

# Q is for Quality

The voices of  
older people  
on the need  
for better  
quality care  
and support

**AGE**  
*Concern*



Each and every person shown on the front cover of this report, plus hundreds more, have been sharing their thoughts and their personal experiences of the current care and support system with Age Concern.

Age Concern England would like to thank everyone who has contributed to the Big Q listening events including: Age Concerns who arranged and hosted an event, all the MPs including ministers and shadow ministers who listened and responded to all the issues raised and, of course, every individual who gave their time to attend and share their experiences and thoughts about care. Without your help and support the events, and this report, would not have been possible. Thank you.

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## What does this symbol mean?

The discussions at ten of the listening events were video recorded. Wherever you see this symbol it means there is a video clip to accompany the picture. Clicking on the picture will play the video in your default web browser. To view the video clips in this way requires an internet connection and access to [www.youtube.com](http://www.youtube.com).

All of the videos can also be viewed directly at <http://www.youtube.com/ageconcernengland>.

A larger version of this pdf containing all of the videos is available on a cd-rom. To obtain a copy of the cd-rom, email [care@ace.org.uk](mailto:care@ace.org.uk).

# Introduction

*“I had a stroke four years ago and I’m paralysed down the left side and use a wheelchair. I’ve spent a lot of money on adaptations so I can stay at home. I get four lots of care a day: a carer comes in four times a day – different ones. I get an hour in a morning, a quarter of an hour at lunchtime, half hour at tea time and quarter of an hour at bedtime.*

*I’m privately funded because I have a bit of savings, but not a lot. This care costs between £700–£800 a month, and, no, it’s not good value. I get enough, but the standard of care is the problem. The care is very varied as some of the carers haven’t got the ability to do it, they come in and have no interest in the person themselves.*

*For that amount of money I would expect them to do their job as they are expected to do. They just don’t do things. I would prefer to have a regular carer who comes at regular intervals, as I could build a relationship with them. At the moment I get lots of people doing personal care for me, I feel uncomfortable if it’s a new carer. I’ve told the care manager when there have been problems with the carer and they say they will speak to them, but nothing happens or changes. You should get more of a say, but it doesn’t work that way: you pay for your care but you don’t get a say.*

*I get quite daunted thinking about future care. If I went into 24-hour care I would have to sell up and go, but I don’t want to do that. I think you should have independence. I want to get care to be able to stay in my own home as long as I can.”*

Pat, 71 from Cheshire

Pat's story is just one of the many experiences that have been shared with Age Concern in the last few months as our Big Q campaign toured the country.

The Big Q is Age Concern's campaign to improve the quality of care, and Pat actively supported the campaign by sharing her experience with Age Concern. Her concerns were echoed by many older people around the country who have first-hand experience of the care and support system.

We also heard from people in their 50s, 60s, 70s and 80s who are not yet in need of care or support but are deeply worried about the thought of relying on an already ineffective system in the years to come.

It should be clear to anyone who reads the real-life experiences and concerns on the following pages that the current care and support system is failing many older people.

Older people have told us they want a better care and support system: a system that provides everyone with good quality care and treats all with dignity and respect. The call for action from older people is loud, clear and unified: something must be done, and it must be done now.

Age Concern agrees. We believe that the better care and support system that older people want can only be achieved if radical changes are made. And these radical changes must be made now, not in twenty years' time when the system will be beyond repair.

Following our discussions with older people, Age Concern wants to see:

### Care today

Today's care system needs urgent attention. Dignity, respect, fairness and human rights must lie at its heart. Information, advice, assessment and advocacy must be free for all who need it. And we need a new national entitlement to high quality care and support.

*To achieve all this will take £1-2 billion.  
This money needs to be spent now.*

### Care tomorrow

Looking into the future, our society must decide whether it wants to make a radical move away from the means-tested system of today. Most of the people we've spoken to wanted a more collective solution where we all pay tax or insurance so that the system is there for us when we need it. Politicians must lead the public debate and win support for a new system for paying for care and support.

The older people who made our Big Q listening events possible shared their doubt that things will change for the better. As a participant at Age Concern Redbridge's listening event put it:

*"This situation has been going on for years, will things change this time?"*

We hope for Pat's sake, and for all those who need care and support now and in the future, that the answer is 'yes'.

# Age Concern's campaign for quality in care



The way our social care system operates is little short of a national disgrace, forcing many older people to soldier on without the support they need, stripped of their dignity and robbed of their independence.

Up and down the country, the care system is creaking at the seams. Starved of funding, and facing ever increasing demand, local authorities are making severe cuts to their services. Nearly three quarters now only provide help to those with the highest needs, and the quality of the services provided is often woefully inadequate. Older people who need help with everyday tasks such as getting dressed, getting in and out of bed, eating, washing, taking medication and going to the toilet are forced to struggle on alone, or rely on the support of friends and relatives.

