

The hidden cost of dementia in Wales

Document purpose	This is an overview of the findings of research commissioned by Alzheimer’s Society and conducted by the Personal Social Services Research Unit (PSSRU), London School of Economics. It follows on from research published in Dementia UK: Update, (Prince et al, 2014). This report aims to provide an accurate understanding of the cost of dementia to society in Wales, and to assist in policy development, influencing, commissioning and service design.
Title	The hidden cost of dementia in Wales
Publication date	July 2015
Target audiences	The hidden cost of dementia in Wales is intended for a wide range of organisations and people who can improve the quality of life of people with dementia in Wales. This includes the research community, local authorities, partners from the public sector, commissioners of healthcare, civic organisations and the government.
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Foreword

The hidden cost of dementia in Wales exposes the immense financial and human impact of dementia in Wales. It estimates that, in 2013 the total cost of dementia to society in the country was £1.4 billion per year, with an average cost of £31,300 per person per year.

These costs are expected to rise as the number of people with dementia increases. This is a staggering figure, especially considering the fact that during the same period, the Welsh Government spent £6.4 billion on all aspects of health and social care in Wales (Welsh Government, 2014).

I am pleased to see the progress that has been made in the four years since the publication of the National dementia vision for Wales. Dementia now has a higher profile in Wales than ever before. I particularly welcome the Health Minister's announcement in April 2015 of additional resources for, and greater focus on, dementia over the next year. While I am optimistic that this will lead to real improvements, I am reminded every day that there is still so much more that needs to be done.

When we talk about such big numbers, we must not forget that this also represents the human cost for people with dementia and their carers. The report found that people with dementia, carers and their families currently shoulder around two-thirds of the costs themselves. This amounts to £298 million for private social care, and £622 million in providing unpaid care to people with dementia.

During my time at Alzheimer's Society, I have spoken to many carers for whom their lived reality is struggling to balance time and money while ensuring the person they look after gets the quality of care that they deserve. These are the people paying the price for the underfunding of social care, and we owe it to them to hear the stories that these numbers are telling us. Where would we be if these people could not, or chose not to, provide this care?

The hidden cost of dementia in Wales really brings home to us the scale of the challenge ahead. Meeting this challenge will require collaborative action, and I am certain that by working together, we can deliver on improvements for people affected by dementia in Wales and create a truly dementia-friendly nation.



Sue Phelps
Director of Alzheimer's Society in Wales

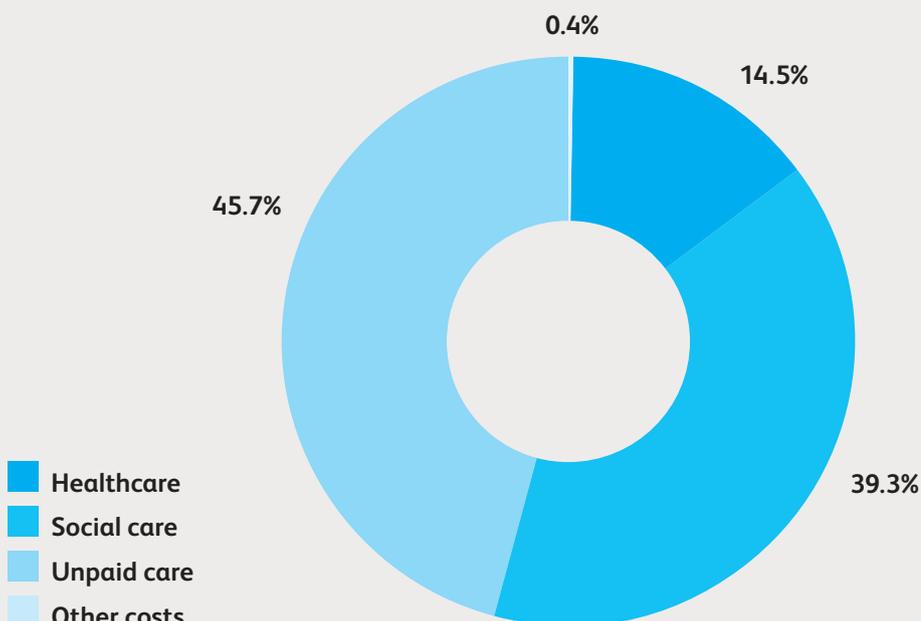
Summary

This report provides the best available evidence for the current cost of dementia in Wales. The report was commissioned by Alzheimer's Society. It was researched and written by London School of Economics in 2015.

Some of the key findings from the report are:

- The total cost of dementia to society in Wales is **£1.4 billion per year**, with an average cost of **£31,300 per person per year**.
- **£196 million** is spent on healthcare costs.
- **£535 million** is spent on social care costs (publicly and privately funded).
- **£622 million** is contributed by the work of unpaid carers of people with dementia.
- **£6 million** is spent on other costs, including police costs of missing person enquiries, advocacy services and research.
- Unpaid care accounts for **74.8%** of the total cost of people with dementia living in the community, and **45.7%** of the total cost of the overall dementia population in Wales as shown in Figure 1.

Figure 1 Estimated breakdown of costs of dementia for Wales, 2013



1 Introduction

Dementia changes the lives of people with the condition, as well as the lives of their families and other carers. People living with dementia experience declining cognitive function that, over time, affects their ability to live independently and shortens their life expectancy.

Unpaid carers – usually spouses or adult children – experience often quite heavy demands on their time and energy, which can affect their own health, employment and wellbeing. These changes can have a devastating human impact but they also have an economic impact – both on the individuals directly affected and on society as a whole. This report attempts to measure the economic impact of dementia in Wales.

