

Care in Crisis

What's next for social care?



careinCRISIS

Introduction

The social care system in England is in crisis. For many years the system has been severely under-funded.

With more people living longer, the demand for care services increases year on year. Recent cuts to local authority budgets have had a huge impact on the care system, and we are now witnessing the devastating effect of this ever growing funding gap.

What is social care?

Social care is any service designed to help people with support needs to live well. This could be someone coming in to your home to help with tasks like washing, dressing, getting in and out of bed and going to the toilet, right up to 24/7 support in a care home. Care services should protect people who are vulnerable, enable a decent quality of life, support independence and encourage people to remain active.

In real terms, spending on social care has fallen by around £770 million since 2010¹ and we have seen a steep rise in the length of time people are waiting for care home places, home care and home adaptations.

Age UK hears too many stories from older people who are unable to access the services they need, experience poor quality care or have to face alarmingly high costs to pay for their care.

Despite significant steps in the right direction – the Care Bill, a cap on care costs, and proposals to prevent and tackle abuse and neglect in health and care settings – there are still questions that must be answered. Everyone hopes the Government's reforms will transform social care, but how much better will the new system really be? We need to know who will be eligible for care in the future and how the system will be funded. The Government must urgently address these issues. It is our belief that unless there is sufficient funding the new system established under the Care Bill will fall far short of its aims.

1 Health and Social Care Information Centre (2013); *Personal Social Services: Expenditure and Unit Costs, England, 2012-13*, Provisional release. <http://www.hscic.gov.uk/searchcatalogue?productid=12389&topics=1%2fSocial+care%2fSocial+care+expenditure&sort=Relevance&size=10&page=1#top>

In real terms, spending on social care has fallen by around £770 million since 2010.¹



Age UK wants a care system where people can access the care they need and we've been campaigning to make this a reality. In 2012, we identified seven building blocks needed to make the social care system work for older people. This report returns to the seven building blocks and discusses what has been addressed so far, how this will help people on the ground and what still needs to change.

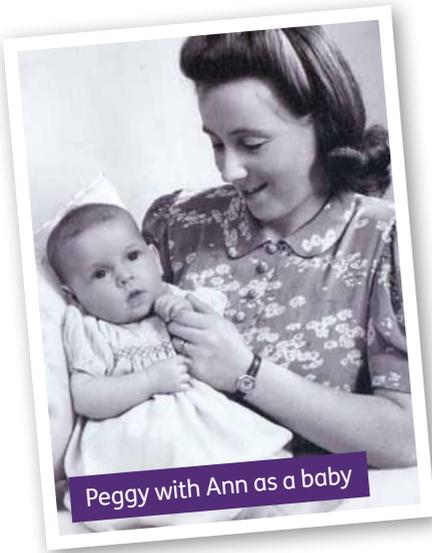
The Government must recognise that although the Care Bill is a step in the right direction, it is not the end of the journey. The current uncertainty over crucial details could hinder the progress we need to make in preparing for an ageing society. In the run up to the General Election in 2015 we hope to see all the political parties make clear commitments in their manifestos to improving the social care system so it is fit for purpose and up to the standard we should all expect in the twenty-first century.

Seven building blocks for reform

- 1 **Paying for care** in a fair and transparent way.
- 2 Having **access to care and support** with no chance of being left without it.
- 3 Receiving **high quality** care and support.
- 4 Receiving **dignified care** and support in order to live safely and with self-respect.
- 5 Ensuring **carers are supported** so that family or friends providing care are not expected to sacrifice health, career or financial security.
- 6 Having a **simple, easy to understand system** in place.
- 7 Being able to **plan in advance** before needing care.

Paying for care

The way that people pay for care is complicated and unfair. There is financial support available for people who meet the eligibility criteria set by their local council and who are on low incomes with low levels of savings. However, the majority of people have to pay the full cost of their care and face losing everything.



