Quality not Inequality

Age Concern’s vision for the future of quality social care
Age Concern has a vision for the future of quality social care

It is a vision where older people who need care and support have dignity, rights and control of their everyday lives. Where they have the same choice as anyone else about where they live, and how they live: with the option of living in their local communities rather than being segregated in institutions or imprisoned in their homes.

It is a vision of care and support that older people can trust: trust that they will be treated fairly and equally; trust that it is safe and of good quality; trust that they will get clear information and help to choose the best service for them; and trust that help will be on hand if the system fails them.

It is a vision where people who care for relatives or friends who need help to remain independent are not expected to live in poverty or to sacrifice their health or their chance to live a fulfilling life.

It is a vision for tomorrow that we must build today.
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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 have 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.
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 this 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. Only last year, the Prime Minister described it as a key priority. Yet, time continues to slip by. The Prime Minister must keep his promise and the Government must not allow this issue 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. 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.

There is no one standard definition of social care. When we talk about social care we are talking about a range of services and support including help with everyday tasks such as cooking and shopping as well as personal care, which includes washing and help with eating. Whatever the service is, it must support the person with dignity and enable them to live their life in the way they want; whether that is to live in their own home or to receive support in a care home.

There are three broad types of care:

**Home:** When paid care is provided to someone living in their own home. This could be personal care and help with everyday tasks in the home, or support at a day centre. Many older people want to live independently in their home for as long as possible. This enables them to do this.

**Residential:** When an older person requires a lot of support, it may be necessary to have this care provided in a care home which provides care that meets their specific needs.

**Informal:** When family and friends provide care and support to a loved one. This can include help with everyday tasks and also personal care. The skills used may be highly specialised but it is called ‘informal’ because relatives or friends do not get paid.
“We had to move my mum from the first home she went in to. This was because there was never any hot water in the bedrooms and the showers were always flooded. Also, because of the low pay and lack of proper training awarded to care staff, many seemed poor spirited and disinterested. But the most annoying thing about it is that the bad home got a better inspection report than the really good home she is in now!”
Christine, 57, Hucknall

“We had wonderful care. We had the choice of two homes, we chose the one because you could just go in and out when you wanted. He [Audrey’s husband] had wonderful care in there, the food was fantastic, the care was amazing, loads of care people around, really caring, there was always somebody there.”
Audrey, 79, Kingston

As the experiences of Christine and Audrey show, there is no consistency in the quality of care that older people receive.

More than a million older people aged 65 and over are receiving social care services from local authorities. While many of these older people receive care that is of a high quality, many do not.
Through Age Concern’s work with older people, we know that many receive care that is of a poor standard or does not meet their needs. For example, a 94 year-old man in London who is blind had his care package cut to 15 minutes at lunchtime and in the evening. This was not enough support to meet his needs and he ended up in hospital with malnourishment and dehydration.

This is not right and must change. We do not want to hear any more stories like Christine’s.

The year ahead will see a new debate on the reform of social care, and a key focus of Age Concern’s campaign will be on quality.

Age Concern wants to see a quality care system which enables older people who need care to keep their dignity, their rights and control of their everyday lives.

We believe that five building blocks must form the foundations of this system:

- Services need to respect people’s dignity
- Services should give people independence
- Services must deliver fairness to all in need
- Services should be designed to provide people with clarity
- To deliver all this, the Government must provide sufficient funding.

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.

Of course, this does not mean that there are not lots of other things wrong with today’s system. 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 low care needs and prevent problems getting out of hand.

There is also the question of who should pay for care? Today only people with very little money receive free care leaving many older people worried about how they will pay expensive care bills. Many feel penalised for saving or having a home.

To address these problems Age Concern is also campaigning for support to be made available earlier and for a fairer balance between the contributions made by individuals and the State.
In 2006-7, public bodies spent £5.7 billion on care services for older people.

It has been estimated that there is a £1.8 billion shortfall in social care funding.

The number of people receiving local authority funded care has declined by more than a third since 1991, despite a significant increase in the number of older people.

Nine out of 10 people believe everyone should receive some State funding to pay for their care.

Nearly three quarters of people believe that the costs of long term care should be shared between the Government and individuals.
Money matters because everyone who needs quality care should be able to obtain it for free or only pay charges that they can afford.

Currently, public bodies spend around £6 billion on care services for older people, but even this considerable sum is not enough to provide care and support to all of those who need it.

Shockingly, seven out of 10 local authorities have cut off support to all but those with the most severe needs. This leaves many older people with three options; fund their own care – no matter what their financial situation is; rely on family and friends; or receive no care at all.

As the current level of funding is not meeting the needs of older people today, investment in the care system is needed urgently.

And this investment must continue: over the next twenty years, the number of people aged 85 and over is set to double and the number of people with an impairment and dependency is also likely to rise – increasing demands on the care system.

Investment to keep the system going in its current state is not enough. More money is needed to ensure that the quality of care is improved for all older people now and in the future.