The report builds upon two pieces of research previously commissioned by Alzheimer's Society. The original Dementia UK report (Alzheimer's Society, 2007) contained the first comprehensive evidence-based estimates of the numbers of people with dementia in the UK. It also included estimates for the societal costs of dementia. The report marked a step change in awareness of the impact of dementia across the UK.

The results were updated at a UK level last year. Dementia UK: Update (Prince et al, 2014) contained information about the numbers of people estimated to be living with dementia across the UK. It also included detailed information about the number of people with dementia estimated to live in different areas in Wales. The information about the cost of dementia to society was originally only available at a UK level. However, The hidden cost of dementia in Wales changes that and, for the first time, provides estimates of the cost of dementia to society in Wales.

Estimates of this type are by nature provisional and subject to reappraisal when the coverage and quality of evidence improves. In this instance, some of the data on which the calculations are based is not available for Wales, so English or UK-level data has had to be substituted. However, the findings represent the best estimates that are currently available. It is hoped that they will provide a useful knowledge base for critical policy-making going forward.

The hidden cost of dementia in Wales has been published at an exciting time for dementia in Wales. However, despite the increased focus on the topic, there is still much that needs to be done. This report demonstrates the scale of the challenge before us today, and helps us to make the best decisions today in order to face the further challenges of tomorrow.

2 Methodology

This report provides an estimate of the overall economic impact of dementia in Wales. The impact is estimated from a societal perspective. This includes the costs of health and social care services, providing unpaid care, and other services, such as police expenditure on missing person enquiries and expenditure on dementia research.

A methodology called the Expert Delphi Consensus was used to calculate dementia prevalence. The expert consensus group, consisting of 13 senior academics, reviewed all the evidence available and used their judgment to estimate prevalence. The same data has been used in this modelling for Wales as was used in our earlier modelling for the UK, except for population data and care homes fees (Prince et al, 2014). The overarching framework used to bring these data together is a new version of a model of the costs and outcomes of dementia. It builds on previous versions of the PSSRU aggregate long-term care model (Wittenberg et al, 1998, 2001) and the PSSRU dementia care model (Comas-Herrera et al, 2007).

The model is summarised in Figure 2 and makes estimates of four key variables:

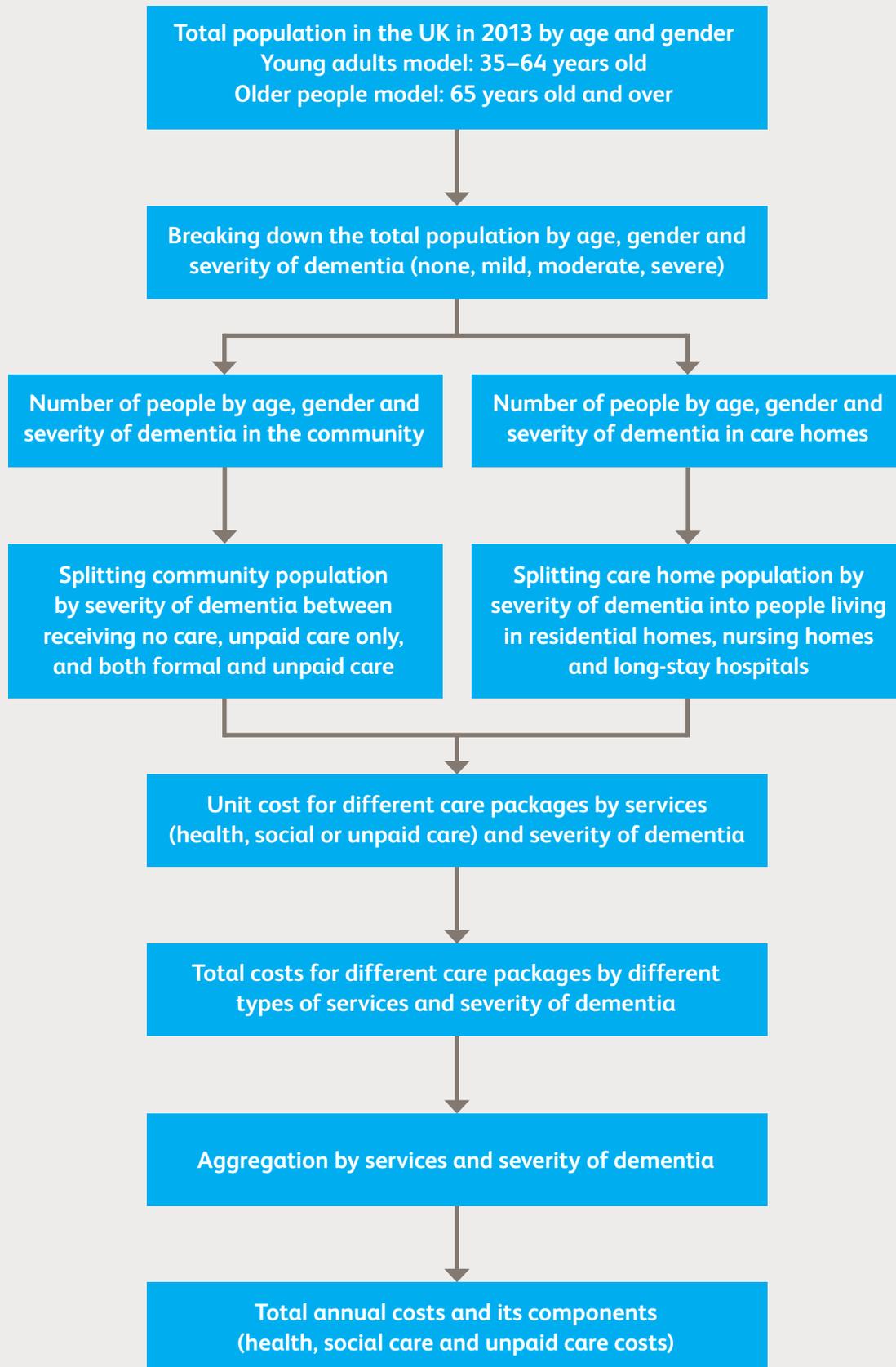
- the number of older people with dementia
- their receipt of unpaid and formal health and social care
- the costs of this care (including opportunity costs of unpaid care)
- and the outcomes in terms of quality of life .