Peggy with Ann as a baby

Ann and Peggy's story

Ann's mum Peggy has lived in a nursing home with late stage dementia for nine years. Ann has been responsible for organising Peggy's care.

'My Mum has paid over £222,000 for her care.

Mum's lived in various care homes since she started getting sick about nine years ago. She's not mobile, and can't communicate very well. I don't think she knows who I am, though she does seem happy when we spend time together.

When she started getting ill, I sold her home for £176,000, so we could pay her care home fees. Alongside the money from the house sale, Mum had some savings through inheritance when her dad and her sister both passed away earlier in her life.

Mum's current nursing home costs approximately £800 a week. The quality of the care is very good, there are lots of staff and activities. But it doesn't seem fair that Mum has had to spend so much over the course of her life. She wasn't rich, her money came from working hard to pay off



Ann visiting Peggy in her nursing home

her mortgage and from the money she received through inheritance. It doesn't seem right that she's been left to shoulder this enormous financial burden on her own.

I was very worried Mum would run out of money, I didn't know if the local council would pay to keep her in this nursing home. I know it costs more than they are normally willing to pay for people and the idea of

moving Mum terrified me. She has now been granted Continuing Care status which means her care is paid for by the NHS – so that worry has finally been removed.'

It doesn't seem right that she's been left to shoulder this enormous financial burden on her own.

What has been done so far?

In 2011, the Dilnot Commission² suggested that the cost of care to an individual should be capped at £35,000. In theory this would have meant that when an individual reached the cap, the Government would take over their care payments. From 2016, the Government will introduce a cap on care costs but have set the level significantly higher, at £72,000, and this will rise over time with inflation.

The cap only covers what is defined as ‘care costs’. People will still be responsible for paying other related costs even after they reach the cap. So if you’re in a care home you will still need to pay for your general living costs such as food and living accommodation, regardless of how much you’ve already spent on your care. The contribution to general living costs is capped separately at £12,000 a year, none of which counts towards the £72,000 cap.

Also, under current proposals any money that people pay out on care will only count towards the cap if it

is spent on substantial or critical care needs that would be considered eligible by your local council. So if you pay for care to meet low or moderate needs the amount you spend will not count towards the £72,000 cap.

Age UK is pleased the Government followed the Dilnot Commission’s recommendation to increase the means test threshold, currently £23,250. In the future if you have assets and savings under £118,000 (at today’s prices), you will be entitled to some financial assistance on a tapering scale, depending on your income.

The Government is introducing a national deferred payments scheme which we hope means fewer people will be forced to sell their homes before the end of their life. However, the Government has proposed that the scheme should only be available to those with savings of less than £23,250. This could mean people would still need to run down their savings before they can access deferred payments.

² The Dilnot Commission was set up in July 2010 by the coalition Government, tasked with making recommendations for changes to the funding of care and support in England. It published its recommendations on 4 July 2011. The independent Commission was chaired by the economist Sir Andrew Dilnot.



Another problematic issue is that the amount of spending which contributes towards the cap will be based on what the local authority would have to pay for the same care. As local authorities can often purchase care more cheaply than individuals, many older people and their families will continue to pay more than they feel is fair or can reasonably afford. We think it is important that the Government is clear about what is and is not included in the proposed funding reforms.

We believe deferred payments should be available to all older home owners with a reasonable need and expectation of them, before they have run all their assets down.

What needs to be done now?

Unfortunately, setting the cap at such a high level means that fewer people will benefit from it than we had hoped. Older people and their families need to understand that the lifetime cap only applies to care needs, not to living costs and that their spending only counts towards the cap once they have been assessed as meeting the eligibility threshold, not necessarily at the point they feel they require care.

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Access to care and support

Becoming ill yourself or seeing a loved one decline can be incredibly distressing. When the time comes to seek help, people often assume they will be supported financially and practically. Unfortunately, for many this is not the case.