This is causing mounting anger in town halls and among local residents but this anger has yet to filter up to a national level. Instead, politicians talk glibly about how people should not have to sell their homes to pay for their care.

The reality is harsh for thousands of poor and vulnerable people who worked hard all their lives and put aside as much money as they can, only to see it swallowed up by a punitive means-testing system and spat out in the form of care that often falls below the standards they have the right to expect regardless of whether they are paying for it themselves or being helped with funding.

And it will only get worse. The population is ageing rapidly and will put further strain on our crumbling care system in the years ahead.

Unless this situation is urgently addressed, we will be betraying the current and future generations of older people.

Radical changes are needed, but so far the Government has only tinkered at the edges. It is over a decade since the new Labour Government promised to do something about the care system. This issue cannot be allowed to drift any longer.

Happily, there may be a light at the end of the tunnel. The Government has promised to publish a Green Paper containing new proposals to reform social care in early 2009. This presents a once in a generation opportunity to get the message across that we are no longer prepared to tolerate a second class care system.

Age Concern wants to see a high quality care and support system that enables older people who need care to keep their dignity, their rights and control of their everyday lives. That is why we launched the Big Q campaign.

In our previous Big Q campaign report on care and support, '*Quality not Inequality*', we described the five building blocks that must form the foundations of this system:

- Services that respect people's dignity
- Services that give people independence
- Services that deliver fairness to all in need
- Services that provide people with clarity
- Sufficient funding to deliver all this.

## Why quality?

Age Concern's top priority is to ensure that the system delivers high quality care and support that meets the expectations of older people.

High quality care and support will maximise an individual's quality of life, sustain their independence, and promote and protect their human rights.

However, for many people, help comes too late. Often support is only offered once someone is severely disabled. Services should be on offer earlier, to help people cope with lower level care needs and prevent problems getting worse.

There is also the question of who should pay for care. Today, only people with very low incomes receive free home care, and nearly everyone has to pay something for residential care. This leaves many older people worried about how they will pay expensive care bills.



# The Big Q listening events



*“It’s not quick and it’s not easy, but thank goodness there are organisations around like Age Concern to facilitate this debate and make sure we hear the voices of the people that matter the most, the carers and, more importantly perhaps, the people who need the care.”*

Rt Hon Alan Johnson MP, Secretary of State for Health



*“It’s a testament to the frustration that meetings like this are taking place. If there wasn’t a real sense of anxiety and need there would be no need for Age Concern to be having this discussion session.”*

Stephen O’Brien MP, Shadow Minister for Health

During 2008, Age Concern centres, libraries, village halls and community centres have been filled with older people sharing their thoughts and experiences of the care and support system at listening events.

A listening event is just that: an event organised by local Age Concerns which gives MPs the opportunity to listen to older people from their constituency discussing, in this instance, care and support.

At each event, older people met to discuss their concerns about the current care and support system as well as their thoughts on what a high quality care system would look like. These considered views were then put to their local MP for discussion.

The listening events started in April in Staffordshire, and quickly spread across the country taking place in Hull, Cheshire, Leicestershire, Torbay, Cumbria, Sutton, Stafford, plus many other towns and villages with the final event taking place in Bournemouth in November.

In fact, since the first one in April 2008, there have been 47 listening events involving more than 700 older people. 45 MPs, including ministers and shadow ministers have attended to hear the concerns and ideas put forward by the participants.



*“This morning what we did was spend about an hour and a quarter, hour and a half, looking at a whole range of issues that came up around care, and then we focussed in on two particular aspects. One is the cost of care, one is the quality of care.”*

Age Concern Norfolk listening event

The participants came from a wide range of backgrounds and were aged from their late 40s to their 80s. Many who attended were either receiving some form of care and support, or were providing it themselves. Others attended because they were concerned that they may need care and support in the future and were worried that it may be of poor quality.

*“The care system is in need of a thorough overhaul and if this helps to contribute to it I am very glad.”*

Age Concern Norfolk listening event

At each listening event, participants had the freedom to choose which aspects of care and support they discussed. Consequently, the discussions varied from event to event with some concentrating on a particular aspect of the care and support system, while others discussed a wide range of issues.

However, the majority of comments, concerns and ideas broadly reflected the five building blocks – money, dignity, clarity, fairness and independence – which were described in Age Concern’s report, “*Quality, not Inequality*”.

Space does not allow us to include every issue and comment raised at each event. Instead, we have pulled out the two or three key concerns that emerged most frequently under each building block.

The suggestions and ideas put forward by participants to improve the care and support system can be found on pages 32 – 35.

## The Big Q Postcard

As well as organising listening events around the country, Age Concern also produced a postcard to gather even more comments and suggestions from members of the public.



The Big Q Postcard

Age Concern's campaign for quality care

I am concerned about the quality of care because *so many of the elderly are not receiving the care they need. My husband is 86, I am 82 and I fear for us when we need care.*

I call on the Government to urgently reform the care system to make sure that all older people are treated with dignity and respect and receive the care they need.