This last element is measured using EQ-5D, a standardised questionnaire used to measure people's health outcomes. This is only used in a limited way for the purposes of the current study.

There are four main parts:

- the first divides the projected older population into subgroups by age, gender and severity of dementia
 - the second assigns people to different care settings: care in the community (including care in special housing) or in care homes (or, in a few cases, in hospital)
 - the third part estimates cost of care by attaching an average weekly cost to each type of care and each severity category
 - the fourth estimates quality of life in a similar manner (but is not reported here, since this study concentrates on costs).
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Figure 2 Structure of aggregate dementia models for younger adults and older people



The population data comes from the mid-2013 estimates for Wales published by the Office for National Statistics (Office for National Statistics, 2014). We estimated that fees in Wales are 10% lower than England for residential homes and 20% lower for nursing homes (Laing & Buisson, 2014). The costs of health and social care relate to the total costs of care for a person with dementia and not just to the marginal extra costs due to the dementia.

It is not possible, with the data currently available, to separate the costs associated with the treatment and care of dementia from those costs associated with treatment and care linked to other health or social care needs. The costs for police time, research and advocacy (categorised as 'other costs' in the results) are estimated as a share of the total UK costs, using the share of the older UK population who live in Wales.

3 Prevalence

The Delphi exercise concluded that in 2013 there were 43,477 people with dementia in Wales (Prince et al, 2014). Of those, 41,273 people were aged 65 years and over, and 2,204 were aged under 65 years.

The estimated prevalence rate of dementia in the Welsh population was 1.4%, compared to 1.3% in the UK population (Table 1). In general, prevalence rates of dementia are higher in the older age groups. Wales has an older age structure than the rest of the UK: in 2013, 4.8% of the entire UK population lives in Wales but 5.4% of older people aged 65 and over. As a result, the prevalence rate in Wales was higher than the average level in the UK.

Table 1 Estimates of the prevalence of dementia in the UK and Wales in 2013

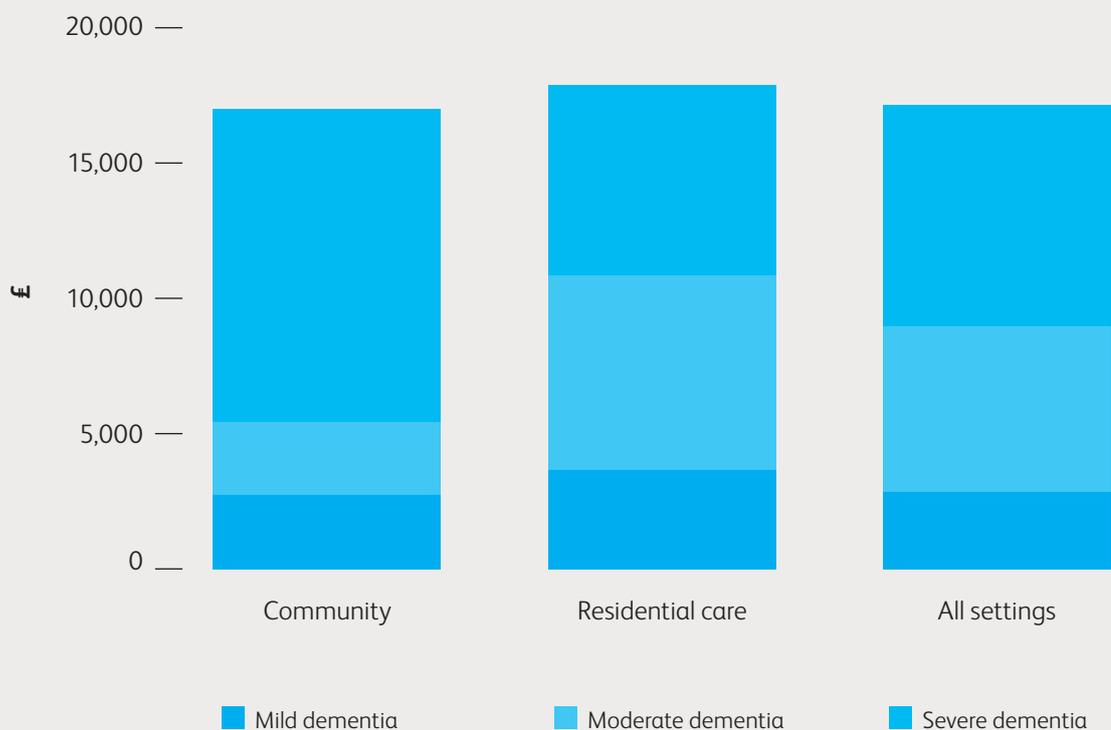
	UK	Wales
Number of people with dementia	815,827	43,477
Estimated prevalence rate	1.3% (1 in every 79)	1.4% (1 in every 71)
Older people with dementia (65 year and over)	773,502	41,273
Younger people with dementia (<65 years)	42,325	2,204

4 Healthcare costs

An average healthcare cost per person with dementia was calculated for each of the three severity levels (mild, moderate or severe dementia) and two settings (in the community or in residential care). This was done by drawing on data from a number of trials and other studies.