Age UK believes that everyone who needs support with basic, everyday activities should be able to get the help they require to live an independent and fulfilled life. Under the current system the decision as to whether you receive this help is taken by your local council. Using the national definitions for eligibility – low, moderate, substantial and critical – the council decides how much help they think you need. Every local council can choose the level at which they begin contributing financially for someone to receive care. A few councils pay for people with low and moderate needs to receive care in order to prevent them reaching crisis point later on. Other councils decide only to fund people with the most severe needs. The result is a postcode lottery.

As council funding has come under increasing pressure, they have raised eligibility thresholds. This results in fewer people being able to access care services. By 2012, 85 per cent of local authorities had set their eligibility threshold for adult social care at ‘substantial’ and a further 2 per cent set their threshold at ‘critical’. This decision means that hundreds of thousands of people with low and moderate needs who don’t meet these criteria are missing out, even though they may need assistance with essential tasks like going to the toilet and getting washed or dressed.



Dean and Patricia's story

Dean's mother, Patricia, is 70. She has dementia, arthritis, and can't use one of her hands very well which causes trouble when she tries to dress herself, wash or cook. At times she is incontinent and can't shower alone. Her mobility is poor. Dean himself has his own disability and worked part time while providing care for his Mum.

'Mum has been getting more and more poorly over time. Her local council got involved and agreed she had serious problems.

As Mum had no savings or income, they paid for carers to come in every day to help her and ensure she was ok. As she got worse, she moved to live in a bungalow, because she struggled with stairs.

After the move, her new local council insisted on assessing her from scratch. When they decided Mum was not severe enough to get any help I was astonished. They judged that she was independent other than doing housework, for which they recommended she pay a cleaner.

That meant the council would not give us any help. I didn't know what to do as Mum was so vulnerable. I had to rely on other people to help her, which got harder and harder as time went on. I stayed on her sofa regularly, as well as paying for a carer myself to come for 16 hours a week, but that didn't even touch the sides as far as the care Mum needed. Mum got worse and worse.

She disappeared regularly, set fire to the kitchen toaster and microwave, had two falls and took an accidental overdose requiring an emergency admission to hospital. It was one of the worst times of my life. It was only when we moved her again, back to her original area, that she started getting care again. The ridiculous thing about it was that it was only a few miles down the road.'

By 2012, 85 per cent of local authorities had set their eligibility threshold for adult care at 'substantial' and a further 2 per cent set their threshold at 'critical'.



What has been done so far?

Central Government has reduced the funding local authorities receive. Many councils have therefore felt forced to cut social care budgets and raise their eligibility thresholds to reduce the number of people they are responsible for. As a result in 2011 there were over 800,000 older people with care needs not being met.³

In the Care Bill the Government has said that all local councils will be required to provide care to people who have the same level of need. This national eligibility threshold will ensure that people with the same needs will receive support wherever they live, though councils will have to decide exactly what support best meets those needs and they will also be able to set more generous criteria if they wish. We hope this change will make the system fairer and reduce the chances of someone who moves house finding their support taken away because their new council only funds people with greater care needs.

What needs to be done now?

The Care Bill does not make clear at what level the national threshold for support will be set. Early indications have suggested that this threshold will be set to help people with critical or substantial needs, similar to what most local authorities currently provide. If the national eligibility threshold is set at this level, and no local authorities set more generous criteria, 99,000 older people⁴ currently in receipt of care would no longer be eligible for local authority funded care.

Age UK wants a commitment from Government to set the national eligibility threshold at ‘moderate’ (or its equivalent in the new system). This would be in line with the Government’s commitment to prevention and we know that the right support for people with ‘moderate’ needs can help people retain their independence for longer.