Name:  
Address:  
Postcode:

I would like to receive updates on this campaign

No stamp required

FREEPOST AGE CONCERN CAMPAIGNS

By the end of October, more than **8,000** postcards had been returned to us. The comments – which echo the experiences and concerns raised at the listening events – have also contributed to this report and examples can be found throughout its pages.

Age Concern England/Mencap listening event in Sheffield, 11 July 2008



# Building block 1



*“Top up fees of a £100 for residential care and £200 for nursing care are now the common, not the exception.”*

Age Concern Hampshire listening event



*“It’s going to have to cost more money. It’s this ageing thing that you touched on. Older people are living longer, people with disabilities are living longer. It’s expensive to try and keep this to a high quality.”*

Age Concern/Mencap listening event, Sheffield



Throughout the listening events the issue of money was raised and concerns over the cost of care were strongly expressed. The main concerns raised were:

## 1. Care is expensive

Older people are well aware that care does not come cheap and that many will have to pay for their own care: the average cost of residential care in England is £467 a week, for instance.

However, the true cost of care is much more than the cost of a care home or home care services. For the partner or family member, it can also include loss of earnings and pension rights; the cost of extra visits to the doctor or hospital; trips to seek reassurance that their loved one is managing; the expense of car parking or day activities. Extra laundry, special diets, heating costs, etc can also be necessary. All of these additional costs must be remembered when considering the true cost of care – a large amount that many will struggle to pay.

*“A lot of pensioners are still on the breadline. When they go into care they don’t know how to pay for it and it puts them in a difficult situation.”*  
Age Concern Norfolk listening event

*“Modest savings can soon be exhausted if long-term care is needed.”*  
Quote from Big Q postcard

## 2. The system penalises those who save

There is a strong feeling that the care and support system is unjust to those who have managed to save a little throughout their lives. Often they will have a small amount of savings that takes them over the threshold (£22,250) meaning they receive no state-funded care, but it is not enough to pay for the full cost of care.

*“It’s confusing and unfair on those who save.”*  
Quote from Big Q postcard

*“No encouragement to save - spend, spend, spend and get everything free.”*  
Quote from Big Q postcard



*“The system’s not fair. It’s a disincentive to save. It’s a disincentive to work and put money aside for your future retirement because if you need care you’re going to have to pay, well in Cheshire you’re paying £17 odd an hour domiciliary care which will just eat up savings that you’ve made.”*  
Age Concern Cheshire listening event

Older people have told us this leaves them worrying about how they are going to afford care and support, and are often scared to spend their savings in case they need every penny to pay for any care they may need in the future.

*“Although not poor, we could not afford to pay for help in our home where we wish to remain.”*

Quote from Big Q postcard

### 3. Why does Carer’s Allowance stop while caring continues?

Given that there are more than three million people over the age of 50 in England who are providing unpaid care for a family member, friend or partner, it is not surprising that many of the older people at our listening events were carers.

Many of them expressed their anger at not being entitled to some or all of the Carer’s Allowance because they receive a State pension or other benefits. Others were equally angry that they will stop receiving their Carer’s Allowance for the same reason at some point in the future.

*“My husband lost his Carer’s Allowance of £168 per month to look after me when he was 65.”*

Quote from Big Q postcard

Older carers provide many hours of care – sometimes 24 hours a day – for their loved ones and can experience drastic changes in their own lifestyle. The loss of Carer’s Allowance at 60 or 65 hits them hard.

*“For me the burning issue is the fact that Carer’s Allowance stops at 60 because I just think it discriminates against older people. To use the argument that it is a benefit and you can’t have two [overlapping benefits], actually I think is immoral.”*

Age Concern Hampshire listening event



*“It’s discrimination against older people that if you have state pension you can’t have the Carer’s Allowance. I know they think they have a good reason for it, but I don’t see it as a good reason, and nobody else in this room thinks it’s a good reason either.”*

Age Concern Dacorum listening event

*“I’d just like to add that if they don’t invest in family carers long term, it’s going to cost more.”*

Age Concern North Tyneside listening event

Age Concern Hampshire, 23 May 2008



# Building block 2



*“Social care in the way that people are spoken to; the way they are valued. Older people are sometimes not valued and that is so hurtful.”*  
Age Concern Dacorum listening event



*“I have an aunt who’s 86 and she had a carer who was going to give her a bath and when I went to see her the other week, she said ‘I’ve had a carer, they sent a man’ and she said ‘you’re not bathing me’. So, he replies ‘well, I’ll put it down that you refused to have a bath’. Which is true, but not the whole truth!”*  
Age Concern England/Mencap listening event

At every listening event, without fail, the word ‘dignity’ was mentioned when discussing care and support. Older people were passionate that a care and support system must maintain a person’s dignity. For those who have not yet needed care or support, their biggest fear was losing their dignity and independence if they needed help in the future.

