



DEMENTIA 2010

The prevalence, economic cost and research funding of dementia compared with other major diseases

Executive summary

A report produced by the Health Economics Research Centre,
University of Oxford for the Alzheimer's Research Trust

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About the Alzheimer's Research Trust

The Alzheimer's Research Trust is the UK's leading research charity for dementia.

We are dedicated to funding scientific studies to find ways to treat, cure or prevent Alzheimer's disease, vascular dementia, dementia with Lewy Bodies and fronto-temporal dementia.

We do not receive any government funding and instead rely on donations from individuals, companies and charitable trusts, money raised by individuals and gifts left in people's Wills to fund our vital work.

Our registered charity number is 1077089.



Find out more at: www.alzheimers-research.org.uk

Dementia costs UK plc £23 billion a year

How do you put a price on life? How do you demonstrate the cost of doing nothing? Thanks to the Alzheimer's Research Trust who commissioned this study we have an answer: £23 billion in care costs and lost productivity.



Dementia poses many challenges. Challenges to scientists, challenges to policy-makers, challenges to society: left unanswered costs will continue to rise.

On present trends the UK's approach to managing dementia is unsustainable. Leading scientists have already warned that the NHS will struggle to cope if the prevalence of dementia continues to rise.

The Government's dementia strategy offers the prospect of a better model of care. But it offers no answer to the inexorable rise in the demand for care.

The answer must surely be human ingenuity and discovery. More funds are needed to enable scientists to research and understand dementia, to research and develop new treatments. Yet today for every pound spent on dementia

care, less than a quarter of a penny is invested in research.

The Government held a summit on dementia research, but new money came there none. Instead, a Ministerial taskforce on research has been set up.

As Dementia 2010 shows dementia directly afflicts 820,000 people in the UK. Yet it touches the lives of so many more people. The economists may say dementia costs £23 billion; the true social impact is incalculable.

Dementia costs the UK twice as much as cancer, three times as much as heart disease and four times as much as stroke. Yet when it comes to research funding dementia is the poor relation. For every one pound spent on dementia research twenty six pounds are spent on cancer research and fifteen pounds on research into heart disease.

Dementia 2010 makes clear the scale of the challenge; it brings dementia into the spotlight. The case for investment in dementia research is powerful and clear.

A handwritten signature in black ink, appearing to read 'Paul Burstow'.

Paul Burstow MP

Liberal Democrat Member of Parliament for Sutton and Cheam

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INTRODUCTION

A wake-up call for us all

In 2009, the Alzheimer's Research Trust commissioned the Health Economics Research Centre at the University of Oxford to produce a report on the economic cost of dementia to the UK, and the country's investment in



research to find new treatments, preventions and cures. They were asked to calculate the care costs of dementia to health services, social services, unpaid carers and others, and compare this to the other great medical challenges of our age: cancer, heart disease and stroke. The outstanding work of Prof Alastair Gray, Dr Ramon Luengo-Fernandez and Dr Jose Leal on Dementia 2010 has produced important new evidence.

The Oxford team's findings are astonishing. Every one of the 821,884 people in the UK with dementia costs our economy £27,647 per year; that's more than the UK median salary. By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year. Despite this, government and charitable spending on dementia research is 12 times lower than on cancer research. £590 million is spent on cancer research each year, while just £50 million is invested in dementia research.

This should be a wake-up call for all of us who can influence the priority given to dementia research: government, charities and the public as a whole. The Alzheimer's Research Trust is aiming to increase its annual investment in research and quickly; with extra support from the public, we could do so much more. All three main political parties accept that dementia research deserves more funding and – as the Prime Minister put it in a meeting with the Alzheimer's Research Trust – that “dementia has been neglected for too long”. We now need to translate this political sentiment into government action. We welcome the government's Ministerial Advisory Group on dementia research as a promising start.

If we spend a more proportionate sum on dementia research, we could unleash the full potential of our scientists in their race for a cure. Spending millions now really can save us crippling multi-billion pound care bills later.

Most importantly, we must not forget what these statistics really represent: hundreds of thousands of devastated lives, millions of families and friends, incalculable potential squandered.

