

Alzheimer's Society public policy report

The Dementia Tax 2011

June 2011

First published 2011 by

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Registered charity no. 296645

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Alzheimer's Society is the UK's leading care and research charity for people with dementia, their families and carers.

The Dementia Tax 2011

Introduction

- Do British people aspire to live in a nation where it is possible to grow old well?
- Is Britain a place where the human rights of older people and all those who face disability are recognised?
- Do British politicians have the will to understand and respond ambitiously to the care needs of an ageing population?

In the months ahead an answer to these important questions may emerge as the Government-commissioned Dilnot report into the funding of care and support is published. Following the Commission's report the Government is expected to consult and publish a new set of proposals for reform by the end of 2011 with a Social Care Bill expected in Spring 2012.

As the population ages and more people live longer with disabilities in every age group, the care and support system has collapsed. Despite the hard work of many care staff and care providers there are many thousands of people who cannot access the quality care and support that they need to have a good quality of life. Latest reports from the Equality and Human Rights Commission, Age UK and others show that the system is not simply in need of repair but is fundamentally broken.

One of the largest groups of people needing care and support, and one of the fastest growing groups, is people with dementia and their carers. There are currently 750,000 people living with dementia in the UK and this number will grow to over 1 million by 2021.ⁱ Two thirds of people living in care homes and one quarter of all people in hospitals are people with dementia. A new solution to the challenge of providing care and support has to by definition be one that much more appropriately responds to the care and support needs of people living with dementia and their family carers.

The purpose of the report

To inform the forthcoming debate Alzheimer's Society has written this short report that follows up the Society's Dementia Tax report published in 2008.ⁱⁱ Included for the first time in this report is data from a large survey of nearly 4,000 people with dementia and carers that took place in March and April 2011. This asked people to respond to questions about their experiences and views in relation to insurance for social care, which is one of the major questions that the Dilnot Commission has been exploring.

This report covers:

1. What does the current system of care deliver for people with dementia and their carers?
2. The current system of funding and charging for care.

3. Why funding care for people with dementia is an important issue and why the current system is a 'Dementia Tax'.
4. What do people with dementia and carers think about social care insurance?
5. What would a better system of funding and charging look like for people with dementia, their carers and families?
6. What must the Government consider in its response to the Dilnot Commission?

1. What does the current system of care deliver for people with dementia and their carers?

People with a range of long term conditions need care and support to live well. In the case of people living with dementia many people don't realise that if dementia is diagnosed early and if people are given appropriate information, support and care it is possible for them to have a good quality of life and to reduce the need for services.

As the symptoms of dementia progress people need increasing amounts of care because of their medical condition. This is likely over time to include help with eating, washing, dressing, using the toilet, medication and other aspects of living. Once the symptoms of dementia become very severe it is often appropriate for an individual to live in a care home.

A series of reports has identified that people with dementia, their carers and families are not getting the care and support they need, showing that the issue of care has been a crisis in the making for many years. The most recent of these reports, relating to care for people with dementia are as follows:

- The National Audit Office found in 2007 that as a country we are not responding well to the challenge of dementia. Less than half of people are being diagnosed and far too much of the help that is offered to people is offered late. The NAO said that resources in dementia are not being used well.ⁱⁱⁱ
- The Alzheimer's Society report 'Home from home' identified that large numbers of people with dementia living in care homes are not receiving person-centred care that maximises quality of life.^{iv}
- The Commission for Social Care Inspection (prior to the formation of the Care Quality Commission) found that many care homes that were supposed to be providing specialist care for people with dementia did not have dementia training in place.^v
- The All Party Parliamentary Group on Dementia found in Always a Last Resort that over 100,000 people with dementia were being over-prescribed antipsychotic drugs.^{vi}
- The National Dementia Strategy for England identified that a new approach to improving quality of life for people with dementia is needed and set out 17 recommendations for action.^{vii}
- The Alzheimer's Society report 'Counting the Cost' found that people with dementia are often leaving hospital in poorer health than when they went

- in, making it difficult for people to return home without more care, or meaning that they have to go straight into a care home from hospital.^{viii}
- The Alzheimer's Society report 'Support, Stay, Save' found that while many people who get help in their own homes greatly value it, far too few people get that help.^{ix}

2. The current system of funding and charging for care

In terms of where the resources for care come from it is important to begin by noting that family carers provide the majority of care for people living with disabilities in the UK. Carers UK has recently estimated that it would cost £119 billion a year to replace the care provided by families to people with disabilities.^x In the case of people living with dementia the cost of care provided by families is estimated to be at least £6 billion per year.