Sadly, at each event, participants could recall experiences where the care and support system had neglected a person’s dignity. Three particular issues were identified:

## 1. Discharge from hospital

Many participants expressed deep concern over the loss of dignity experienced when they or their loved one left hospital, either to return to their own home or to a care home.

Discharge from hospital can be an anxious time for older people. They may be feeling vulnerable and nervous; wondering how they will cope when they return home, and worried about having to rely on family and friends. It is, therefore, crucial that services are in place to maintain their dignity and help them to recover their health and wellbeing.

Unfortunately, many older people told us of a lack of support when leaving hospital. Many had to rely on friends and families, or a voluntary organisation, as their only source of support.

*“My husband who was 83 was let out of hospital with no support.”*

Age Concern Cheshire listening event

*“I was in coronary care this time last year and nothing was mentioned to me about going home. I live alone. I went home without any support. I was lucky as I have good neighbours and friends.”*

Age Concern Norfolk listening event

*“My husband had no idea where he was going when he left hospital - I wanted to see him and tell him but I wasn’t allowed.”*

Age Concern Eastbourne listening event

However, some older people shared with us a much more positive experience:

*“Been in hospital, staff came to me before I was discharged and asked me questions - ‘have you got any one to help you, do you think you require help’. Someone was sent to the house to assess if I needed anything before discharge. When I got home a social worker came and assessed me.”*

Age Concern Hampshire listening event

Participants agreed that this should be the experience everywhere, for everyone, and that there is no excuse for it not to be.

## 2. Quality of care homes

Through the course of the listening events, older people shared with us their experiences of care homes. For some, their experiences were positive, with care homes providing a very high level of care, above and beyond their expectations. For many though, their experience was of poor quality care that failed to respect people’s dignity.



*“Going to different homes, some of them are good but I saw some I’d be horrified to be put into because the staff don’t seem to care. They’re just there as a job, and that’s the end of the story.”*  
Age Concern Norfolk listening event

### 3. Quality of home care

There was vigorous discussion about the variation, and poor quality, of home care. Many participants agreed that a key reason for this is that many careworkers are badly paid and often poorly motivated and, therefore, lack pride in their work. This leads many to not care about their job, or the people they care for – resulting in many older people being treated with a lack of dignity.

*“In the flats where I live I used to sit with an old lady each day because she was isolated and when I saw what was happening with her carer I was absolutely amazed. I was there on a couple of occasions when the carer called, she opened the door and called in ‘is everything alright dear? Ok’ and she was gone. No she didn’t even come in.”*  
Age Concern Torbay listening event

*“Two care workers were meant to come at teatime as usual, to supervise her mother using the commode and then feed her tea. The one who should have come to give her mother her meal did not turn up and the other was asked to feed her, which she proceeded to do while her mother was still on the commode.”*  
Age Concern Hertfordshire listening event

*“Paid carers are not trained in how to look after someone and treat them with respect and dignity.”*  
Age Concern Stafford and District listening event



*“The quality of care: a lot of these carers are untrained. They come into the house, which, as we’ve just said, is a matter of need that these people want, but they don’t get what they need because the person who comes in to do the caring is off somewhere else after an hour or whatever it is, and they don’t get proper care: they’re left for hours before they come back again. And it should never be in this age, 2008, with the money that, what is it, third or fourth [richest] country in the world.”*  
Age Concern Norfolk listening event

Age Concern Sutton, 24 October 2008



# Building block 3



*“First of all, we think the care system is very complex and it’s hard to find your way around it. From a personal point, and listening to other people, you find out things by accident. By talking even today I’ve learned things I didn’t know were around. Nobody comes to tell you what to do, you’ve got to find out for yourself.”*  
Age Concern England/Mencap listening event



*“There’s not enough information: we get a lack of information. The information we do get is mainly by word of mouth; the way people find out through such services as Age Concern.”*  
Age Concern Hull listening event

Three issues about clarity were raised time and time again at our listening events.

## 1. The care system is like a maze

For many older people, the care system itself is the problem: baffling in its complexity, with its different assessment criteria and funding levels.

*“It’s a complex system and people understand different bits of it.”*

Age Concern Eastbourne listening event

*“We don’t know who to ask.”*

Age Concern Hertfordshire listening event

Many have to find their way through this maze within a short space of time, often under great pressure, and while also trying to come to terms with the fact that either they or their loved one is going to need care and support for the rest of their lives.

*“Your whole world collapses when your husband is diagnosed with a mental illness.”*

Quote from Big Q postcard

*“When I was told my husband needed to go into care I was just given six phone numbers and told these are the homes that are available, go and have a look at them.”*

Age Concern Eastbourne listening event

## 2. Lack of the right information and support at the right time

The right information and support is essential when making any decision. When that decision is about the care and support that either you or your loved one requires, it is vital to know all the options available to you. Older people tell us that this crucial information and support is often lacking when they are making this decision.