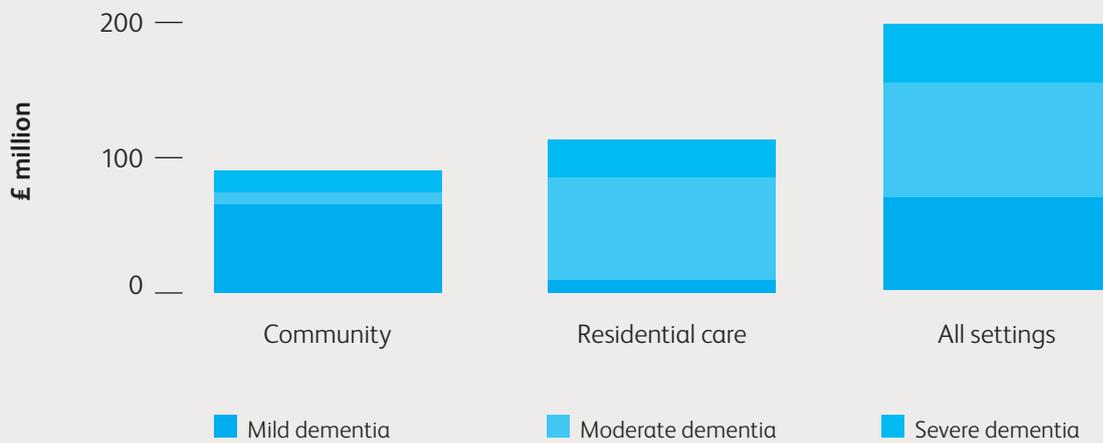
These healthcare costs cover all primary, community and secondary care services used (Figure 3). For people living in the community, average healthcare costs are: £2,752 per annum for those with mild dementia; £2,669 for those with moderate dementia; and £11,529 for those with severe dementia. The pattern of healthcare costs differs for people in residential care: £3,650 (mild); £7,208 (moderate); and £7,034 (severe). Over the full prevalent population of people with dementia, healthcare costs average £4,543 per person per year.

Figure 3 Average annual cost per person with dementia (healthcare), by severity and setting (£, 2012/13 prices)



Applying these per person averages to the corresponding prevalent populations generated estimated total healthcare costs for each of the severity and setting categories, as well as an overall figure combining all settings (Figure 4). In making these calculations, an adjustment was made to exclude the costs of dementia-specific services, such as memory clinic attendances, for the proportion of people whose dementia, it can be assumed, is undiagnosed. For those people with a diagnosis of dementia, the overall cost of diagnosis is estimated on the basis of £650 per diagnosis. The overall total cost of dementia is £196 million per year, of which around £4.6 million is spent on diagnoses. Healthcare accounts for 10.8% of total cost for people with dementia living in the community, 19.4% for people in residential care, and 14.5% overall.

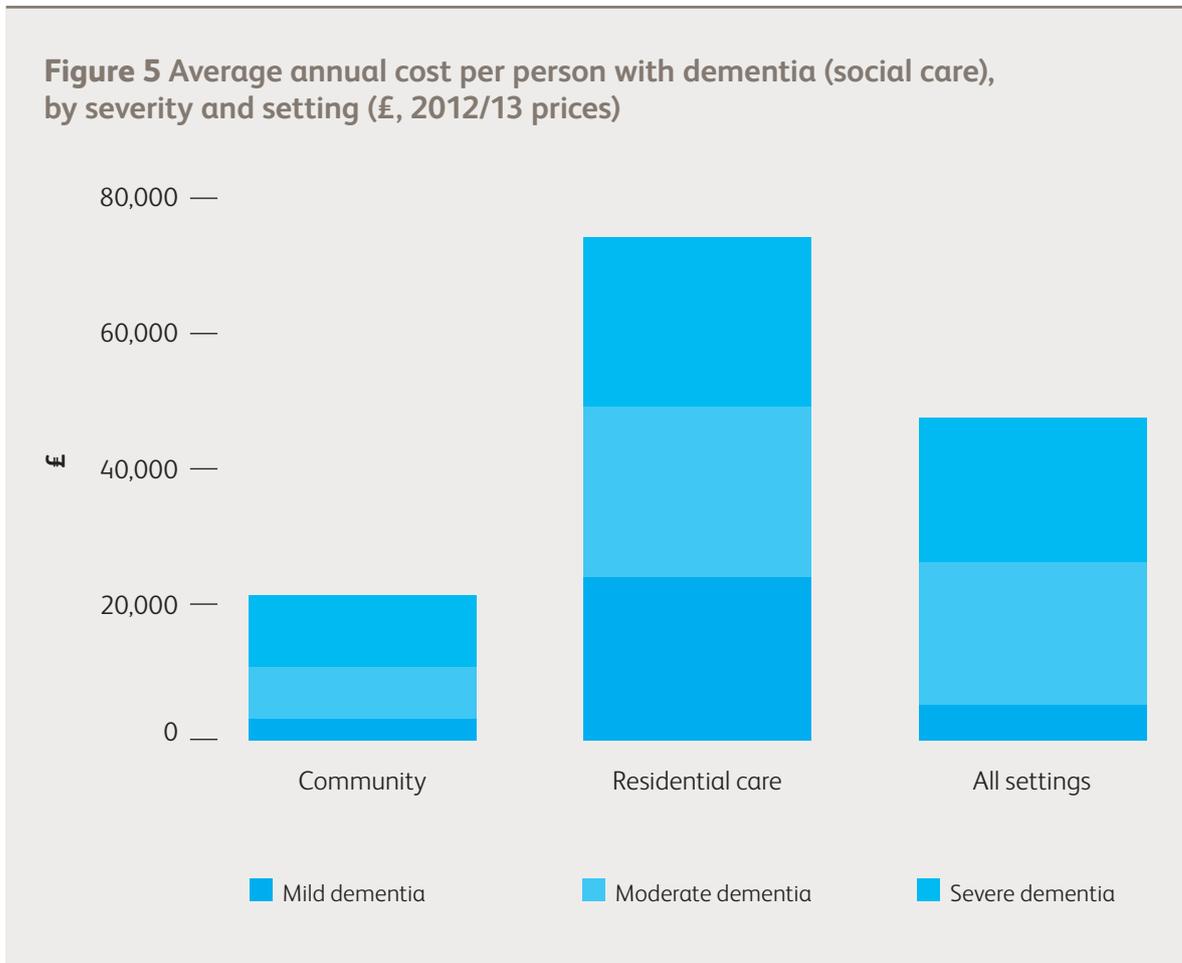
Figure 4 Total annual cost (healthcare), by severity and setting (£, in millions, 2012/13 prices)