While families provide £119 billion of care themselves, there are also care services provided by local authorities. In all parts of the UK care services provided by local councils are funded by a mixture of state funding raised through taxation and contributions made by individuals. State funding of care services for adults with disabilities is estimated to be £13.25 billion per year.^{xi} In addition, disability living allowance is provided to people of working age and attendance allowance to people who need care and support from others.

Local authorities are required to assess people who may have care needs. If they judge that there is a need for care they will decide whether the individual may be eligible for local authority funded care and will then conduct a financial assessment (means test) to see whether the person is eligible for state funding or care. There are differences between the systems used in England, Wales, Northern Ireland and Scotland. However, the huge costs associated with having a complex, long term condition can affect people with dementia in all four nations within the UK.

3. Why funding care for people with dementia is an important issue and why the current system is a 'Dementia Tax'.

Alzheimer's Society has been working closely with a large number of organisations called the Care and Support Alliance to press for long-overdue reform to the funding system for care and support. Recent scandals in care and evidence from numerous agencies including Age UK, the Equality and Human Rights Commission, the Care Quality Commission and through Panorama has shown definitively that the system of care and support is not just faltering, it is fundamentally broken. It is failing to offer large numbers of people with disabilities the quality of life that they need and deserve.

In 2008 Alzheimer's Society published 'The Dementia Tax'. The report surveyed thousands of people with dementia and their carers on their experiences of care services and the financial contribution that they have to make towards the costs of care. People described how angry they felt that having paid taxes, and having spent years caring for people, they could not

access good quality care. They also described how they felt discriminated against because most of the dementia care people receive comes from social care which is means-tested and therefore charged for, while care for people with other medical conditions such as cancer comes from the NHS and is free.

People with dementia face the highest costs of care of any group and have to pay the most towards their care. This is why charging for care is described as 'The Dementia Tax.' The reasons why people with dementia face the highest costs are:

1. Care provided for people with dementia such as help with eating, washing and dressing is not classed by the government as 'medical care', but instead as 'social care' which people are charged for depending on their ability to pay.
2. Care in a care home can be very expensive with bills of as much as £700 per week amounting to over £35,000 a year.
3. Care for someone with dementia can take place over many years, and an individual may be living in their own home and then in a care home, meaning that there can be years of care bills totalling hundreds of thousands of pounds. This is what Andrew Dilnot has described as the catastrophic costs of care that some people face under the current system.

Alzheimer's Society argues that the time is now right to develop a new long-term settlement which takes a more ambitious approach to living with disability at whatever stage of life people find themselves in.

4. What do people with dementia and carers think about social care insurance?

A survey placed in the Alzheimer's Society Living with Dementia magazine was sent to 23,000 Society members in England, Wales and Northern Ireland in March 2011. The survey asked people to respond to questions about their experiences and views in relation to insurance for social care.

4.1 Details of the survey sample

3,702 people responded to the survey. Of those who responded 3,291 people were carers or former carers and 411 people were people with dementia. Survey respondents were therefore a self-selecting group as they chose to respond and this is likely to have a bearing on the results of the survey. However, it is a large enough sample to make the results an interesting snapshot of what a large number of people with dementia and carers think about social care insurance.

- 92% of survey respondents were from England, 6% from Wales and 1% from Northern Ireland.
- 5% of people with dementia responding were up to 60 years old, 36% were between 61 and 75 years old, 23% were between 76 and 80 and 30% were over 80 years old.

4.2 How many people surveyed have purchased social care insurance?

People were asked whether they had purchased social care insurance.