*“I feel that many people miss out because much of the information is so much jargon that it is difficult to understand.”*

Quote from Big Q postcard

*“Social Services should provide information to people about care but they are leaving them high and dry instead.”*

Age Concern Eastbourne listening event



*“Information has got to be clear, at the right time and it must be written. And I think most people’s concern initially was the lack of information, although that in turn then turned round to how people could actually obtain that information.”*

Age Concern Hampshire listening event

### 3. The benefits system is just as confusing

At several listening events, the mention of the word 'benefits' resulted in discussions breaking out among small groups around different benefits. By the time everyone had explained what they knew about them, many were in utter confusion over the vast range of benefits available, while others had discovered benefits they never knew existed.

There is widespread confusion over the benefits system and no one is really sure about what they are entitled to.

*"The benefits system is very complicated - people know different levels of information and some people know about some benefits but not others."*  
Age Concern Dacorum listening event

*"I'm concerned because I am getting older and I want to know what I am entitled to."*  
Quote from Big Q postcard

As well as not knowing what benefits they are entitled to, many older people are put off from applying for the extra help that can make a huge difference to the quality of their lives because of the length and complexity of the forms involved.

*"Many people do not claim benefits they are entitled to because the forms are too difficult to complete."*  
Age Concern Redbridge listening event

A participant at Age Concern Hull's listening event described to Alan Johnson, Secretary of State for Health, the impact on one elderly couple of lack of awareness of what is available, and the complexity of claim forms for benefits:



*"I was talking to an elderly couple. Both of them care for each other, both of them have their frailties. They are independent by themselves. But for the last two weeks, they've been sitting there with no cooker. Now, unbeknown to them, they didn't know that because they are receiving Pension Credit they could actually get the FS300 form. It's a community grant that they can actually have. Now that normally goes for one-off payments, it's not a loan, it's a one-off payment. Now that itself is 36 pages long. They want something £250 – £270. Their cooker has gone and they want something for £270 and they have to fill in one form which is 36 pages long which is probably going to cost about £300 – £400 processing time just to get £270 of stuff."*

Age Concern Harrow, 17 October 2008



# Building block 4



*“Why does one [county] provide more facilities than what the other one can? You can get certain things from one county and not from another.”*  
Age Concern Hampshire listening event



*“My concern which I mentioned before, is the diversity of provision for activity in residential homes. One in particular includes the person I am looking after, very little activity provided at all. You go in, they’re sitting around reading the paper or sleeping. Whereas others you can go to, there’s somebody appointed to provide activities all of which are stimulating and helpful to the people concerned.”*  
Age Concern Hampshire listening event

Older people strongly believe that everyone who uses the care system, no matter what their needs, should be treated fairly and equally. Unfortunately, participants at our listening events described the system as anything but fair, and identified three main areas of particular unfairness:

## 1. Lack of help around the house

Many older people just need a small amount of support, such as help to carry the shopping home, help with cleaning or a bit of help to keep the garden neat and tidy. In fact, many receive no support at all and often struggle on alone. This can have a significant impact on their health and well-being.



*“There’s an awful lot of small things in between that allow people to actually live in the community which are currently being forgotten because the local authorities... somebody said what Bury was doing was changing the bed: they’ve withdrawn that service so, they can’t change their bed.”*

Age Concern Metro Bury listening event

*“Lower level, preventative services are preferred by older people but they’re in short supply.”*

Age Concern Exeter listening event

*“Older people want to remain independent, doing their own cleaning and gardening etc, if necessary with a little support.”*

Age Concern Redbridge listening event

*“The criteria have become unacceptably stringent in many areas.”*

Quote from Big Q postcard

## 2. Different levels of care in different areas of the country

Participants at all the events were concerned that the care and support system treats people with the same needs differently, depending on where they live. They protested that geography should play no part in deciding what level of care a person gets now or at any point in the future.

*“I’m concerned because I know the level of care is very different from one area to another.”*

Quote from Big Q postcard

*“There is no fair and level playing field across the country and across the differing care needs.”*

Quote from Big Q postcard

*“I live in Norfolk which is a large rural county and good quality care is not available in all parts of the county.”*

Quote from Big Q postcard



*“Assessment of need takes too long to sort out. People leave hospital and it can be 3–4 weeks before they are assessed. Often the assessment is done over the telephone.”*

Age Concern Norfolk listening event

*“Assessment of need does not always happen, often the local social services will do a financial assessment first.”*

Age Concern Eastbourne listening event

*“It’s postcode lottery again. The fact that Hull City Council’s criteria levels are totally different to every other single authority’s. And what with the constant changes, one day I receive services, next month, next week, next day, I might lose all of my services because of that criteria changing. My condition hasn’t changed, my lifestyle hasn’t changed, but for some reason or another I lose services because of some meeting nothing to do with my life.”*

Age Concern Hull listening event

### 3. Assessment of needs

Older people at the listening events agreed that assessments must happen – how else would you know what care a person needs? However, much anger and frustration was regularly expressed over the current assessment system.