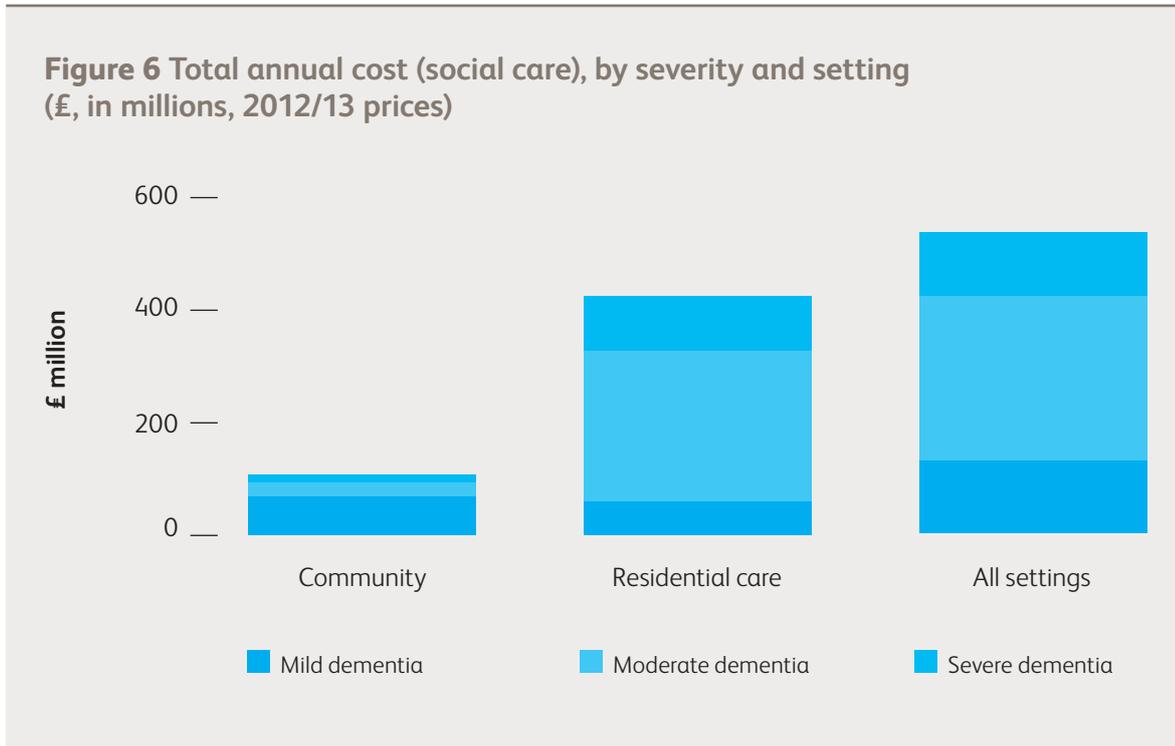
5 Social care costs

Average annual social care costs per person with dementia, by severity level and setting, are shown in the figure (Figure 5). They cover the public and private costs of assessment and care management, residential care and home-based community care.

For people living in the community, these average annual social care costs are: £3,129 (mild dementia); £7,712 (moderate); and £10,571 (severe). For people living in residential care settings there is much less variability, partly because of the difficulty of identifying per person differences within care homes: £24,129 (mild); £25,177 (moderate); and £25,084 (severe). Over the full prevalent population of people with dementia, social care costs average £12,302 per person per year.



Applying these per person averages to the corresponding prevalent populations gives the total social care costs shown below (Figure 6). The overall social care figure for Wales in 2013 is £535 million. This total includes costs for assessment and care management of around £24 million. Social care accounts for 13.9% of the total cost of people with dementia living in the community, 73% of the cost of people with dementia living in residential care, and 39.3% across both settings.