Only 3% of people surveyed had purchased a social care insurance plan

It might be expected that this group of people who face particularly high costs of care might have been among the most likely to purchase care insurance. However, there are so few insurance products available and the costs of taking out a policy are so prohibitive for most people, care insurance isn't a realistic option. The number of people buying care insurance, as identified by this survey, is so low as to indicate that a meaningful 'care insurance market for dementia care' does not currently exist. This needs to be the starting point for any discussion about creating a social care insurance market.

4.3 Why didn't people surveyed buy social care insurance?

If people hadn't bought care insurance they were asked why. People were able to select more than one response from a list of options.

The top reasons people with dementia stated for not buying care insurance were:

- Didn't know it existed 54%
- Didn't expect I would have to pay for care 28%
- Didn't know I would need care so didn't think it worth buying insurance 26%
- I knew I didn't need to pay because I was below the threshold for assets 8%
- I had a pre-existing condition that meant I was ineligible for insurance 5%

The top reasons carers stated for not buying care insurance were:

- We didn't know it existed 42%
- We didn't expect to have to pay for care 18%
- We didn't know whether care would be needed, so didn't think it worth buying insurance 14%
- The insurance is too expensive 12%

The biggest barrier to people buying care insurance is therefore a lack of awareness about its existence. In addition, the fact that 12% of carers identified that insurance market was too expensive shows that people had probably spent some time investigating the possibility and been put off by the premiums required.

However, a significant additional barrier is that people do not anticipate care needs and also do not understand that people are expected to pay for care. This identifies that a new settlement will need to be accompanied by a process of public education to ensure that people understand how care is funded and what the partnership is between the individual and the state.

4.4 Why did some people surveyed buy social care insurance?

Of the small number (3%) who had purchased care insurance the main reasons cited by people with dementia and carers were:

- To protect against high care costs 47%
- To help protect assets so family members could inherit them 27%
- So that we could make choices about care without having to involve social services 25%

4.5 How has paying for care impacted on the money carers have for their own retirement?

- 41% of surveyed carers stated that they contributed towards care home fees from their own money.
- 38% of surveyed carers stated that paying for care for someone with dementia had resulted in them having less money available themselves for retirement.

The current system of charging for care assumes that families make an equal division of assets. For example, in financial assessments made by local authorities, assets that a couple have saved over their lifetime to pay for the costs of living in retirement are split in half with the assumption being that half of assets are for one person and half are for the other. What is becoming increasingly clear is that this is not the way that people plan their finances. In reality, families are already paying large sums to top up the care that local authorities pay for. The impact of this is that carers and families have less money to support themselves in their own retirement, making it more difficult for them to live independently.

4.6 Do people wish that in retrospect they had purchased care insurance?

- 34% of people with dementia stated that they wished they had bought care insurance, while 49% stated that they didn't wish they had bought insurance.
- 40% of carers stated that they wished care insurance had been bought, whereas 44% stated that they didn't wish insurance had been bought.

The answers to this question show that people are very divided on whether it would have been better for them to buy care insurance. This is likely to reflect the responses to the previous question on why people have not invested. Even with the high costs for care that people with dementia and carers face many of the people surveyed do not believe it would have been worth investing.

4.7 What would have encouraged people surveyed to buy care insurance?

People were asked to tick all that applied from a range of options listed.

People with dementia stated that the things that would have encouraged them to buy insurance were:

- If I had known it exists 38%
- If I had understood I would have to pay for social care 35%
- If it had been more affordable 25%
- If it was possible to pay for long-term care insurance from my estate after death 9%
- 15% stated that they would never choose to buy long-term care insurance.

Carers stated that the things that would have encouraged them to buy long term care insurance were:

- If we had known that it exists 25%
- If we had known that it was likely that we would need social care 21%
- If it had been more affordable 17%
- If we had understood that we would have to pay for social care ourselves 15%
- If it was possible to pay for long term care insurance from our assets after our deaths 7%
- 7% of stated that they would never choose to buy care insurance.