*“You can phone social services and ask for help and get told they will come and assess you in 28 days – this is too long.”*

Age Concern Dacorum listening event



*“Who assesses the assessors? Because, at the end of the day, government now says ‘you can all have this assessment’, which is great, and these assessments take place, and government is told they take place. The government thinks ‘that’s great’, but there needs to be some sort of qualitative assessment as to whether the assessments are identifying the need. And where is the monitoring that, having identified the problem, that there is a package put in place to enable it to be rectified? And I don’t see that.”*

Age Concern Torbay listening event

Age Concern Exeter, 4 July 2008



# Building block 5



*“Care is 24 hours a day, 365 days a year: exactly the same as health. It doesn’t stop at half past four on a Friday afternoon and restart again on a Monday morning. It goes on over that weekend. The people who need caring and looking after have just as much right to have a life over that weekend, with dignity, as they do during the week if they get it. Why is it cut off?”*

Age Concern Hull listening event



*“Two examples we had were someone who wants to go to the pictures with a friend on Monday and the carer will only take one of them, not both of them together. And the other example was someone who didn’t want to go out when it was raining but the carer said ‘no, we’re going out’.”*

Age Concern England/Mencap listening event

Along with dignity, independence was the main issue raised by older people in discussions around care and support. Many told us that they want a system that helps to support them to be as independent as possible, for as long as possible. Unfortunately, far too often, the system deprives older people of their independence.

## 1. Home care

Home care is fundamental in helping maintain independence for older people. Sadly, we heard too many examples where home care has actually limited a person's independence.

*“Rationing of home care often means that only the basic mechanical things can be done. Someone knew of 20 minutes being allowed to get an older person out of bed, washed, dressed and fed. This allowed no scope for the sort of care that might improve the older person's quality of life and demoralised the staff as well.”*

Age Concern Norwich listening event

*“Carers are not given enough time to travel between one person and another, therefore they are always rushing and don't spend their full amount of time with each person.”*

Age Concern Dacorum listening event

*“She has to get up at 7.30, whether or not she wants to, and go to bed at 5.30, as carers only come for half an hour.”*

Age Concern Dacorum listening event



*“They come on Mondays and Thursdays and I go shopping. But I want to go to town and they will not take me to town unless I pay for them to go in a taxi with me. So, I just don't go to town... I'd like to go to town, yes, but they say that they can't take me to town. And when I ring them up, say it's someone's day to come and visit me, and I say to them 'can you take me to town': 'oh no, we haven't got time'. So what do I do?”*

Age Concern England/Mencap listening event

*“Paid carers are not trained in how to look after someone and treat them with respect and dignity.”*

Age Concern Stafford and District listening event

## 2. Family support for older people

The care and support that family and friends provide is an important resource that helps older people maintain their independence. However, participants at our listening events were very concerned about the lack of support for these carers.

*“Carers struggle on and on until it gets critical – no one goes in to support the carer. The social worker says to go away and take a break but how can you with no support?”*

Age Concern Cheshire listening event



*“Family carers feel as though they are taken for granted, they are out on their own, they are unrecognised. We have to rely on the support of family, friends – if it hadn’t been for my neighbour helping out, I wouldn’t have been here, for instance. Nobody recognises that. And sometimes you have to ask people, and people have a bit of pride sometimes and they don’t feel like asking.”*

Age Concern England/Mencap listening event

*“It’s difficult for me to give the care to my mum that I want to – and sometimes what I need is an hours break during any week.”*

Age Concern Cheshire listening event

### 3. Older carers

In many discussions around care and support, little attention is paid to the substantial role that older carers play and the impact this has on their own individual needs. There are many older carers who are either supporting their husband or wife, or their son or daughter with a learning disability.

*“Sadly carers do not receive help. I am 96 and the carer of an 88 year old with very serious health problems.”*

Quote from Big Q postcard

For older carers who are caring for their son or daughter, they may have spent many years fighting to ensure they have the care and support they need.

*“The first thing, we just wanted to make a point of is that between the six families that are represented on this table, they have a combined experience of caring of 284 years. The youngest person is 28 and the oldest person is 62 and we’ve got older carers in their 50s up to their 90s.”*

Age Concern England/Mencap listening event

A key concern for older carers is what will happen when they are no longer able to provide care and support themselves.

