

# Insufficient care placing hundreds of thousands of people with dementia at risk

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Quarter of a million people with dementia are being let down by care and support that fails to meet their needs an Alzheimer's Society report found.

According to 'Support. Stay. Save. Care and support of people with dementia in their own homes', this substandard care will result in 50,000 people being forced into care homes early. For each avoidable month these people spend in care, the state will face a bill of at least £70million. Tens of thousands more will be admitted to hospital unnecessarily.

Carers who said the person with dementia was not receiving sufficient care and support (50%) spoke of people being left bedridden, wearing unchanged incontinence pads and malnourished. More than half (52%) of carers were also being put at risk of stress, depression and other serious illnesses because they were being left to struggle unsupported.

There is clear evidence home care staff want to be empowered with additional training and support to help them provide quality dementia care and 72% said they appreciate people with dementia have special needs. However only 10% said they think the care people with dementia living at home receive meets all their needs.

In the current environment of spending cuts, Alzheimer's Society predicts the situation is set to get much worse. The charity is now calling on commissioners to think long term and invest in dementia services and training to keep more people out of hospitals and care homes and to save the NHS and councils from bankruptcy.

Jeremy Hughes, chief executive of Alzheimer's Society said:

'It is an absolute travesty that so many people with dementia are being forced to struggle without the care and support they need. The consequences of this represent an unacceptable human and financial cost.'

'Half a million people with dementia live in the community and many will need help with everyday tasks such as eating meals, washing or going to the toilet. This help not only maintains dignity but prevents serious health issues. While staying at home is not right for everyone we know many people want to remain in the familiar surroundings they are used to with family or loved ones. Only with the right support will this be possible.'

Kevin Whately, Alzheimer's Society ambassador and author of the report's foreword, said:

'I know from caring for my mum just how much care and support people with dementia can need to help them live a quality life in their own home. We were fortunate that we had access to some excellent carers and the difference they made to my mum's life was immeasurable. It pains me to think that there are so many people out there struggling alone. This is an unacceptable situation that we can't let continue.'

Delia Fox, who cared for her husband Bill who had dementia until he died last year, and who now gives talks to Alzheimer's Society carer groups, said:

'Trying to get help with caring for Bill was an absolute nightmare. Even after he was left bedridden following a hospital stay, social services refused to provide any support. I was able to get some care privately but this was nowhere near enough and I had no choice but to become a 24 hour carer.'

'Bill eventually died at home which is what he would have wanted but the end of his life could have been so different had we had the right support. He wouldn't have ended up in hospital, he could have walked for much longer and wouldn't have been stuck in bed. I want to do everything I can now to prevent more people going through what Bill and I were forced to endure.'

'Support. Stay. Save. Care and support of people with dementia in their own homes', which is based on a survey of 1,436 people with dementia and carers and 989 home care workers found:

- 50% of people with dementia who live at home aren't getting the care and support they need
- 1 in 10 carers said poor care resulted in the person with dementia having an avoidable admission into hospital
- 1 in 10 carers said poor care resulted in the person with dementia going into residential care earlier than expected
- 52% of carers said they weren't receiving enough care and support to help them fulfil their caring role. This has a negative impact on their health and the health of the person with dementia
- 83% of carers say living at home is very important to the person with dementia
- 44% of carers said the person with dementia was receiving enough care and support. Around half of these people believed this had a positive impact on symptoms of dementia and on carer health
- Only 10% of home care workers think the care and support people with dementia receive in their own homes meets all their needs

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## **Contact the Society**

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## **Putting care right campaign – care at home**



There are 750,000 people with [dementia](#) living in the UK and two thirds of people with dementia live in the community. [Alzheimer's Society's Support. Stay. Save. report](#) reveals many people with [dementia](#) and [carers](#) receive insufficient support and care at home. Part of the Society's ongoing [putting care right campaign](#), Support. Stay. Save presents findings from over 2,400 people with dementia, carers and home care workers.

### **What are the headline findings of the report?**

[Support. Stay. Save](#) found that people with dementia and carers greatly value living in their own home and being able to play a part in the community and want services to enable them to meet these aspirations. However, many are not receiving sufficient support and care for this to be a reality.

Half of those who responded to Alzheimer's Society survey said that people with dementia and their carers living at home do not receive adequate support to meet their needs. This lack of support not only leads to [admission to hospital](#) and early entry into [care homes](#), but also risks leaving hundreds of thousands of unpaid carers at risk of stress, depression and other serious illnesses.

[Separate analysis on Support. Stay. Save](#) suggests that as many as 50,000 people currently living with dementia in the UK may end up going into care homes early because of insufficient support in the community. For each month these people can be supported at home, rather than in care, the state will save £70 million in care home bills.

The research also found that the home care workers who responded regularly worked with people with dementia and understood that they could have a [good quality of life](#). However, many reported they still needed more training on delivering good dementia care.

- Download a copy of the [report](#) and [executive summary](#).

### **What the Society is calling for**

These findings show that while people with dementia greatly value living in their own home, many are not receiving sufficient services. Alzheimer's Society is calling for:

- An urgent and concerted effort to support people with dementia to live independently in their own homes and avoid early and unnecessary admission to long term care.

- Commissioners to recognise the considerable resources already being spent across health and social care on dementia and the opportunity to use them more effectively.
- Carers to be supported to carry out their caring role.
- Joined-up working across health and social care to become the norm
- Variable experiences of care and to be tackled through expanded sharing of good practice.
- Home care workers to be supported to provide good care to people with dementia in their own homes.

More detailed recommendations can be found in [the report](#).

## **Take action**

Alzheimer's Society campaign makes clear the need for improved services and we need you to help us make that case.

- If you live in England or Wales you can [take action now](#)
- If you live in Northern Ireland you can [take action now](#)

## **Development of the report**

To build up evidence for this report, the Society ran two surveys in autumn 2010, one on [people with dementia and carers](#) and one on [care workers](#). 1436 carers and people with dementia and 989 home care workers responded to these surveys and the Society would like to thank all those who responded.

In addition to these surveys, the Society conducted group discussions and one to one interviews with people with dementia and carers and interviews with commissioners of social care services.