3 Forder, J and Fernandez, J (2011); *The Cost of Social Care for Older People: The Importance of Unit Cost Growth*, PSSRU report for Age UK, <http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The%20cost%20of%20social%20care%20for%20older%20people.pdf>

4 Fernandez, J., Snell, T., Forder, J., & Wittenberg, R. (2013). *Implications of setting eligibility criteria for adult social care services in England at the moderate needs level* (p. 38). London: PSSRU discussion paper 2851. <http://www.pssru.ac.uk/archive/pdf/dp2851.pdf>

There are over 800,000 older people with care needs not being met.³

Eligibility is also crucial as it affects the cap on care costs. If someone with moderate needs has difficulty washing themselves and decides they want to pay for help, they may assume this money will go towards their care cap. This is only the case if their needs are considered high

enough by the local council to require care. If their local council assesses them and concludes their needs are below the national eligibility criteria their care costs will not count towards reaching their cap. Their 'care meter' will only start running when they have needs that are eligible.



Dean visits his Mum regularly

High quality care

Even when older people are assessed as needing care, there is no guarantee the care they receive is high quality.

Jan's story

Following complications during surgery, Jan now receives a care package in her own home.

'I came round from a relatively straightforward operation and I was unable to move much below my neck. It turned out that during the operation I'd had a stroke in my cervical spine. Having been a nurse in my working life I understood I would never fully recover. It was an enormous shock and meant I was thrust into the care system with no warning.

When I got home I was informed that a care agency would be coming in to provide care. I had no choice about which agency provided my care. The professional carers were not treated or trained well and as a result I was left with care that was not of a high standard.



The biggest problem for me was lack of continuity. In one week I could have as many as eight different carers, all of whom I had never met before. Having different people performing personal tasks like helping wash myself or use a bedpan was quite unnerving, and they had never met me before so didn't know what I required.

Visits were often hurried. My rural location meant carers were often late and left early to get to their next client, as travel time is not included in their schedule.

I think what's happening is frightening. If the Government want people to stay in their own homes, it's vital we can receive good quality care.'

What has been done so far?

The Care Bill addresses this issue in two ways. It states that local councils should seek to ensure that people in their community have a choice about who provides their care. It also raises the issue of training and ensuring that the professional care workforce is able to deliver a high quality service. However it is not at all clear how this will be achieved.

What needs to be done now?

It's vital that the people who use the care system have a choice about the care they receive and who provides it. National and local Government must ensure that older people get good quality care in their own home, in care homes and when attending community activities like day centres and lunch clubs. The care system should be regulated more effectively to make sure high quality care is received.

The underlying issue surrounding these problems is lack of funding. Unless the Government provides local authorities with enough money to enable them to commission high quality services, many older people like Jan will continue to receive poor quality care.



Jan receives a care package at home

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Receiving dignified care

Good care should strive to provide more than a basic service that meets minimum requirements.

Older people in need of care are usually adjusting to a new way of life, where they are coming to terms with being unable to look after themselves as fully as before. Their dignity and quality of life should be at the forefront of the care they receive.



Darren and Sheila's story

With a diagnosis of dementia, living independently became too challenging for Sheila, so her son realised that she needed to be moved to a care home.

‘During my visits it wasn’t uncommon for me to see Mum in clothes that were much too big and clearly weren’t hers. Virtually every time I visited, Mum’s clothes were dirty with spilt food and drink. The food had often dried, so had clearly not just happened. Mum was a very tidy and proud woman, she always took care of her appearance so this was very undignified for her.

When Mum was in the dining room she would be given food and drink and if she hadn’t consumed it within ten minutes the assumption was she didn’t want it and it was taken away. It was as if she was an inanimate object. There seemed to be no realisation that she struggled to use cutlery or became easily distracted. On some of my visits, Mum hadn’t even made it to the dining room. When I asked if she was going to get anything to eat, I was told ‘she’s not here and it’s dinner time’ – no one made an effort to go and get her.

What made eating even more difficult was the fact that Mum’s dentures disappeared without any proper

explanation. It really reduced her quality of life. When we tried to sort a replacement, she became very distressed because of her dementia so we had to give up.

It felt like all Mum's dignity was being stripped away, she wasn't being treated like a person. As her son it was very distressing to watch.'

What has been done so far?