Assuming the breakdown of publicly and privately funded social care costs is the same in Wales as in the whole of the UK, of the £535 million spent on social care for people with dementia in Wales, £212 million is met through public expenditure, £298 million is borne by the individuals directly affected by dementia, and the remaining £24 million is the cost attributed to assessment and care management.

6 Unpaid care costs

While dementia cost of illness studies differ in their methods and coverage, they consistently show that the largest single cost element is borne by unpaid carers. Caring for a person with dementia usually involves very long hours, some of which are clearly identifiable as active caring, such as assisting with activities of daily living (ADLs). Some caring involves less ‘hands-on’ care, such as performing household tasks (eg cooking) or supervising and ensuring that the person with dementia is safe and comfortable.

The two most widely used methods to analyse the cost to unpaid carers are the replacement cost and opportunity cost methods:

- The replacement cost method assigns a cost to an hour of unpaid care, equal to the cost of employing a professional carer such as a homecare worker.
- The opportunity cost method attempts to reflect the value to carers of the activities that they are no longer able to carry out because of their caring commitments (such as paid employment, leisure, housework and caring for other dependents).

The approach adopted in this report to produce the ‘core’ estimate of unpaid care costs draws on both replacement and opportunity cost methods. It distinguishes between types of care activities provided, using all available information about carer characteristics and circumstances.

The imputed total cost of unpaid care for people with dementia in Wales is £622 million, using ‘core’ assumptions, which distinguish between the estimated time spent providing different types of care. This is done by valuing the more ‘hands-on’ ADL-type care using the replacement cost method, and valuing other hours using the opportunity cost method. It also takes into account carer age and employment status. The per person costs are summarised in Figure 7, and the aggregate costs in Figure 8.

For people living in the community, the average annual costs of unpaid care are: £19,714 for people with mild dementia; £31,966 for those with moderate dementia; and £34,247 for those with severe dementia. Unpaid care accounts for three-quarters (74.8%) of the total cost for all people with dementia living in the community.

For people with dementia in residential care, the inputs from unpaid carers are considerably smaller. The average costs of unpaid care for people in residential care are: £1,067 (mild); £2,909 (moderate); and £2,104 (severe). Overall, 7.2% of the total cost of residential care for people with dementia is accounted for by unpaid care. For the full population of people with dementia, unpaid care costs average £14,314 per person per year.

Data on the costs of services (such as counselling, carers' assessment and health care services) used by carers that might be associated with the responsibility of providing unpaid care was not included, even though it is well known that caring can have adverse health consequences and can necessitate the use of such services (Lamura et al, 2008). The two primary reasons for this exclusion are:

- the paucity of data on carers' service use patterns (this information is collected in very few studies)
- the difficulty of disentangling which health, social care or other services used by carers are exclusively or predominantly as a result of their roles as carers, and which are as a result of their other needs.

Figure 7 Average annual cost per person with dementia (unpaid care), by severity and setting (£, 2012/13 prices)

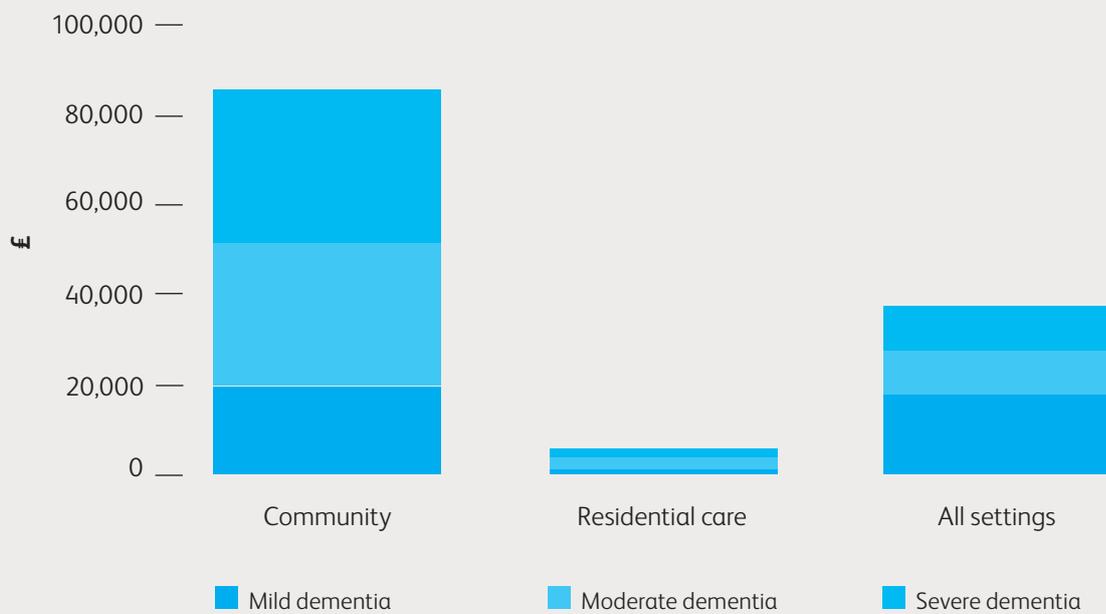
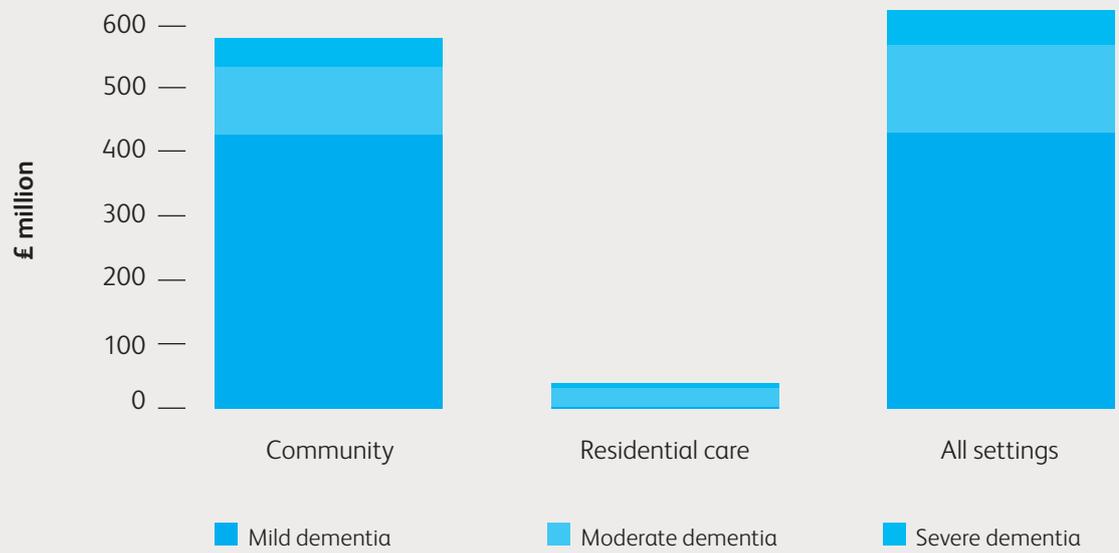


