Care in Crisis
Seven building blocks for reform
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Care is in crisis and needs urgent, lasting reform. Many of those who need help and support are being badly let down. Age UK is calling on the Government to take action.

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Introduction

The current adult social care system in England is in financial crisis and needs urgent lasting reform. Many of those who need help and support are being badly let down by a faltering system, while others find themselves having to sell their homes in order to pay for the support they need.

Social care was a key battleground for the 2010 General Election and the issue of reform was addressed in the Coalition Agreement. The Government has promised a White Paper on care reform in the spring. This is a crucial moment to influence the future direction of policy in this area – possibly for a generation.

The challenges facing those who need care and support cannot be understated. The system is confusing, unfair and unsustainable.

• The system does not provide support for those that need it. In 2011/12, nearly 80 per cent of local authorities have set their eligibility threshold for adult social care at ‘substantial’ and a further 3 per cent set their threshold at ‘critical’, meaning that hundreds of thousands of people who don’t meet these criteria are missing out, even though they may need assistance to go to the toilet, get washed or dressed each day.

• The system is unfair. There is a postcode lottery for care. Eligibility varies depending on where you live and there is no portability if you move between local authorities.

• The system makes it impossible to plan ahead to meet future care needs. People do not know what to expect from the state or understand what they are personally responsible for. And, with potentially unlimited costs, people often find themselves having to sell their homes to afford care payments. Without any idea of how much it could cost, no one is able to plan ahead.

• The system is not treating people with dignity. Too often, there are stories of people being left unfed, unclean and ignored. Older people regularly tell us that they feel invisible and that what they want and need is not taken into account.

• The system is complex and difficult to understand. Information and advice is poor and the current legal framework surrounding care is complex and confusing. Too often services do not join up.

• The system is under-resourced. There is not enough money available to provide good quality care. This situation is likely to get worse while local authorities seek to balance their budgets by cutting social care at a time when demand for services is only going to increase. From 2010/11 to 2011/12 older people’s social care expenditure was cut in real terms by £331 million (4.5 per cent), this is despite the Government providing additional money for care in the 2010 Comprehensive Spending Review.
This report demonstrates the impact that this crisis in care is having. From the impact on those who have been forced to sacrifice all they have worked for to pay for care, to the effects on others who have been treated with a lack of respect and dignity. This does not have to be the case. This report outlines seven building blocks required to form the basis of a new care and support system; a system that helps and supports those who really need it.

Of course, reform comes at a price – but, as a nation, the cost of inaction is potentially devastating as fewer and fewer people receive the support they need. We cannot afford to fail to reform care again. Cutting back on social care does not make economic sense. We have already seen the rising cost to the NHS of emergency admissions and delayed discharges in England, at a time where care is being cut.

According to Department of Health Statistics during September and October 2011, 128,517 hospital bed days were lost as the result of the delayed discharge of people who could have been cared for in the community if the right support was available. This is an increase of nearly 13,000 bed days, compared to the same two-month period in 2010. Many people will make the connection between health and social care services and see that cutting social care appears to push the costs directly onto healthcare.

The process of reform will involve trade-offs. We need a public debate about how additional money for care is raised, and Age UK is looking forward to providing constructive input into these discussions.

It is possible that the Government will decide that wealthier older people may be required to contribute more for their care. There would need to be strong guarantees that an acceptable quality and quantity of care would be provided for this additional investment.

While it is impossible to ignore the difficult economic position the country currently finds itself in, the Government must not use this as an excuse for delay. There are millions of older people, both now and in the future, who can wait no longer; the time for reform is now.

‘We’ve worked hard all our lives and also given so much to others in additional voluntary work, now we should be given something back. We have used half of our joint savings on private care but have no idea how long the money will last.’

Ray

‘I still have flashbacks at some of the things that went wrong (like carers not turning up on time and Dad being left in his own urine) and I know that without something being done now it can only get worse for people like my Dad.’

Marian

‘It’s a double whammy – a reduction in time with the carers and a big increase to the charges I pay for the care.’

David

‘I am appalled by the whole system and the way in which Dad was let down by his care co-ordination team.’

Becky
What is social care?

Social care is any service ranging from help in the home for dressing, washing, getting in and out of bed and going to the toilet, to 24-hour support in a residential care home. These services are designed to maintain a good quality of life, help people to remain independent, stay active and protect them in vulnerable situations.

Facts about social care

- There are 2 million older people in England with care-related needs.
- Nearly 800,000 people are unable to get any formal support for care.
- Spending on social care has been cut by 4.5 per cent in the past year.
- One in two people can expect to pay up to £20,000 in care costs. One in ten will spend over £100,000.
- 80 per cent of local authorities have restricted care to those with critical or substantial need, leaving hundreds of thousands to miss out.