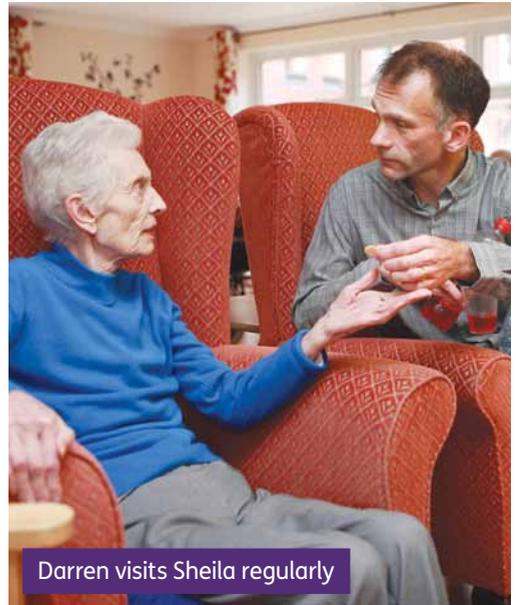
The Care Bill states that local councils will have a duty to promote wellbeing when looking at an individual's care. This specifically includes considering a person's dignity and ensuring that they are treated with respect. Age UK strongly endorses and supports this.

What needs to be done now?

This is not only about what care and support is provided, it also depends on how it is provided. It is vital that we have properly trained care workers who are themselves treated with respect and who are working within a positive management culture. Effective regulation, diligent monitoring of care, and care homes that are open and part of the local

community should all help to ensure older people are treated with dignity and prevent neglect and abuse.

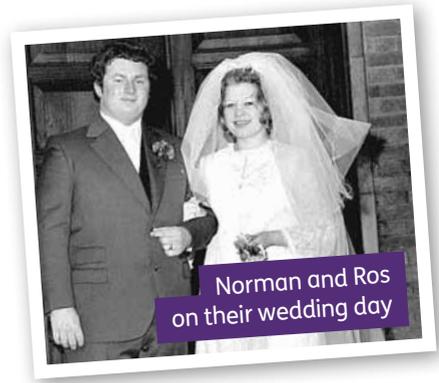
We believe that care providers should have a collective responsibility if people are abused as well as the individual perpetrator. We also believe there should be better protection for adults at risk of abuse and neglect and we're seeking to strengthen the Care Bill to achieve this.



Darren visits Sheila regularly

Supporting carers

The majority of care provided in England is delivered by the 6.4 million unpaid carers. They could be a parent, child, sibling or friend. They are often themselves older people. Unfortunately, it's usually the case that informal carers receive little support from the system.



Some struggle to stay in work, have poor mental and physical health and become isolated themselves as a result of their caring responsibilities. The cost to the economy of people dropping out of work to care is a massive £1.3 billion a year through foregone taxes and benefits for carers.⁵

Norman and Ros' story

Norman looks after his wife Ros who has had multiple sclerosis for years. The pressure on Norman as her carer has been immense.

'I was trying to work and provide care for Ros but three years in I couldn't cope and my health fell apart. I was depressed and at the point of walking away. I went to my GP and asked for help but I was just given more tablets. No one pointed me in the direction

of carer organisations or linked my carer role to my state of physical and mental health.

Trying to get the help I needed became a full time occupation alongside my actual job. To say that it's a struggle is an understatement. I thought if I worked until I reached sixty years old I'd have my mortgage paid off and that I would qualify for a good company pension. But before that could happen, I collapsed. I was forced to take early retirement which resulted in me getting a much reduced pension.

I didn't know anything about what financial assistance we might be entitled to so I just paid for the care myself. Paying for care, and adapting our home absorbed a massive amount of our money and we reached financial breaking point. I paid for Ros' care for

⁵ Pickard, Knapp, King, Perkins and Brimblecombe (2012); *Overcoming barriers: Unpaid care and employment in England*, NIHR School for Social Care Research. http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/Findings_10_carers-employment_web.pdf

The cost to the economy of people dropping out of work to care is a massive £1.3 billion a year through foregone taxes and benefits for carers.⁵



15 years. I had no idea we could have been helped. All our savings were gone, I took out an additional loan on our house to help cover care costs but when my health failed we couldn't afford the payments so we no longer own our home. I felt I had failed.'