With enough support, our scientists can defeat dementia and halt this tidal wave of suffering.

A handwritten signature in black ink, appearing to read 'Rebecca Wood'.

Rebecca Wood

Chief Executive, Alzheimer's Research Trust

WHAT IS DEMENTIA?

Dementia describes a group of symptoms associated with a progressive decline of brain functions, such as memory, understanding, judgement, language and thinking. The most common form of dementia is Alzheimer's disease. People with dementia are at an increased risk of physical health problems and become increasingly dependent on health and social care services and on other people. Hence, dementia has a significant economic impact on the health care system, on patients, on family and friends who provide unpaid care, and on the wider economy and society.

OVERVIEW

The study reported here estimates the economic burden from a societal perspective that includes not only health care costs but also those costs falling outside the health care sector, such as the opportunity costs associated with unpaid care to patients, or productivity losses associated with premature death or absence from work due to dementia. The aim was to compare the economic burden of dementia with that of cancer, coronary heart disease (CHD) and stroke using the same methodological approach. Cancer, CHD and stroke are the three main causes of death in Europe and the USA. The UK government and charity research funding was also examined for each of the four conditions in the financial year 2007/08. The aim was to compare the levels of UK research funding with the respective economic burden of disease. It was expected that research into the causes, treatment and prevention of a particular disease should be broadly related to its economic burden.

METHODS

Estimating the economic burden of illness

A prevalence approach was adopted whereby all costs within the most recent year for which data were available were measured regardless of the date of disease onset. A "top down" approach was used to estimate the total costs using aggregate data on morbidity, mortality, hospital admissions, disease related costs, and other health related indicators. Costs categories used included health care, social care, informal care, and productivity losses due to premature mortality and absence from work.

Dementia was defined as the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD10) F00-F03 and G30, which include Alzheimer's disease, vascular and unspecified dementia, as well as dementia in other diseases such as Parkinson's. Cancer was defined as ICD-10 codes C00-D48, stroke as ICD-10 codes I60-I69, and coronary heart disease as ICD-10 codes I20-I25.