For the next four building blocks to be cemented into place, it is essential that the Government commits to investing more money in the care system. The Government must also strike the right balance between public and individual funding in the future.

Age Concern wants to see significant Government investment in the care system so that it can provide a minimum level of care for all older people now and in the future.
We want more money invested in improving the quality of care.

We want the money that is currently spent on care to be spent better.
We want to be partners in our care with the State paying for a guaranteed minimum quality of care and us paying for more if we can afford it.
Building block 2

Inspections by the Commission for Social Care Inspection (CSCI) show that, on average, 20% of standards for residential care and 22% of standards for home care are still not met.

50% of older people are not confident that they would be treated with dignity and respect in a care home.

60% of people say the long term care system does not provide high quality care and over 50% say it has got worse in recent years.
Everyone has the right to be treated with dignity.

For older people receiving care, dignity means being treated with respect and receiving the care that meets their needs and enables them to live their life in the way they want.

Henry, 93, Southwark, has a carer who treats him with dignity:
“Well, he takes me to the hospital, he takes me everywhere, he takes me shopping. He comes whenever I want him. He came in when I was in hospital, 10 o’clock at night to see me.”

Unfortunately, many older people are not treated with dignity. As an older woman from Peckham explains:
“I haven’t got a lot of time for the carers, I just don’t think they do their job properly. They take everybody to the toilet at a certain time, but if you want to go in between times, they make you wait.”

Laura, 91, from Peckham: “You want people to be cheerful and not to treat you like a child, because they often talk down to you.”

Laura is not alone.

Across the country, many social services are being restricted or worse, cut.

This means that many older people either get no help at all or only get the care they need to remain alive. This is not treating them with dignity.

In England, more than 400,000 people live in care homes for older people (or for people with physical disabilities). Many of these older people are not being treated with dignity: Action on Elder Abuse has found that a disproportionately high number of allegations of abuse of older people concern care home residents.

Older people who do not qualify for State help, and have to buy their own care, are among the most vulnerable. Local authorities do not monitor the quality of their care, they cannot complain to inspectors and they are not currently protected by the Human Rights Act. Some local authorities even ignore their duty to protect people from abuse or neglect.

Age Concern wants everyone who receives care to be treated with dignity.
I want to be treated as a person, not as a set of care needs.
I want to get the care I want, not the care you think I need.

I want to get a minimum quality of care regardless of who pays for it.
In 2006-07, 23% of home care agencies failed to meet the national minimum standards for information.

Nearly half of people say that finding out any information about the care system is confusing.

Over 60% of people who expressed a view found it difficult or impossible to get the advice and information they need to navigate the care system.
Clarity is the third fundamental building block, as it enables individuals to make an informed choice about the care they receive.

The care system needs to be straightforward and clear, and people need accessible information. When this happens, it empowers older people to make an informed decision.

At the moment, however, this is not happening and many older people and their families find the care system complicated and daunting, and do not know where they can get information.

As a man from Kingston explains: “Social services are very poorly publicised or not publicised at all. I’m astonished by what I find out by accident.”

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Laura, 91, from Peckham highlights that there is a lack of information on care homes: “How can you find out about the standard of these places?”

Sometimes organisations provide older people and their families with that support and this can have a huge impact.

“You go to Age Concern and they say ‘oh yes we’ll do it’ and it’s done like that.”
Audrey, 79, Kingston

The largest number of enquires to Age Concern’s information and advice line are on the issue of social care. The majority of the calls are concerning problems arising from older people and their families having difficulties in finding clear and reliable information on what services are available and how they can access them.

Counsel and Care also report that the largest number of enquiries to their helpline are from families asking for information about how to access services, due to a lack of information being provided by the local authority.

In the past, many older people and their families and friends would have received information about the care system when they received care services from their local authority. However, now that seven out of 10 local authorities only provide services to those people whose needs are substantial or critical, older people with moderate needs are having to arrange their own care, often without any information or support being provided from the authority.

Age Concern wants a care system, and information about it, to be delivered with clarity.
When I need care, I want to get clear, simple, timely advice, and support to choose the options that are right for me.

As my care needs change, I want to continue to get clear, simple, timely advice, and support to choose the options that are right for me.
I want to be clear about the future:
What will the State provide?
What do I need to do to plan ahead?
Average unit cost for residential care for older people is £444 per week. For younger people, the average unit costs range from £591 to £975, depending on their disability.

The average unit cost of home care for older people is £129 per week. For younger people with disabilities, the average cost ranges between £152 and £351.

The average direct payment for older people is £143. For younger people with disabilities, average direct payments range from £193 to £208.

Only three in 10 local authorities provide services to those people with moderate needs.
Fairness is an essential building block. Every person who uses the care system, no matter what their needs, should be treated fairly and equally.

“If I have to use the care system in the future, I would like to think it’s fair and that I can get help regardless of my age.”
Chris, 29, London

Unfortunately, the care system treats people with the same needs differently depending on their age and where they live.