What has been done so far?

Unpaid carers currently have the right to ask for an assessment of their own needs, but they are not entitled to services following the outcome. The Care Bill addresses this issue and says they should also be able to access services if they are eligible.

The Bill also contains a new definition of what it means to be a carer. Currently a carer is someone who is deemed to provide substantial support. The new definition will be broader and 'care' could include providing practical and emotional support. This definition will help more informal carers to access the support they need.



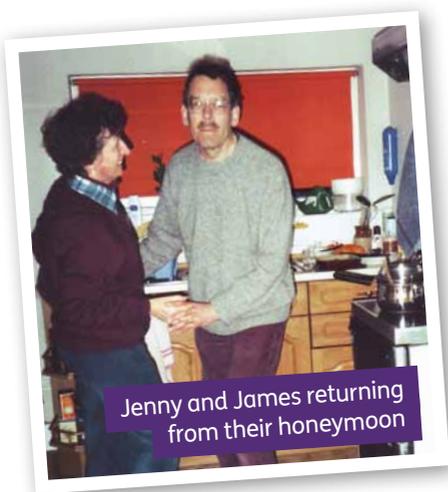
What needs to be done now?

The whole care system could collapse if unpaid carers reach breaking point, so it is vital we give them the support they deserve. More must be done to identify carers and ensure that they are given the help they need to care for their loved ones. We also believe the benefits system should be reformed to ensure all carers have adequate incomes. This should include financial support for older carers who often receive no financial recognition of their role.

Establishing a simple system

The care system is complicated and can also be intimidating. There is limited information and advice available and finding support can be a big challenge.

Too often the organisations involved in the health and care system do not share information effectively, resulting in additional stress for families and carers who are forced to repeatedly provide information or challenge poor decisions about their loved ones' care.



Jenny and James returning from their honeymoon

Jenny and James' story

Jenny cares for her husband James at their home. James uses a range of care services.

'We had been so excited about my upcoming retirement but soon after I stopped working, James became ill and he was eventually diagnosed with dementia.

He was wandering all the time, he didn't know where he was, couldn't feed himself, it was just horrendous. The shock of losing the James I loved was so immense, and at the same time I knew I had to discover a way to enable James to stay at home with me. I was floundering and no one came to help.

In my working life I was a nurse, but even with that background I knew very little about how to arrange help in our home. I knew the term 'care package' but I thought that somebody somewhere created a care package for you, even if you then had to pay for it. But that wasn't the case at all, I had to do the whole lot myself and it was so daunting.

The system is very complicated. Slowly, bit by bit, I discovered what



options were open to us and what services we would need. At a time when I was emotionally vulnerable as well as exhausted and frightened, it was incredibly stressful. It would have helped so much to have had some guidance, support and thought about what I was going through and how difficult I would find the whole process.'

What has been done so far?

Age UK warmly welcomes the Care Bill's ambition to make free information, advice and advocacy more easily accessible to those in the care system. The Care Bill also states that people with eligible needs who are not eligible for local authority funding – because they can afford

to pay for their own care and have not yet reached the spending cap of £72,000 – will be able to ask the local authority to arrange care for them. However the local authority will be able to charge for doing this.

What needs to be done now?

Age UK is pleased the Government has recognised the vital need for information and advice to be readily available for all those who rely on the care system. However the Care Bill does not explain how this information will be given. Access to information about public services commonly happens online. However, many older people have never been online or are unable to get online. It's crucial that information is available to all those in need of it.

The Government must ensure older people who need care understand who is responsible for particular aspects of their care and what services are available to them. It is equally important that they are able to challenge decisions quickly if they believe their local authority has not made a proper assessment or that the outcome does not appropriately reflect their needs.