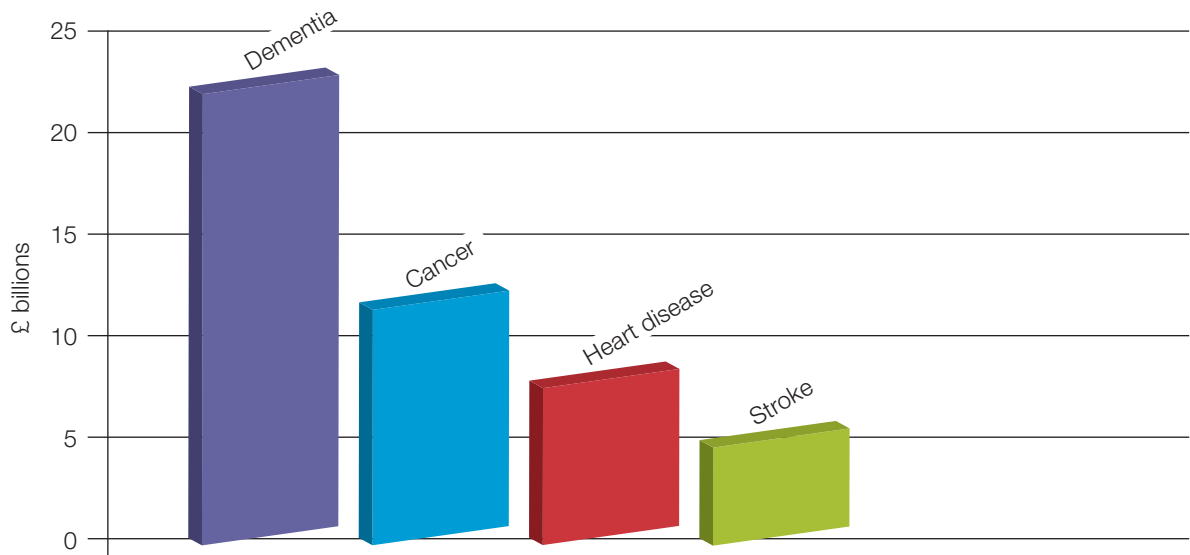
Research funding

We identified UK governmental agencies that provide health research funding and contacted them to determine the levels of funding for dementia, cancer, CHD and stroke in the financial year 2007/08. These agencies included research councils, such as the Medical Research Council (MRC), and research agencies from the Department of Health and its devolved administrations, such as the National Institute for Health Research (NIHR). Charity organisations that fund health research were also identified from the Association for Medical Research Charities (AMRC) and the Charity Commission for England and Wales. Due to the large number of charities in the Charity Commission register that potentially fund health research, only the top two hundred charities of these in terms of their annual income were considered in this study. These two hundred charities accounted for over 75% of the total income of all health charities potentially funding research. The levels of charity research funding for each of the four conditions were obtained from annual reports or direct contact with the charities.

KEY FINDINGS

821,884 people in the UK live with dementia

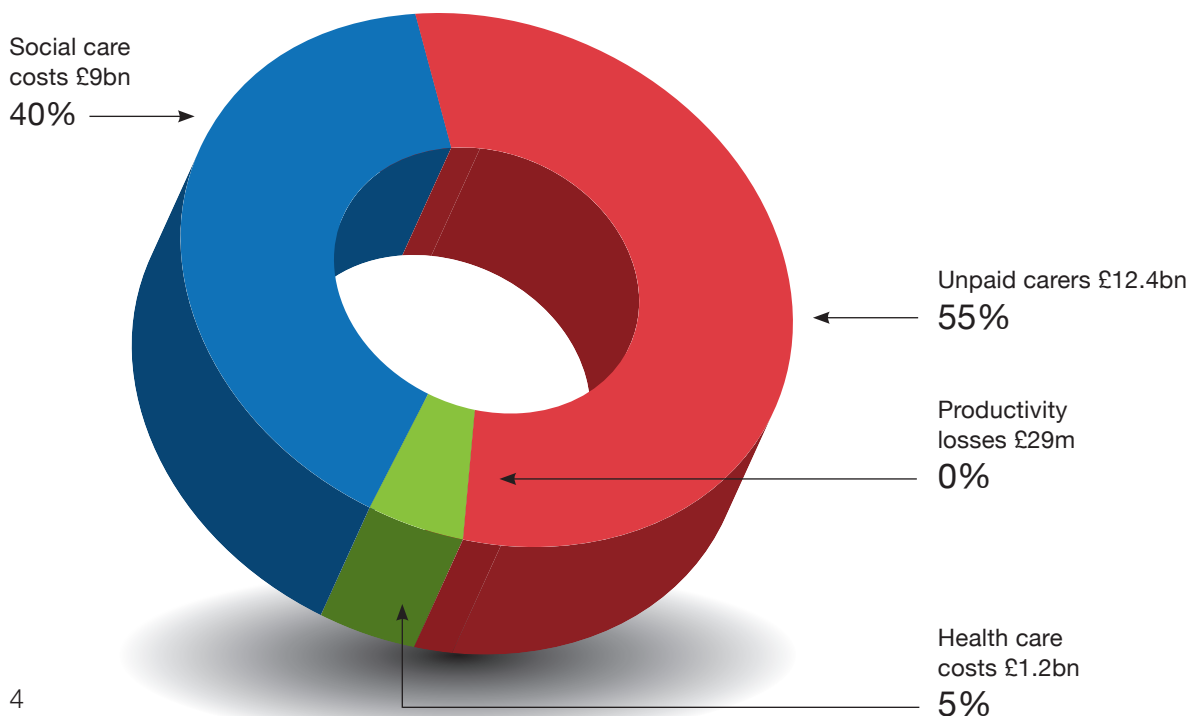
Dementia costs the UK economy £23 billion per year. This is more than cancer (£12 billion per year) and heart disease (£8 billion per year) combined.