Social care services are designed to maintain a good quality of life
Personal stories of a care system in crisis
Chris and Ray

Chris wants to receive the care and support she needs with no chance she’ll be left without it.

Chris, 72, has been bedbound for years. She has ME, is doubly incontinent and her fingers are so deformed she cannot use them. She is cared for by her friend, Ray, 83, who helps her with eating, washing and changing.

Ray says: ‘I have looked after Chris for the past 20 years ever since I retired and I have saved the state over half a million pounds in the process.

‘Chris was very independent, an athlete and an academic, making it particularly galling to be utterly dependent on others for her very existence, but she never complains. Even eating is a problem – ME being a muscle disease, she cannot chew, so all her food has to be pureéd then fed to her. In the mornings, I change her incontinence pads and prepare her breakfast and feed her.

‘When we used to live in London, we received £10,000 a year in direct payments. We used this to buy in care for two hours in the morning and evening – I couldn’t cope without a bit of help each day. But since we moved to another local authority, the council considers us too rich to need financial support.

‘We still needed the care so we have had to pay for it out of our own savings. Together we had £50,000 in savings when we retired. That has gone down to £8,000. We have had to reduce the amount of care we buy in.

‘We’ve worked hard all our lives and also given so much to others in additional voluntary work, now we should be given something back. We have used half of our joint savings on private care but have no idea how long the money will last. I am over 80 and I feel thoroughly unsupported. The thing that worries me most is what will happen if something happens to me.’

Chris says: ‘I am so grateful to Ray for the way she looks after me. She does everything and I hate to think where I would be without her here. I just wish that there was more help for people like us. It feels doubly unfair that we are left to fend for ourselves just because we moved. What happens if our savings run out?’
David wants to receive high-quality care and support.

David, 76, lives in sheltered accommodation. He has severe mobility problems and relies on carers four times a day.

David says: ‘My condition means that I have great difficulty moving around. I can only manage a few steps with a walking frame. And it is hard for me to do even the simplest of tasks like picking things up or opening an envelope.

‘I rely on carers four times a day to help me with my personal care – morning, noon, afternoon and night-time. My local authority has already had to pare down my home care service as much as it can. For instance, the carers are already hard pushed to get me out of bed, washed, toileted, dressed and breakfasted, with the bed made, in the allotted 45 minutes time. It’s a tough job for the carers because my mobility is so restricted.

‘It’s a double whammy – a reduction in time with the carers and a big increase to the charges I pay for the care. I share my home care costs with the local authority and my contribution has recently gone up from around £260 to £324 a month. I struggle with my payments – on top of my rent and bills – from my pension and dwindling savings.

‘I’m worried that the local authority is pushing for the “Big Society” option where the emphasis is to push my care more and more onto friends and family. This is not an option for me. My relatives don’t live nearby. What I want is a proper “carers’ service”.

David
Marian wanted the care and support her father received to have enabled him to live safely and with self-respect.

Marian’s late father had a stroke at the age of 67 and other severe health needs. He was looked after by Marian’s stepmother, Pearl, until his health deteriorated so much that he went into a care home.

Marian says: ‘We started to arrange care for Dad to give Pearl a break. My dad was set in his ways, being in the RAF, and things had to be done on time and meals on time. But the carers often arrived late to give him breakfast.

‘We needed someone to sleep over, to make sure Dad did not fall out of bed when Pearl had to be away overnight. They often did not arrive until very late. On one occasion, the carer had not turned up by 10pm so we were frantically phoning round. Because of the uncertainty of carers turning up, Pearl looked after Dad herself, as it caused more worry to her wondering if they had turned up.

‘When Dad’s condition deteriorated, he was moved to a nursing home. Sometimes he was well looked after, he was changed regularly and turned in his bed to avoid bedsores. But I found that weekends he would not be dressed and got out of bed as that was when they have staff shortages.

‘His room often smelt of urine. It was very strong and took your breath away; I could not sit next to him. Dad was always a very clean man and I just hope that he did not know what was happening to him.

‘The staff in the nursing homes are underpaid and made to do the work of two, which means they cannot take people to the toilet when asked, which results in some cases – like my Dad’s – in them having accidents in their chairs, which is distressing. The reason for working in the caring profession should be that you want to, not that it is the only job going and it brings in the money.

‘I still have flashbacks of some of the things that went wrong and I know that without something being done now it can only get worse.’
Sheila wants to be able to plan in advance.

Sheila is 75. Her husband Tom is 77 and has had Parkinson’s disease for five years, but helps with their disabled son, Craig, around the house. Sheila also cares for her mother and sister.

Sheila says: ‘My son, Craig, has Down’s syndrome. I am also carer for my mum who is 98. She lives in a Methodist home – I don’t go to see her every day. I take her food and wash her clothes, wash her hair and generally look after her. She sometimes spends time in hospital and I go to visit.

