



“Why call it care when **nobody cares?**”

An Age UK campaign report about how older people
and their families experience the crisis in social care

Quick Summary

We asked 127 older people and their families, around the country, in depth about the social care system, its successes, failures and how it could be improved.

What is the problem?

- Too many professional carers just don't have the time, skills or resources to deliver quality care
- When you do get care it too often isn't very good
- The cost of social care is crippling families and older people financially
- Everyone's trying their best to care for a loved one but they're often at breaking point
- Working out what to do and navigating the system is a nightmare when trying to arrange care for yourself or a loved one

And the solution?

- The responsibility needs to be shared across society
- People were only happy to pay more if what they received in return was going to be proportionate and fair
- Ring-fenced funding is important to older people and care users
- As a society we need to establish what is reasonable for families to do and the help they'll get to support them
- People want to feel secure



Freda, Surrey

Key stats

- Over 1.2 million people aged 65+ don't receive all the care and support they need with *essential* daily living activities - this rises to over 1.5 million when you take into account *instrumental* activities of daily living such as managing medication
- There are now over 2 million carers aged 65+, of these more than 400,000 are aged over 80. Amongst the oldest carers (80+) 37% are providing 20 hours or more of care a week, and 34% are providing 35 hours or more
- 1 in 5 social care providers were rated as inadequate or requiring improvement by the Care Quality Commission in 2017
- Tightened eligibility criteria have led to an estimated 25% reduction - more than 400,000 - in the number of older people accessing publicly funded care since 2009/10

The current situation

The social care system has been in crisis for too long and it is only getting worse, with too many people having unmet needs and not getting the help and support they desperately need. Due to underfunding at a national level and resultant cutbacks from local authorities services can no longer cope with the growing demand for social care. A bold and ambitious solution is needed to tackle the social care crisis.

Age UK welcomes the promised Social Care Green Paper announced in November 2017, but notes that this is the latest in a long series of commissions and

reports: this time it must deliver for older people, who need change NOW.

The Green Paper is a chance to address the fundamental failures that exist within our social care system and to think about how we support people as they age. A meaningful consultation with a broad scope could lead to a sustainable solution that addresses unmet needs and enables vulnerable older people to live their later lives with the dignity they deserve. It must result in an improved system.

What we did

We set out by asking the question, ‘what do older people and their families think are the problems in the social care system and how can the Government find a solution?’ We went to 13 different locations across England to hold ‘listening events’ with older people and their families to ask them these questions. The participants were older people and their unpaid carers who had used Age UK services locally and the locations were diverse and included poorer and better off areas, rural and urban, North and South. Interestingly, although these places were varied we heard very similar views and experiences in each place.

In all we spoke to 127 people in depth about the social care system, its successes, failures and how it could be improved. We also invited their local MPs along to hear directly from their constituents about how they experience the system and what they think some of the solutions could be.

This is what older people and their families said they think about the care crisis and how a solution can be found.



Elizabeth, Reading

So, what's the problem?

Too many professional carers just don't have the time, skills or resources to deliver quality care.

Over and over again, older people and their families told us that the system does not allow professional carers to give the care they might want to give. They are not trained to a consistent standard, they are in such a rush that they do not stay for the full length of their planned visit, they 'box tick' and there is no continuity, with many seeing multiple different carers each week. As a result, there is no time to build a relationship or even establish good communication. Older people don't receive 'person centered care'; indeed what they get can often not be called 'care' at all.

People didn't blame professional carers – they saw it as a failing of the system which needed to give carers good training, decent pay, the time and resource to be able to do the job properly and the recognition that they deserve.

“My relative received care at home that was so poor, she had advanced dementia and was found naked on the sofa 10 minutes after the carer had signed the log book and an ambulance had to be called to bring her to hospital.”

When you do get care it too often isn't good.

The majority of the people we spoke to highlighted the poor quality of care that they and family members received. They were shocked at some of their experiences of home care and of care

provided in care homes. A carer said her husband often wasn't properly washed and went for hours without being fed or given a drink. She had resorted to putting signs around his room as a reminder for staff to do basic tasks such as washing, brushing hair and leaving a drink in his reach. Another said her Dad had fallen in a care home and broken both his hips but the staff had not notified the family or sought urgent medical help.

Many felt that if they had more money, they would be able to pay for a significantly better standard of care. Many older people feared going into a care home because of how poor they thought the care would be.

“The quality of care I receive is not worth paying for.”

The cost of social care is crippling families and older people financially.

Among those who had to pay for their social care many were shocked by the cost and said it was crippling their families financially. There were huge misconceptions about how care is funded and how people can access support. Many feared that they might lose their homes. When people were entitled to free care and took it up they found it wasn't enough to pay for a decent standard so they had to 'top it up' themselves. Those who weren't entitled to support had to pay a lot more and felt like they were signing 'an open cheque'. People who worked their whole lives to pay for their home were worried



James, Trafford

The Council waited for things to get so bad before they intervened. It always felt like a cost-cutting exercise; they were reactive rather than proactive, they only acted when they absolutely had to.

So, what's the problem? (cont)

they'd lose it because they fell ill and needed high levels of care. People felt guilty about leaving their families in debt in order to pay for higher-quality care.

One participant financially supported 3 older family members who needed care at home and had personally paid over £100,000 in care fees. People felt generally wholly unprepared for the high cost of social care at home and many said that they were not receiving value for money.

The idea of there being a 'care postcode lottery' came up repeatedly; participants thought that where you lived had a huge impact on the quality of care you received and how much you paid for it.

