

# A fairer system of charging for care

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For too long, too many people have had to pay the dementia tax- having to pay huge amounts for the essential care they need. Enough is enough - it's time to change the way we pay for care.

Time is running out to ensure that the needs of people with dementia are taken into account in any reform of the social care system, and we need your help to make the case for change right now. This is a once in a generation opportunity to create a new, fairer system of funding.

**Watch Society Ambassador Tony Robinson explain how everyone can get involved in the campaign**

## How can I help?

- Spread the word about the campaign by sharing [Tony's video](#). Did you know that unlike care provided by the NHS, social care isn't always free? If you did then you're in the minority - we need your help to spread the word and end the scandal of vulnerable people paying huge sums of money for their essential care.
- [Join our Campaigners' Network](#) and sign up to regular campaign updates. Our campaigners are at the heart of the work that we do for people with dementia. By joining the network you'll be signing up to receive regular emails, all with quick and easy tasks designed to ensure that people with dementia have their voices heard.

[More information about our Charging for care campaign](#)

## The five point test for a fairer system

We have called for our political parties to commit to a new care system that delivers better quality care for [people with dementia](#) and their [carers](#) at a fair price. However, any recommendations must take into account people with dementia. Alzheimer's Society has developed a five point test to verify whether any new proposals eliminate the [dementia tax](#) that leaves thousands in the UK paying huge bills for their care.

1. **Early intervention** Does a new system of funding ensure that people can access care far earlier in their condition than at present, before their needs become more complex? Currently most local authorities only provide access to care when care needs are judged to be critical or substantial. The National Audit Office and Public Accounts Committee have both reported that people with dementia and carers only get help far too late.
2. **Dementia Tax** Will a new system reduce the catastrophic costs faced by people with dementia, their carers and families? For example, does any cap on fees include the cost of care in people's own homes and the total package of care in care homes? If a cap only includes a partial element of the care in care homes then it will not protect people from high costs.
3. **Carers** Does a new system of funding and charging for care recognise the contribution made by family carers who provide £119 billion of care? This will require that greater support in terms of information and support services is available, but also that the carer contribution is recognised through the charging system.
4. **Quality** Can a new system guarantee better quality of care for people living with long term conditions? There need to be guarantees in place about the quality of care that people can expect, backed by a system of regulation which is able to ensure that quality is being delivered. This is something that the current Care Quality Commission has not been set up to do.
5. **Simplicity** Is a new system easy for people to understand so that they can plan for future care needs?

## Evidence on how charging affects people with dementia

Alzheimer's Society believes that radical change is needed to the system of charging for care, based on the experiences of people affected by dementia today.

### The Dementia Tax 2008

In 2008, the Society published [The Dementia Tax](#), which described how charging affects people with dementia and their carers. [The Dementia Tax 2008](#) found:

- Although unpaid carers deliver the majority of care to people with dementia, many people also need significant amounts of care and support from care services arranged through social services, often for a long period of time. Individuals pay significant amounts towards the cost of this care
- Charging affects people from all kinds of backgrounds, including those on low incomes because of the means-test thresholds
- Services for people with dementia are limited and vary considerably in quality
- The state has a responsibility to make a significant tax-funded contribution towards the cost of dementia and people are only willing to make a contribution if good quality care can be guaranteed.

### The Dementia Tax 2011

A further survey with over 3,700 people with dementia and carers in 2011 asked for people's experiences and views in relation to insurance for social care. It found that just three per cent of people with dementia have long term care insurance. The [Dementia Tax 2011](#) report also found that:

- A quarter of people with the condition said they would have bought insurance if it was more affordable
- 52 per cent of carers said they or their loved one had to contribute to the cost of their care
- Nearly half of all people surveyed (44 per cent of carers and 49 per cent of people with dementia) said on reflection, they did not wish they had taken out insurance
- The main reasons people did not take up insurance were: not knowing it exists; not anticipating care needs; not knowing that people have to contribute to care costs.

### Alzheimer's Society consultation responses

- Alzheimer's Society [response](#) to the 2009 Welsh Assembly Government Green Paper on the future of paying for care in Wales
- Alzheimer's Society [response](#) to the Dilnot Commission on Funding of Care and Support call for evidence in December 2010.

## Charging for care - what's the problem?

Alzheimer's Society believes that radical change is needed to the system of charging for care, to make it fairer for people with [dementia](#) and their [carers](#).

The current system of charging for care, such as help with [eating](#), [using the toilet and bathing](#), hits people with dementia hardest. This is because the majority of care that people with dementia need, is classed as social care, which is means tested, and not provided free on the NHS.

**Angela Smith cared for her husband and her mother, who both had dementia. Watch her story to understand why the care system is failing people with dementia.**

People with dementia are willing to make a contribution towards the cost of care, but want a system that clearly and fairly shares the cost of care between the individual and the state. It is also equally important that people are able to access more and better quality care services.

We have called for our political parties to commit to a new care system that delivers better quality care for people with dementia and their carers at a fair price. However, any recommendations must take into account people with dementia. Alzheimer's Society has developed a five point test to verify whether any new proposals eliminate the dementia tax that leaves thousands in the UK paying huge bills for their care.

Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9.00am-5.00pm Monday-Friday

10.00am-4.00pm Saturday-Sunday

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