Sadly, age discrimination is entrenched within the care system. This means that people over 65 have less choice in the support available and are often forced to make do with second class services. For example, having to put up with short, infrequent home visits, rather than having a carer to help them live an independent life.

Age discrimination is most visible at ‘cliff edges’ where one service begins and another ends. For example, Annie suffers from depression following bereavement. For five years she has attended a drop-in centre where her condition improved but, now she is 65, she has been asked to leave because the service is only for people of “working age”.

Worst of all, long-standing patterns of age discrimination seem to be feeding through into the brand new system of personal budgets.

There are signs that people with identical needs are being allocated different budgets to buy the support they want just because of their age.

If that is not enough, older people are also treated differently depending on where they live.

“How do we explain to someone in Northumberland why their care package has been reduced to “critical” needs only when a family member a few miles down the road in Sunderland gets help with all of his needs?”
Marie McWilliams, Campaigns manager, Age Concern Northumberland

Local political decisions and financial difficulties have created a so-called “postcode lottery”. Vast discrepancies in access to services and quality of care provided have grown up between neighbouring local authorities. These discrepancies bear no relation to the needs of older people.

The way people are assessed for support varies widely, leading to people with the same needs receiving very different packages of care.

Many councils will also not pay the full cost of residential care, leaving the families of residents forced to top up the difference.

Age Concern wants a system that treats everyone fairly and equally regardless of their age or where they live.
My age should not be a barrier to receiving the support I need.
The care and support I get should be based on my needs not where I live.
Building block 5

The number of households receiving local authority funded home care during an annual survey week has declined from 530,000 in 1991 to 350,000 in 2007.

It is estimated that if all councils were to set their eligibility thresholds at ‘substantial’ and ‘critical’, the average provision of council-supported home care would fall by nearly 20%.

In England there are approximately 5.86 million unpaid family members and friends who help to care, and it is estimated that three million of these are aged over 50.

A third of carers have incurred debts as a direct result of taking on caring responsibilities.

70% of people think the Government is not providing adequate support for carers.

33% of local authorities are providing services to less than 6% of carers in their area.
“I want to get out, I want to see a bit of life and two of them [carers] at the weekend take me out. I feel back in life again, otherwise I’d just be sitting at home watching the telly.”
Margaret, 84, Kingston

For many older people, having the independence to get out and be involved in their community is life changing. Some older people, perhaps those who have mobility problems, will need some support to do this.

Henry, 93, from Southwark, explains the difference it has made to him to have a carer who enables him to be independent: “If I didn’t have a carer I’d be under there [pointing to the ground], yes, because I can’t do some things.”

For other older people the provision of day centres, such as Age Concern’s Active Age Centres, provides them with the independence they need. As Joan, 73, from Peckham explains: “Without the centre I’d be sitting indoors, in four walls as I can’t get out on my own.”

However, many older people do not receive the level of support they need and independence is denied to them.

“Well, Social Services’ idea of a carer is someone who gets you up, to wash and dress you, puts you in a chair, gives you some food, leaves you there for the rest of the day then they come round and put you to bed.”
Margaret, 84, Kingston

Older people have told Age Concern that they would prefer to receive care and support in their own home to maintain their independence for as long as possible. They also want to be able to choose between different services and pick those that suit their lifestyles.

Despite this, the actual number of older people receiving home care is in decline. If more local authorities follow the trend to restrict their eligibility criteria, it will have a huge impact on the amount of home care provided.

Because many older people do not get the support they need to remain independent in their own home, many rely on their family and friends to provide this support – and this is not always what they want.

“When I can’t look after myself, I don’t want to go to either of my sons.”
Laura, 91, Peckham

For many there is no alternative, and local authorities are failing to support these carers. Without the right support, caring for a loved one can have a detrimental impact on the carers themselves, with many experiencing markedly worse health than the general population and ending up in debt as a direct result of taking on caring responsibilities.

Age Concern wants a care system that supports older people to be as independent as possible for as long as possible.
I should not be denied the support I need to be independent and participate in my community because I have a low or medium income.

If I have severe care needs, I should get the support I need to live at home as long as I want to.

I shouldn’t be forced to rely on my family or friends to provide care.
Likewise, I shouldn’t be forced to provide care to my relative or friend.
The Big Q is Age Concern’s campaign to make our vision of quality care for all older people a reality.

During the campaign, we will be listening to the experiences and thoughts of older people, their families and friends. And we will be asking them the big questions: what is quality care? And who should pay for it?

As well as other activities, we will be:
• Holding listening events across the country where older people can raise their concerns with their local MP
• Asking people to share their thoughts through our online survey and discussion forums at www.ageconcern.org.uk/care

We will listen to what people say, and we will make sure that Ministers listen too. We will push the Government to make radical changes to the care system which address the needs of those who need support both now and in the future.

Please join the Big Q today. The more people who join us, the more chance we have to ensure that people are treated with dignity and respect, and receive the support they need.

You can share your experiences and ideas, and show your support, by emailing care@ace.org.uk, visiting our website, or writing to us (see the back cover for our address).
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.