5. What would a better system of funding and charging look like for people with dementia, their carers and families?

A system of care and support which ensures that people with dementia and their carers receive help from the beginning of their journey is critical if we are to ensure that people can have better quality of life and that money going into care that achieves better outcomes for far more people. Some key measures of success will be:

- More people with dementia able to live in their own homes for longer.
- More people with dementia reporting that they have social contact and can make a positive contribution within their community.
- Fewer people with dementia going into hospital and those who do need to go in staying for a shorter amount of time.
- People with dementia and families having a more varied choice in relation to the care that they can receive at home and a choice of care homes.
- Care homes that are able to offer specialist dementia care, where there is lower staff turnover and staff who are trained in how to support people with complex medical problems and cognitive impairment.

6. What must the Government consider in its response to the Dilnot Commission?

A new settlement on the funding of care and support is vital if we are to ensure that older people are able to live well in later life. Few people are arguing that the state should fund everything or that the individual should

have to fund everything. We need to increase the amount of money available for care and it will need to come from a mixture of sources.

The Society recommends that the following issues need to be considered in the months ahead if we are to arrive at a long term settlement with wide public support for a partnership model of funding where the state and individuals are both required to find more money for care:

1. There must be an open debate over the summer and into the Autumn of 2011 that discusses the Dilnot proposals with the public. The debate must seek to understand whether the proposals are the correct way forward and whether they can be improved upon rather than presenting a 'take it or leave it' proposal.
2. Political parties have a responsibility to ensure that the debate happens with cross-party support and leads to solutions rather than being seen as a short-term opportunity for point scoring.
3. The media have a responsibility to ensure a balanced debate. People with disabilities already have to pay large amounts for care and talk of 'new taxes' is disingenuous when people are already paying large amounts for care. Discussion which suggests that paying for care is 'a middle class issue' is also inaccurate as people from all walks of life are having to make a contribution towards the costs of care and are still likely to under any future proposals.
4. The Dilnot proposals must be scrutinised to understand whether they really provide enough money for better quality care as well as more care. Will the funding proposed allow more to be spent per individual with care needs or simply ensure more people with care needs get the same?
5. There must be clarity about what might and might not be covered by a cap on charging for care. For example will costs of care in people's own homes and in care homes be covered? Will the range of costs for people in care homes be covered including the costs of being in a care home, besides the 'care costs'. If they are not covered by a cap then people will continue to face large bills for care that will not be covered by a cap. This will be fundamental to understanding whether a new system is fair and whether it reduces the impact of the 'Dementia Tax'. Claims must not be made that a new system 'will prevent people selling their homes to pay for care' if that is not true.
6. Any new system of care provision and charging needs to recognise the massive contribution made by family carers to the care of people with disabilities.
7. People paying for care, the taxpayer and Government will need greater guarantees about the quality of care they can expect in future. This will require a substantial change in the regulation of care.
8. Careful consideration will need to be given to how to effectively reward and retain the care workforce given that we will need more and better care for people with complex conditions.
9. Once agreement is reached on the way forward there will need to be a substantial programme of public education to ensure that individuals and families are well equipped to plan for care needs in the future.

References

ⁱ Dementia UK, a report to Alzheimer's Society by King's College London and the London School of Economics (2007) Alzheimer's Society.

ⁱⁱ The Dementia Tax (2008) Alzheimer's Society.

ⁱⁱⁱ Improving services and support for people with dementia (2007), National Audit Office.

^{iv} Home from home (2008) Alzheimer's Society.

^v See me, not just the dementia. Understanding people's experiences of living in a care home (2008) Commission for Social Care Inspection.

^{vi} Always a last resort Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes (2008) Alzheimer's Society.

^{vii} Living well with dementia – a national dementia strategy (2009) Department of Health (England).

^{viii} Counting the cost of dementia: caring for people with dementia on hospital wards (2009) Alzheimer's Society.

^{ix} Support. Stay. Save: The care and support of people with dementia in their own homes (2011) Alzheimer's Society.

^x Valuing Carers 2011. Calculating the value of carers' support (2011). A report to Carers UK by the University of Leeds, Carers UK.

^{xi} NHS Information Centre, net spend using 2008/9 prices.