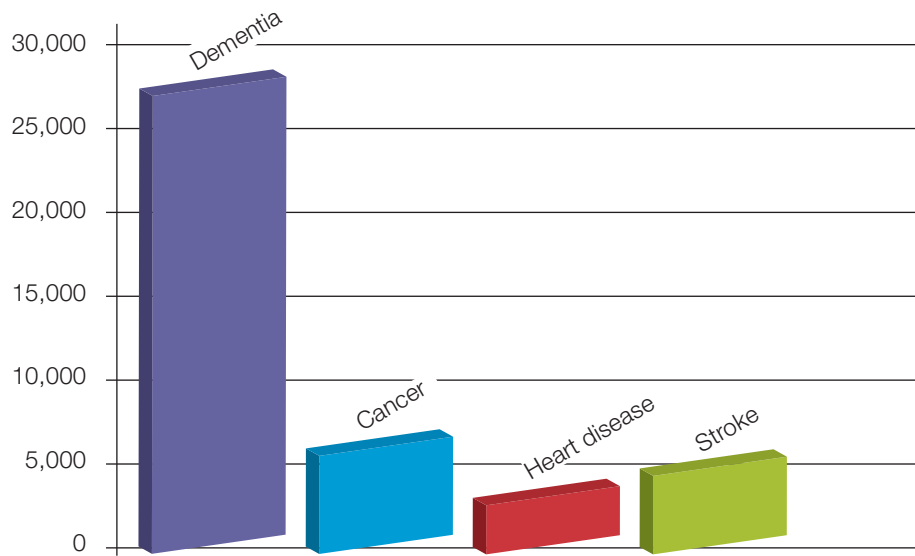
How the £23 billion cost of dementia is met

Long term institutional social care and informal care costs make up the majority of the £23 billion figure.

Most of the cost of dementia – £12.4 billion per year – is met by unpaid carers. Social care costs are £9 billion, health care £1.2 billion and productivity losses £29 million.



Annual cost (£) of one patient



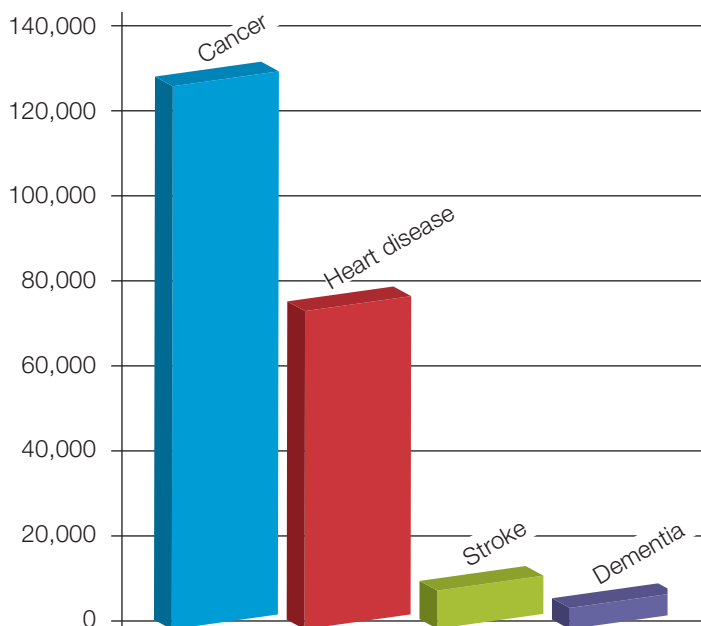
Every dementia patient costs the economy £27,647 per year: more than the UK median salary (£24,700). By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year.

Annual government and charity investment in research

Government and charitable spending on dementia research is 12 times lower than on cancer research. £590 million is spent on cancer research each year, while just £50 million is invested in dementia research. Heart disease receives £169 million per year and stroke research £23 million.

For every person with cancer, £295 is spent each year on research. For dementia, that figure is just £61.

Investment (£) in research for every £1 million in social and health care costs



For every £1 million in care costs for the disease:
 £129,269 is spent on cancer research
 £73,153 on heart disease research
 £8,745 on stroke research
 just £4,882 on dementia research.