Figure 8 Total annual cost, by severity and setting (unpaid care)
 (£, in millions, 2012/13 prices)



7 Other costs

The costs of three other services – police time, research and advocacy and support – are taken into account in our modelling.

The costs capture the different demographic pressure in Wales compared to the rest of the UK. Costs relating to missing person enquiries to the police force are estimated to be £1.7 million. Scientific research on dementia is estimated to cost £4.1 million. Some third sector (voluntary) organisations provide a range of advocacy and support services to people with dementia and their carers – these costs are estimated to be £0.3 million. These three services cost £6 million in total, with an average cost of £138 per person per year.

8 Total costs and their distribution

The analyses suggest that the direct cost of health and social care associated with dementia in Wales is £731 million (at 2012/13 prices) – 73% of this direct cost falling on the social care sector.

Unpaid care costs add another £622 million, and other costs (police time, research and advocacy and support by the voluntary sector) amount to approximately £6 million. Aggregating these components gives an overall cost of £1,359 million, of which the unpaid care element accounts for 45.7% (see Figure 9).

Figure 9 Estimated breakdown of costs of dementia for Wales, 2013

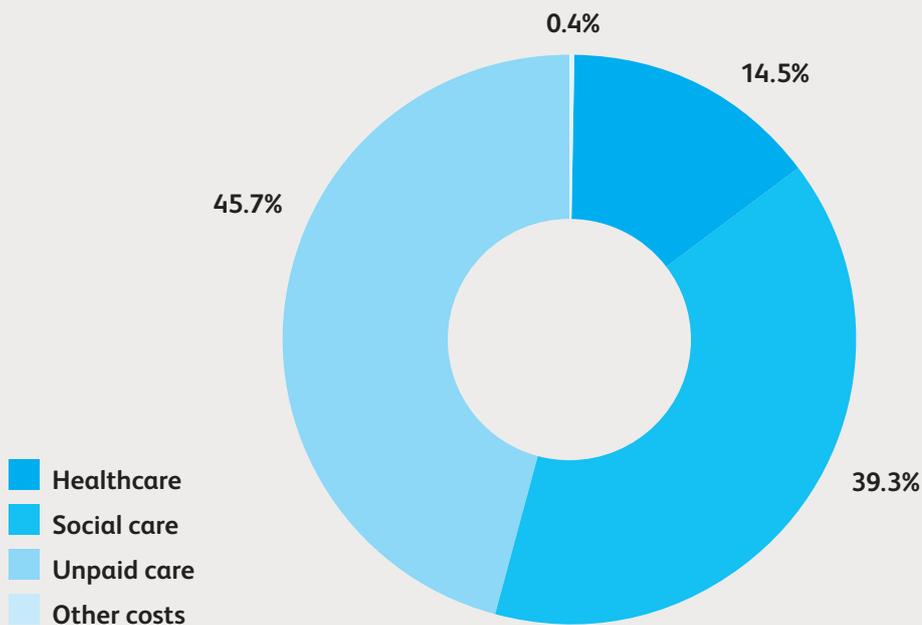


Table 2 Average annual cost per person with dementia, by severity and setting (£, 2012/13 prices)

	Healthcare	Social care	Unpaid care	Other costs	Total
People with dementia living in the community (average cost)					
Mild dementia	2,752	3,129	19,714	139	25,735
Moderate dementia	2,669	7,712	31,966	139	42,486
Severe dementia	11,529	10,571	34,247	139	56,485
All severity levels	3,181	4,082	21,992	139	29,394
(Sector cost as % of total)	(10.8%)	(13.9%)	(74.8%)	(0.5%)	(100%)
People with dementia living in residential care (average cost)					
Mild dementia	3,650	24,129	1,067	137	28,984
Moderate dementia	7,208	25,177	2,909	138	35,432
Severe dementia	7,034	25,084	2,104	137	34,360
All severity levels	6,647	25,002	2,452	138	34,240
(Sector cost as % of total)	(19.4%)	(73.0%)	(7.2%)	(0.4%)	(100%)
All settings (average cost)					
Mild dementia	2,845	5,297	17,790	139	26,070
Moderate dementia	6,122	20,996	9,865	138	37,121
Severe dementia	8,157	21,460	10,131	138	39,885
All severity levels	4,543	12,302	14,314	138	31,298
(Sector cost as % of total)	(14.5%)	(39.3%)	(45.7%)	(0.4%)	(100%)

Note: Figures may not add up due to rounding.