*“As a carer I am worried that if I became ill or too old to look after my wife because she is hospital phobic and would not go into care who would look after her?”*

Quote from Big Q postcard

Age Concern North Tyneside, 24 October 2008



# What older people want to see change

## Money

- The system needs more money

*“There should be a bottom line of care which everyone should receive funded through National Insurance and taxation.”*

Age Concern Trafford listening event

- A fairer system for those who save

*“The thrifty are being penalised. There needs to be a better individual/State balance.”*

Age Concern Exeter listening event

- More support for older carers

*“I think Carer’s Allowance should be continued along with the pension that the carers get. Because it would help tremendously towards giving you greater peace of mind in that you can sort out the household bills but still have extra to be comfortable.”*

Age Concern Redbridge listening event

## Dignity

- ✓ Care and support must be pre-arranged and prioritised for older people leaving hospital

*“Care plan that is set up in hospital should continue on discharge - more continuity needed.”*  
Age Concern in Cumbria (Workington) listening event

- ✓ Care homes delivering poor quality care must be improved

*“Residential care homes should be under obligation to provide good quality training for staff, a stimulating programme of activities for residents, regular baths/showers and toilet calls to be prioritised. No shared rooms unless specifically requested. Staff/resident ratio to be realistic and workable.”*

Age Concern Leicester Shire and Rutland listening event

- ✓ Paid carers must get better pay and working conditions

*“Better pay and working conditions for carers – treat staff with dignity and they are more likely to treat those they are caring for with dignity.”*  
Age Concern Norfolk listening event

## Clarity

- ✓ Older people and their families need to receive the right information and support, when they need it

*“There should be someone accessible by telephone or a visit. One national telephone number to provide a care line.”*

Age Concern Lancashire listening event

- ✓ The care system should be made consistent across the country

*“Having established who needs care, the next point is the information on what care is available should be easy to access and consistent across all geographical areas, ie it’s no good if it works in Bury but doesn’t work in Leeds.”*

Age Concern Metro Bury listening event

- ✓ The benefits system should be overhauled

*“The benefits system should be overhauled to make it easier to get what people are entitled to. Top-up benefits should be automatic.”*

Age Concern Norwich listening event

## Fairness

- ☑ More investment needs to be made into low level services

*“Prevention – low level services to nip problems in the bud and offer social interaction. Low level services are often the most important.”*

Age Concern Exeter listening event

- ☑ The system needs to be made fairer

*“Every person should be treated as an individual, whether 6 or 60, they shouldn’t be judged on their age but on what they want to do and not every older person will want the same type of care.”*

Age Concern Hampshire listening event

- ☑ Assessments must be timely and carried out sensitively and accurately to assess a persons needs

*“Needs should be assessed effectively relating to older people, with more user involvement of service users.”*

Age Concern Salford listening event

*“Social care assessments should be face-to-face and not over the phone otherwise you don’t pick up on other problems that may exist. Phone system is a mistake and puts a lot of people off who need support.”*

Age Concern Exeter listening event

## Independence

- ☑ Home care should be available to those who require it

*“The existing home care service needs a national redesign, improvement and better funding.”*

Quote from Big Q postcard

*“Care should be around domestic tasks, such as gardening, cleaning, washing, not just the physical aspect.”*

Age Concern Metro Bury listening event

- ☑ Family carers should be supported in their caring role

*“I’d like for carers who are caring for family members to have access to training and information more readily available.”*

Age Concern North Tyneside listening Event

- ☑ Older carers should receive the support they need

*“What do we need from an ideal care system? Family carers need to be recognised and valued by decision makers.”*

Age Concern England/Mencap listening event

*“Flexible and reliable respite – especially for people caring for more than one person.”*

Age Concern England/Mencap listening event

MORE MONEY INTO CARE SYSTEM  
EMB

VALUING CARE WORKERS

EQUALITY - OVER 60/65

COORDINATED INFORMATION  
FOR CARERS (+ TRAINING)  
FAMILY CARERS

INDEPENDENCE - TRANSPORT  
COSTS

Affordable  
ACCESS to Care Call

TIME FOR CARERS TO CARE

## INDEPENDENCE

transport, access, cost  
bridge card  
buddy scheme, taxi link, link up  
more information, schemes to  
support people to build confidence

## CLARITY

Having an assessment i.e. for care call  
then several yrs later having a financial  
assessment & having to have care call  
taken out  
Utilising existing resources by  
making sure people are aware. Such as  
getting aids back to L.A or NHS

## \* FAIRNESS

Why billions spent on banks when  
not sufficient money available to L.A  
for care system.

## THE Big Q

Sheltered housing - telecare - good.

Move to remove wardens - worried about  
because they clear problems up quickly.  
- Looking at a 'care taker' model or community  
hubs.

Handyman scheme is great  
should be opt in/opt out scheme in sheltered care

Not linking services in neighbourhoods enough to C&S  
- More preventative services - can be cost  
effective.