ECONOMIC BURDEN OF ILLNESS

The number of people with dementia in the UK is estimated to be 821,884, representing 1.3% of the UK population. We estimate that 37% of all dementia patients in the UK are in long-term care institutions, costing in excess of £9 billion per year in social care. Health care costs are estimated at about £1.2 billion, of which hospital inpatient stay accounts for 44% of the total. Informal care is estimated to involve 1.5 billion hours of unpaid care provided to dementia patients living in the community, which we value at £12 billion. Finally, productivity losses due to dementia account for £29 million. Overall, dementia is found to cost £23 billion in terms of health and social care, informal care and productivity losses in 2008.

The combined health and social care costs of dementia are estimated at £10.3 billion in 2008, compared to £4.5 billion for cancer, £2.7 billion for stroke and £2.3 billion for CHD. Using UK prevalence data, the health and social care cost per person with disease was estimated at £12,521 for dementia, £2,559 for stroke, £2,283 for cancer, and £1,019 for CHD. In terms of societal cost, dementia also posed the greatest economic burden at £23 billion followed by cancer at £12 billion, CHD at £8 billion and stroke at £5 billion.

RESEARCH FUNDING

Research funding by disease in 2007/08					
	Cancer	Heart disease	Dementia	Stroke	TOTAL
Charity, £ thousands (% of total)	323,771 (76)	85,031 (20)	13,913 (3)	5,833 (1)	428,548 (100)
Government, £ thousands (% of total)	266,640 (66)	84,229 (21)	36,331 (9)	17,522 (4)	404,723 (100)
Charity & government, £ thousands (% of total)	590,411 (71)	169,260 (20)	50,244 (6)	23,355 (3)	833,270 (100)

Information on the levels of research funding for dementia, cancer, CHD and stroke in 2007/08 were obtained from seven of the eight identified governmental agencies. A total of £405 million of governmental funds was spent on these four diseases, of which 66% was spent on cancer research followed by CHD (21%), dementia (9%) and stroke (4%). A total of 65 charities that provided research funding for these four diseases were identified from the Charity Commission register and the AMRC. These charities had a combined spend of £429 million on cancer, CHD, dementia and

stroke research. As with the governmental agencies, most of these funds were devoted to cancer (£324 million, 76%) followed by CHD (£85 million, 20%), dementia (£14 million, 3%) and stroke (£6 million, 1%).

In total, the combined research funding into dementia, cancer, CHD and stroke by governmental and charity organisations in this study was just over £833 million. Of this total, £590 million (71%) was devoted to cancer, £169 million (20%) to CHD, £50 million (6%) to dementia and £23 million (4%) to stroke.

COMPARISON OF RESEARCH FUNDING WITH ECONOMIC BURDEN OF DISEASE

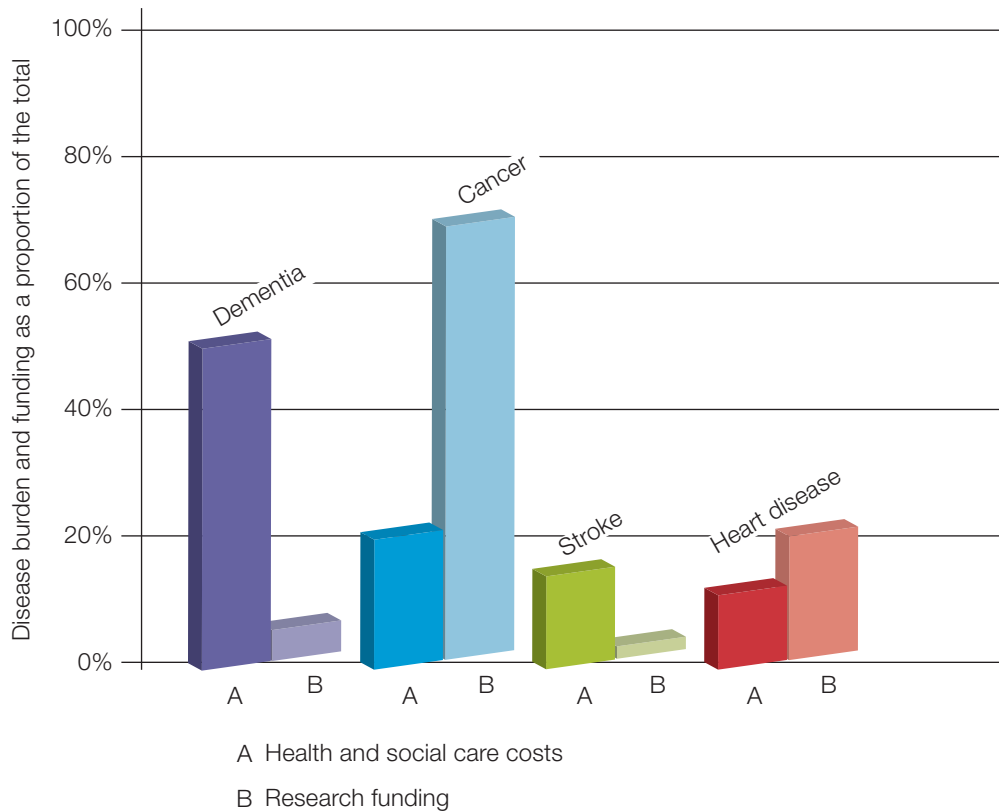
The total levels of research funding per person with the disease were evaluated at £295 per person with cancer, £75 per person with CHD, £61 per person with dementia and £22 per person with stroke. Put another way, for every £1 million of health and social care costs attributable to the disease, cancer received £129,269 in research funding, CHD

