital if they also have dementia. Serious medical conditions are not being identified early and care packages in the community are put in place too late. Without significant focus on improving care across health and social care, outcomes will get worse and resources will be squandered.

The current National Minimum Standards were always meant to be a starting point for good practice. Now it is time to develop stronger requirements. We must go beyond the current dementia options in the Quality and Outcomes Framework for GPs to improve the early identification, diagnosis and management of dementia by GPs.

Recommendation 4: Develop community support

People with dementia need improved home care support packages, including low-level support to retain their independence and dignity.

Stated national policy focuses on early identification and intervention. However, local authorities across the country have been skewing access to home care support towards people with the highest levels of need. It is now very difficult for people not classed as having substantial or critical levels of need to access services. As the population ages and the number of people with dementia increases, this situation will worsen.

People with dementia can stay at home for longer with their families if the right support is put in place.

- The number and extent of home care packages must be increased.
- Home help services such as help with cleaning, shopping, DIY and gardening must be brought back.
- The opportunities for people with dementia and carers to access direct payment and individual budgets must be increased.

Recommendation 5: Guarantee carer support packages

Family carers must have guaranteed access to carer support. In particular:

- **psychological therapies including carer training and support groups**
- **quality respite care for people with dementia and carers.**

The *Dementia UK* report identified that people caring for people with dementia save the public purse over £6 billion a year. Although the total proportion of people who are able to care for relatives may decline in the future, there will remain a substantial proportion of people eager to continue providing informal care for people with dementia. The current policy response to carers is very weak and needs revision. Without formal commitments to an improved package of support for carers, an increasing number will be unable to continue caring and pressures on long term care will increase.

Recommendation 6: Hold a national debate on who pays for care

We must have a national government-backed debate on who pays for care to establish a clear and fair balance between the contributions made by the state and the individual.

Dementia care is expensive and the divide between what the government defines as healthcare which should be free, and social care which should be means tested is becoming increasingly difficult to define.

The *Dementia UK* report demonstrates that the financial cost to society is on average £25,000 per person with dementia per year. Currently the majority of this cost is met by people with dementia and their families through informal care and care charges, whereas other long-term medical conditions receive far more support from the state. We need a national government-backed debate about who pays for care. The evidence is that people are willing to make a contribution towards their care if a number of conditions are satisfied. A new solution must be transparent, easy to understand and equitable. The care being paid for must also be of good quality.

Recommendation 7: Develop comprehensive dementia care models

Develop an integrated, comprehensive range of care models for people with dementia to bridge the gap between care at home and care in a care home.

The direction of health and social care policy in the last 20 years has been to increase the proportion of older people who can be supported in their own homes in the community. This has been partially successful. The impact on long-term care has been that the proportion of people in care homes with complex medical conditions has been increasing. The majority of people in care homes have a form of dementia. The real challenge now, aside from improving the quality of care in care homes, is to support people with dementia for longer in their own homes. More effort is required from the public, private and voluntary sector to find good quality, cost effective options to meet the needs of people with dementia and their families.

More information

For more information please contact the Alzheimer's Society by calling 0207 306 0883 or visit the website at www.alzheimers.org.uk.