Planning in advance

Many people first come into contact with social care during a health crisis such as a hospital admission, when they and their families are often distressed. The system is very complicated and important decisions are often made very quickly and without proper independent information and advice.

Care can be expensive so many people do not have the money to set aside to pay for it. With no idea if you'll need care in the future, and scarcely any insurance products you can buy to protect against the unlimited costs, even if people wanted to plan ahead it is incredibly hard to do so.

Susan and Bruce's story

Susan's husband Bruce has dementia and Parkinson's disease. When they first entered the care system they had no idea who to turn to.

'One morning, my husband woke up with his arm shaking. We didn't think it was anything serious, but it got worse and at the hospital they told us he'd had a stroke. Things went downhill from there and within six months he was diagnosed with Parkinson's and then, later, dementia.

As a carer I feel I've been through everything and have just been left to get on with things alone. Before all this happened Bruce and I rarely visited our doctor. None of my family ever really got sick, they all lived into their 90s. We had no idea who to go to for information or help. We didn't know much about social care as it never occurred to us we might need it. I think I assumed it would be like the NHS, but that's not the case at all.

Mind you, even if we had given it some thought beforehand, I don't know how useful that would have been as things seem to change all



the time. It's very confusing. I would have been in real trouble if I didn't have a computer.

All the information we've come across, we've had to search for. It feels like no one has offered us help. Even now, years in, I only find out about things that could help us by seeing something in the paper or online. I call the council and ask about it, and they say 'oh yes, you could have that'. They rarely contact me and tell me what's on offer.

It feels like people want to avoid talking about this awful journey that we're on.'

What has been done so far?

The Care Bill states that everyone will have access to information and advice when they need care. This includes advocacy, though only for people who would not be able to make decisions about their care without support and who have no one to help them. This will help people plan ahead for possible care needs and understand what the state will provide, but it will not help all those in need of assistance. It is also hoped that a cap on the cost

of care, suggested by the Dilnot Commission but set at a higher rate of £72,000, might stimulate a market for financial products so people can plan ahead.





What needs to be done now?

People should be given a better idea of what their financial responsibilities might be and what support they can expect from the state. This would enable them to plan ahead as much as possible financially in case they do find they need care in later life.

Early indications are that there are many uncertainties about how much insurers might have to pay out over the suggested cap, discouraging

them from creating new products. The Government needs to address this if the private sector is to play a role in helping people to prepare for their care costs in later life.

The Government must ensure that the public understands their responsibilities to plan for their care in later life, giving them access to independent, reliable and user-friendly advice and information when they need it.

Conclusion

The care system in England is in crisis. Older people, their families and carers are often placed under incredible pressure navigating a system which is confusing and unfair. Many are denied access to help, while others are forced to sacrifice what they have worked all their lives for.

We have an ageing population where the fastest growing group is the over-85s. At the same time, council budgets are facing unprecedented cuts and care services are being withdrawn. Unless something changes this means we have an ever growing number of older people who will be left without the care they so desperately need.

We're pleased that some of our recommendations and suggestions have been adopted by the Government – the Care Bill introduces a national eligibility threshold and a cap on the cost of care is being devised. Local authorities will also have duties to provide better information and advice for those using the care system.

However we are concerned that, as yet, we don't know how these plans will work in practice.

The extent to which the new system provides a better alternative to what we have at the moment will depend to a very great extent on the amount of funding it receives. It is crucial that the positive vision for social care set out in the Government's Care Bill is achieved. Otherwise we see a huge risk that the new system will fail to deliver reforms that tackle two major challenges: who can access care and how much it costs.

Join our campaign

Age UK continues to campaign for a better social care system, we need you to help us make this a reality. Join our campaign along with thousands of others:

www.ageuk.org.uk/careincrisis

Or you can write to us at the address overleaf.

We're Age UK and our vision is a world where everyone can love later life. We believe that living longer should be celebrated and everything we do is designed to change the way we age for the better and enable everyone to be part of the solution. Together, we can help everyone make the most of later life.

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