“We do this for nothing. We save this country tens of thousands of pounds, per person, per week, per month, per year. And we just crack on and do it. Because you feel you have to.”

Everyone's trying their best to care for a loved one but they're often at breaking point.

The people we spoke to wanted to do right by their loved ones, but everyone agreed that it had to be voluntary and that people who need care should also receive support from the local authority or NHS. People who were caring for parents or partners with dementia in particular often said they felt out of their depth and 'dumped on', struggling without enough basic help or specialist dementia support. Some older people themselves were acting as carers with no support from other family members, either because they had no family, relatives lived abroad, worked full time or had their own children to look after.

There was a strong sense amongst the unpaid carers who attended of feeling 'abandoned'. They often said they felt lonely, isolated and generally out of their depth. They felt the system had left them to cope alone at a time when they needed its support the most. In caring for his wife a participant had a breakdown because he simply couldn't cope with the endless, intense stress of caring for his wife 24 hours a day with no help.

“Families are at breaking point due to the lack of support and money they get, the disinformation and the disjointed organisations.”

Working out what to do and navigating the system is a nightmare when trying to arrange care for yourself or a loved one.

People experienced huge delays in receiving the information and basic help that they needed and some didn't get it at all.

People were worried and frustrated about the length of time it took to get their older relative the care they needed at home. We heard of this leading to older people with dementia wandering out into the streets and getting lost, locking themselves out of their home, setting fire to their kitchens, or going days without food. All of these things happened while the families were waiting for Social Services to come and assess the older person and decide what care they were entitled to in their own home.

The majority of people we spoke to struggled to find out how to arrange care for their older relatives at home. People were confused about what care is available, who provides it and how it is funded. Many were under the misconception that care at home would be provided free by the NHS.

“My 93 year old neighbour was left 10 days without a care package after a stay in hospital. She relied solely on neighbours to look after her.”



And the solution?

We asked participants what they thought about the key questions and principles the Government must take into consideration when writing its Social Care Green paper, including the solutions.

We found broad consensus over the principles but no preference for a single, definitive solution. When debating possible solutions it's important to note that most people initially reacted negatively but after some discussion about an idea and how it would affect them most became more positive. The 5 main principles older people and their families wanted to see from the Green Paper were:

1. The responsibility needs to be shared across society

- everyone needs to pay into the system, not just care users and their families. Older people felt they had paid into the system all their lives and the whole population should continue to do so. The system should be there for them when they need it and everyone has a responsibility to help fund it. Ideas such as an extra 1p on national insurance and 5% off everyone's estates following their death seemed popular - the common theme was that everyone should contribute in some way(s).

2. People were only happy to pay more if what they received in return was going to be proportionate and fair

- they felt they were already paying a lot of money into the system and most were not getting a very good service as a result. If people are going to pay more out they want a much better offer in terms of the quality of services they receive, in exchange.

3. Ring-fenced funding is important to older people and care users

- if extra funds are to be raised from the public pocket for social care then people are keen to see it ring-fenced. There's concern the money could be diverted elsewhere; and if it was raised to be shared across the NHS and social care they worried that the NHS would take the lion's share and social care would lose out.

4. As a society we need to establish what is reasonable for families to do and the help they'll get to support them

- the Government needs to understand how much many families are already doing to look after their loved ones and how hard this is for them. Many people we spoke to were delivering intimate personal care on a full time basis, and worries were sometimes expressed that this was too much to expect adult sons and daughters to do for their parents. Asking families to do more won't fix the fundamental problems in our social care system and more support needs to be given to those who are carrying enormous amounts of responsibility for older relatives in declining health, as well as providing them with constant, ongoing care and support.

5. People want to feel secure

- older people and their families wanted to feel secure financially and confident living in their own homes, without fear that they would have to sell up or, in the case of some carers, become homeless. They wanted to know there was a properly functioning safety net and many wished for future generations not to have to go through what they've experienced from the care system.

What can you do?

1. Post on social media supporting our campaign
2. Ask a parliamentary question
3. Write to the Secretary of State for Health and Social Care
4. Become a social care parliamentary champion

[@AgeUKCampaigns](#)

[#CareCrisis](#)

Contact us to find out how we can support you to take action in Parliament or your constituency.

Sarah's Story



Taking on the task of caring for Grandma stretched Sarah's family to breaking point. Her mother Jean's care is a huge responsibility that Sarah's family took on while still juggling all aspects of their everyday lives. Even their 14 year old daughter is involved in caring for her Grandma, getting her out of bed every morning before going to school.

Sarah became incredibly frustrated by the lack of outside help. She told us that she understands how some carers became suicidal. Sarah had been in tears on the phone with the council, begging them for some respite care. She felt ignored and left to get on with it, she was struggling to look after a loved one whose care needs had developed beyond what she could cope with.

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Show them **somebody cares.**

About Age UK

Age UK is the country's largest charity dedicated to helping everyone make the most of later life. Our vision is to make the UK a great place to grow older. Our ambition is that all 11.8 million older people across the UK can:

- Have enough money to live without the fear of poverty in later life
- Enjoy life and feel well
- Receive high quality health and care
- Be comfortable and secure at home
- Feel valued and able to participate

Contact us

For more information, to meet with us or take one of our actions please contact our External Affairs team:

- email campaigns@ageuk.org.uk
- or call **020 3033 1226**
- or visit www.ageuk.org.uk/carecrisis