Table 3 Total annual cost, by severity and setting (£, in millions, 2012/13 prices)

	Healthcare	Social care	Unpaid care	Other costs	Total
People with dementia living in the community (total annual cost)					
Mild dementia	59	68	428	3.0	558
Moderate dementia	9	26	107	0.5	142
Severe dementia	15	14	45	0.2	75
All severity levels	83	108	580	3.7	774
(Sector cost as % of total)	(10.8%)	(13.9%)	(74.8%)	(0.5%)	(100%)
People with dementia living in residential care (total annual cost)					
Mild dementia	9	60	3	0.3	72
Moderate dementia	76	267	31	1.5	375
Severe dementia	28	99	8	0.5	136
All severity levels	113	427	42	2.4	584
(Sector cost as % of total)	(19.4%)	(73.0%)	(7.2%)	(0.4%)	(100%)
All settings (total annual cost)					
Mild dementia	68	128	431	3.4	630
Moderate dementia	85	293	138	1.9	518
Severe dementia	43	113	54	0.7	211
All severity levels	196	535	622	6.0	1,359
(Sector cost as % of total)	(14.5%)	(39.3%)	(45.7%)	(0.4%)	(100%)

Note: Figures may not add up due to rounding.

9 Conclusion

It is clear from this research that the overall economic impact of dementia in Wales is enormous. The total cost of dementia in Wales is £1.4 billion per year. Over two thirds of these costs are borne by people with dementia, their carers and their families – either in the form of paying for private social care or through the costs associated with providing unpaid care

The healthcare costs of dementia are considerable, totalling £196 million per year. Healthcare costs are particularly high for people with severe dementia living in the community, and those with moderate or severe dementia living in care homes.

Although healthcare costs are high, social care costs are nearly three times higher. These social care costs amounted to £535 million in Wales in 2013. This total comprises around £212 million from local authority social services for publicly funded care and around £298 million from service users themselves, in terms of privately purchased care and user charges for publicly subsidised care. This breakdown should be treated with caution because of uncertainty about the numbers of service users self-funding their care, and because it is based on UK-wide estimates. It nevertheless illustrates the extent to which the current means-tested arrangements require service users to meet or contribute to the costs of their own social care.

Though the direct health and social care costs of dementia are high, they are dwarfed by the indirect costs associated with unpaid care and support provided by family members and other carers. The costs of providing unpaid care total £622 million. This cost, combined with the expenditure on privately funded social care accounts for over two-thirds of the total cost of dementia to society in Wales per year.

The estimated costs reported here are the averages for people with different severities of dementia living in different settings. Applying those averages to the prevalent population is the most accurate way to arrive at overall national figures for direct and indirect costs. Nevertheless, such estimates cannot account for considerable variation from one individual to another in patterns of care and support and, therefore, the patterns and levels of cost that are found in Wales today. It is beyond the scope of this study to examine those variations, but commissioners and providers will obviously want to be able to respond to individual characteristics and circumstances in making their decisions.

It should also be emphasised that, while the costs of dementia have been calculated in this report, treatment, care or support arrangements have not been evaluated. Consequently, the figures here cannot be used as a basis for guiding detailed decisions by commissioners or providers. It is hoped, however, that the sheer scale of the overall economic impact will help to concentrate their minds on the scale of the dementia challenge facing Wales today and, in all likelihood, in the decades ahead.

Action taken to meet the needs of people with dementia and their carers more effectively would be likely to change the pattern of care and support, and in turn influence overall costs. For example, better recognition of dementia and a higher rate of diagnosis would push up some costs (such as those associated with assessment, diagnosis and immediate post-diagnostic support). However, this could subsequently reduce other costs, such as those associated with care home admissions (Dixon et al, 2014; Knapp et al, 2014). Wider access to good post-diagnostic treatment and care or better support for family carers could also change the pattern of costs, as well as the total costs, as demonstrated in some recent simulation modelling (Knapp et al, 2014). A major contribution to cost containment might come from better preventive strategies, such as those outlined by Norton et al (2014).

Finally, it must be recognised that costs are not necessarily 'bad', even though it might often appear to be the objective of a policy-maker or commissioner to reduce them. What those decision-makers are generally trying to do is to keep costs within the constraints of available budgets, and to allocate resources in ways that are efficient and equitable. Although the distinction between 'good costs' and 'bad costs' is not one that would be found in a standard economics textbook, it is a difference that needs to be recognised.

The 'good costs' are associated with care and support delivered in response to assessed needs and in cognisance of expressed preferences. On the other hand, the 'bad costs' are those economic impacts associated with failure to do just that, ie failure to identify or respond appropriately to needs and preferences, such as crisis admissions to hospital, unnecessarily long periods of inpatient stay and unnecessarily early admissions to care homes. The figures presented here for the cost of dementia do not differentiate between the 'good' and the 'bad' costs.

Overall, the picture painted by this report is of a condition that is exacting a substantial human and economic cost in Wales. It is hoped that these findings will concentrate the minds of all those who have responsibility for improving the lives of people with dementia, and that this focus will help to move Wales closer to the goal of becoming a truly dementia-friendly nation.

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Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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