received £73,153, stroke received £8,745 and finally dementia received £4,882.

As shown below, although dementia accounts for over 50% of the combined health and social care costs of the four diseases under study, it only receives 6% of combined research funding. In contrast, cancer accounts for just over 20% of health and social care costs but receives nearly three quarters of the total medical research funding for these four diseases.

Research funding, number of people affected and total costs of diseases				
	Cancer	Heart disease	Dementia	Stroke
Total research funding, £ thousands	£590,411	£169,260	£50,244	£23,355
Total number of people affected, thousands	2,000	2,271	822	1,044
Funding per person affected	£295	£75	£61	£22
Total health and social care, £ millions	£4,567	£2,314	£10,291	£2,671
Funding per £1 million in disease costs	£129,269	£73,153	£4,882	£8,745

Health and social care costs and research funding by disease



CONCLUSIONS AND RECOMMENDATIONS

The estimated economic burden of dementia is far greater than cancer, heart disease (CHD) and stroke. Despite this, most research funding in the UK is currently directed towards cancer. Our analysis suggests that research spending on dementia and stroke is severely underfunded in comparison with cancer and CHD.

DISCUSSION

Results from this report showed that the health care, social care, informal care and productivity costs of dementia were nearly £23 billion a year. Over 55% (£12 billion) of these total costs was due to informal care, representing 1.5 billion hours of unpaid care provided by relatives and friends of dementia patients. Long term institutionalisation costs represented 40% (£9 billion) of the total annual costs, with an estimated 304,850 patients in care homes. Conversely, the costs to the NHS were comparably low, accounting for just over £1 billion, most of which was due to overnight stays in hospital (42%). Due to the late onset of dementia in most cases, the productivity losses due to morbidity or mortality were very low (less than 1%).

The report also confirms the diagnosis gap between the expected number of people with dementia and the number of patients with dementia on GP registers. For example, in England only an estimated 31% of people with dementia are registered on GP lists. A number of reasons have been proposed for the low rates of diagnosis in primary care settings, the main one being GPs' lack of training and confidence in diagnosing dementia as discussed in a recent National Audit Office report. In early 2009, the National Dementia Strategy for England was published to address some of these concerns and raise awareness about the needs of people with dementia and their carers.

A number of previously published studies have also evaluated the costs of dementia for the UK. In 2006, the total cost of dementia was estimated at approximately £17 billion per year. These costs were derived from a London-based study of 132 people with dementia followed between 1997 and

1999, which were then updated to 2005/06 price levels and extrapolated to the whole of the UK using dementia prevalence estimates derived from expert opinion. In our study we found the cost of dementia to be approximately £5 billion more at £23 billion for the year 2008. These differences in cost were largely explained by the different prevalence rates and methodological approaches used to estimate the costs. So, for example, when prevalence rates obtained from the expert panel in Knapp and Prince (2007) were used in the sensitivity analysis of this study, the total costs of dementia decreased from £23 billion to £20 billion. Nevertheless, regardless of the methodological approach used, the total cost of dementia in the UK far outweighed the costs of cancer, CHD and stroke.