- Integration on site.
- Style of services should change -  
be more empowering.
- Individual budgets

Direct Payments are not used creatively  
→ prob is in the assessments

CONCERNS

DIRECT PAYMENTS - TIME OUT  
ASSESSMENTS - Multiple Too complicated  
RESIDENTIAL CARE STAFFING ↓  
RAISE QUALIFICATION  
VALUE CAREERS  
FRIDAY DISCHARGE - NOTHING IN PLACE  
SYSTEMS FOR BENEFITS TOO COMPLEX (ASSOCIATION)

DIGNITY

ELIGIBILITY CRITERIA - FLUCTUATES TOO MUCH  
LOW LEVEL SERVICES  
SERVICES DELIVERED TO SUIT THE PROVIDER NOT OF  
(NOT 24 HOUR)

## Key Points

- Proper training / vetting of  
carers - attitudes of staff / nurses
- Assessments carried out while  
remaining sensitive to people's  
choice / independence.
- Carers allowance should be  
alongside pension not instead.
- Quality of life including privacy  
in care homes.
- Dignity - no attention to  
detail

Access to information  
languages.

- Care according to needs  
not age. Individual needs  
not "off the peg"
- Form filling for benefits  
ask too many personal questions
- Pay for care staff.
- Direct payments / individual  
budgets need more information  
on how to apply + manage.

# Age Concern's response to the listening events

Throughout this report, you have heard the experiences and concerns of older people who have either relied on the care and support system for themselves or a loved one, or are concerned that they may have to rely on it at some point in their lives.

Their message is simple and clear: the care and support system is not working. It is not delivering quality care that treats people with dignity and maintains their independence. This must change, and soon.



Age Concern wants to see the Government take action to radically reform the care system to improve the lives of older people today and in future years.

Age Concern wants to see:

### Care today

Today's care system needs urgent attention. Dignity, respect, fairness and human rights must lie at its heart. Information, advice, assessment and advocacy must be free for all who need it. And we need a new national entitlement to high quality care and support.

To achieve all this will take £1-2 billion.  
*This money needs to be spent now.*

### Care tomorrow

Looking into the future, our society must decide whether it wants to make a radical move away from the means-tested system of today. Most of the people we've spoken to wanted a more collective solution where we all pay tax or insurance so that the system is there for us when we need it. Politicians must lead the public debate and win support for a new system for paying for care and support.

Age Concern will continue to work with older people all across England to make sure that the Government listens to their concerns about the current care and support system and undertakes reform to improve it.



*"This situation has been going on for years, will things change this time?"*

Age Concern Redbridge listening event

# Calendar of listening events

## April

- 15 AC Staffordshire (Moorlands)
- 21 AC Staffordshire (Cannock)
- 25 AC Staffordshire (Newcastle borough)
- 30 AC Staffordshire (Stafford borough)

## May

- 1 AC Staffordshire (East Staffordshire)
- 2 AC Norfolk
- 16 AC Cheshire (Eddisbury)
- 23 AC Hampshire
- 30 AC Hull

## June

- 13 AC Dacorum
- 13 AC Dorchester
- 20 AC Eastbourne

## July

- 4 AC Norwich
- 4 AC Exeter
- 4 AC Metro Bury
- 11 Age Concern England/Mencap (Sheffield)
- 18 AC Wigan
- 18 AC Norwich
- 18 AC Cambridgeshire
- 30 AC in Cumbria (Carlisle)

## August

- 1 AC in Cumbria (Workington)
- 4 AC Cheshire (Chester)
- 29 AC in Cumbria (Appleby)

## September

- 8 AC in Cumbria (Kendal)
- 12 AC Hertfordshire (Stevenage)
- 16 AC Leicester Shire and Rutland
- 17 AC Stafford and District
- 17 AC Lancashire (Pendle)
- 19 AC Oxfordshire
- 25 AC Lancashire (Chorley)
- 26 AC Redbridge
- 30 AC North Staffordshire

## October

- 3 AC in Cumbria (Whitehaven)
- 3 AC Preston and South Ribble
- 6 AC Sutton Borough (Carshalton)
- 10 AC Torbay
- 10 AC Oxfordshire
- 17 AC Harrow
- 17 AC Salford
- 22 AC Trafford
- 24 AC Wakefield
- 24 AC Hertfordshire (Cheshunt)
- 24 AC Sutton Borough (Sutton)
- 24 AC North Tyneside
- 28 AC Oxfordshire
- 31 AC Boston and South Holland

## November

- 5 AC Bournemouth

If you would like to add your voice to the debate about the future of care and support, please join Age Concern's campaign, the Big Q, today.

You can add your voice and show your support by emailing [care@ace.org.uk](mailto:care@ace.org.uk), visiting [www.ageconcern.org.uk/care](http://www.ageconcern.org.uk/care) or writing to the Campaigns team at the address on the back cover.

Age Concern is the UK's largest organisation working for and with older people to enable them to make more of life. In England, we are a federation of over 370 independent charities which share the same name, values and standards.

We believe that ageing is a normal part of life, and that later life should be fulfilling, enjoyable and productive. We enable older people by providing services and grants, researching their needs and opinions, influencing government and media, and through other innovative and dynamic projects.

Every day we provide vital services, information and support to thousands of older people - of all ages and backgrounds.

Age Concern also works with many older people from disadvantaged or marginalised groups, such as those living in rural areas or black and minority ethnic elders.



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