In order to compare the economic burden of different diseases, the costs associated with each disease must be estimated using the same methods and analytic framework. The methods used to evaluate the costs of dementia in this report were similar to previous approaches used to estimate the economic burden of cardiovascular disease (CVD), coronary heart disease (CHD) and stroke in the European Union and the UK. After updating the results from these studies to 2008 prices, a direct comparison was made between the costs of dementia with those of CHD and stroke without concerns that the estimated variation in costs was attributable to the use of different methodologies. In addition, using the same methodology, we estimated the economic burden of cancer as no other comparable estimates were available for the UK. Stroke and dementia were associated with relatively low costs to the health care system (£1.6 billion and £1.2 billion, respectively) when compared to cancer (£4 billion) and CHD (£2.2 billion). However, with high rates of long-term institutionalisation, dementia generated costs to the social care system of £9 billion per year, compared to £1 billion for stroke, £0.5 billion for cancer and £0.1 billion for CHD. When costs other than health and social care were considered, such as informal care costs and productivity losses, dementia was again estimated to have the highest cost of all four diseases (approximately £23 billion), which was almost twice the cost of cancer, three times that of CHD and over 4 times that of stroke.

However, the aim of a cost-of-illness study is not to suggest how much the UK should spend on a particular disease. Our aim was not to estimate the burden of disease on UK Gross Domestic Product (GDP): for example, we did not include all the costs and transfer payments associated with each of the diseases such as home care, social services such as meals on wheels and day care centres, pensions and other social benefits. One of the main aims of a cost-of-illness study is to help monitor policy initiatives and to inform decisions on the distribution of research effort. This is consistent with a recent governmental review into how public bodies should target medical research funding. The review recommended that an assessment of the impact of diseases on the UK population and economy was necessary to inform the UK health research priorities. Therefore, after estimating the costs of cancer, CHD, dementia and stroke, we also evaluated the link between the impact of these four diseases and the allocation of research funds by charities and governmental organisations.

The results of this report highlight that, contrary to the estimates of the economic burden of disease, research funding is highly dominated by cancer followed a long way behind by CHD. Our results, in line with those from previously published studies, suggest that both dementia and stroke are grossly underfunded when compared to their prevalence and, especially, their health and social care costs. Out of £833 million research funds made available by charities and governmental organisations for cancer, CHD, stroke and dementia research, 71% was devoted to cancer research, 20% was devoted to CHD, 6% was devoted to dementia and 4% to stroke. Comparing the economic burden of these four diseases with the amount of research funding received, results of our study show that for every £1 million in health and social care costs, cancer receives £129,269 in research funding, CHD receives £73,153, followed by stroke with £8,745 and finally dementia with £4,882.

Possible reasons for the underfunding of both stroke and dementia could be that both stroke and dementia are still largely perceived as untreatable diseases, which are difficult to research and occur mainly in the elderly population. Contrary to cancer and CHD, stroke is mostly treated by generalist doctors while there is still no international consensus about which medical specialty should diagnose and treat dementia. This attitude towards care of dementia and stroke patients may hamper the research initiative of health professionals applying for funds. As shown in our results, cancer research funding by charities received an even greater proportion of total funds than stroke, CHD and dementia when compared to governmental funding. This possibly reflects a public preference towards CHD and cancer charities. It is unclear why this happens, but ageism, with a perception that dementia and stroke are confined to the very elderly, has been forwarded as a possible explanation.

In conclusion, dementia creates a significant burden mainly through the costs placed on unpaid carers and long-term institutionalised care. The costs associated with dementia are considerably higher than those of cancer, CHD or stroke. Previous studies evaluating levels of research funding have suggested that research into both dementia and stroke is severely underfunded. This report strongly confirms that finding using up-to-date data. This shows that research on dementia and stroke remains grossly underfunded when compared to cancer and CHD.

For a full version of the report, including citations, go to www.dementia2010.org



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