‘I also have a sister who lives in a dementia centre. My care for her is mainly social. I visit and sit with her and talk to her or take her for a walk. It’s quite hard work.

‘Craig has a full-time job. He is 37. I sort clothes out for him every day. He has been in respite once but didn’t change his clothes. I put him in the bath then he baths himself and I get him out again, wash his hair. He can’t be left alone in the house and we don’t want to leave him alone. Even if I just nip out to the post box, he’s waiting at the window when I get back.

‘He has an eye condition at the moment and is waiting for an operation. His sight is not good so he has to link with me when we go out. I take care of getting his food and do things like fastening his shoes. After 37 years it becomes your life. I have to work around him but he’s very good, very placid.

‘Caring has got a lot harder as I’ve got older, possibly because I am also caring for my mum and sister now. I can’t cope as well as I used to. My health is generally good but I get tired quicker. I get aches and pains – I suffer from arthritis.

‘Tom being diagnosed with Parkinson’s disease was the trigger for thinking about Craig’s long-term future and starting to look for other care for him.

‘What do I need? I would like to be able to phone someone if there’s an emergency so that I can leave him with them while I deal with it. But it would have to be someone who knows him, someone who had already got to know him.’
Pauline wants to able to pay for her mother’s care in a fair and transparent way.

Pauline’s mother, 90, has Alzheimer’s disease and requires 24-hour care.

Pauline says: ‘When my mum needed 24-hour care four years ago, I wanted to ensure that, should anything happen to me, she would still be taken care of. But the cost of mum’s care was so high that we were forced to sell her home to pay for it.

‘We used a lot of the money from the house to pay for a plan that would pay half the cost for the rest of mum’s life. To cover the remainder, we have had to use mum’s savings, pension and Attendance Allowance.

‘So far, mum’s care has cost £96,000 and there is not much left from the sale of her house in her savings. It is a constant worry to make sure mum is looked after properly.

‘It is bad enough watching your mother disappear into a world of her own; sometimes she does not even remember you. It breaks my heart and I often cry. But I cannot afford to go under because I have to make sure my mother gets the best care we can give her: she was a great mum to my sister and me.

‘Being forced to sell her home was absolutely heartbreaking. I think it is wrong that people like my mum, who worked hard all her life and paid her taxes, should be put in that position.’
Becky wants to find the system clear and easy to understand.

Becky has had to fight to arrange care for her father, Clifford, 75.

Becky says: ‘My dad is 75, very physically fit, but has vascular dementia and can be very difficult. His needs are very complicated – hospital staff told me that there were “very few” homes that could cope with him.

‘After being in hospital, it was decided that Dad needed full-time residential care. He was assessed for full NHS funding, but this was declined, not even reaching the referral stage. We were then offered a choice of three homes, funded by a combination of Dad’s pensions and the local authority contribution. On reading his care plan, two of the three homes refused to take him. The third one agreed, but it was 22 miles away from Mum. As his pension income would be needed for the home, Mum (who is 73) wouldn’t have been able to afford a car, and to visit him she would have had to spend two hours on a bus and change three times, each way. We were made to believe that refusing this home due to the distance was unacceptable, and if we “kept refusing” they would place Dad anywhere, without our approval.

‘We were then told that even though we didn’t want this home, if Dad went there, we would have to pay a top-up fee of £150 a week. I had researched top-up fees, and therefore knew that families should not be approached to pay top-up fees unless they have chosen a more expensive home.

‘After I made a formal complaint to the local authority, Dad was reassessed for funding from the NHS. This time, it was granted. We were obviously pleased with this, but we couldn’t understand why, only six weeks earlier, he did not even meet the basic criteria. Dad was subsequently placed in a home four miles away from where he lived for 50 years and where family and friends can visit him easily, he is visited four or five times a week.

‘I know that if I hadn’t fought this, Dad would now be 22 miles away from family and friends, with visits perhaps once a week. I could see the same situation happening to others... and I am appalled by the whole system and the way in which Dad was let down by his care co-ordination team.’
Anne wants his wife, Anne, to have the support she needs and not be expected to sacrifice her health, career, social life or future economic security.

Anne, 64, looks after her husband, Reggie.

Anne says: ‘My husband, Reggie, worked as a doctor and I was a nurse. Reggie had a stroke 11 years ago. He now has right-side weakness and needs to be looked after full-time. He needs help with everything – personal care, eating, getting in and out of bed – and he is incontinent. Sometimes I have to get up two or three times a night.

‘Carers come in to get him up in the morning. There should be two carers at the same time, but they might be late or sick and I end up helping the person who does come. I need more hours of help from carers.

‘It’s good that he goes to the day centre for three days a week. I get some time to myself and he sees other people and gets out of the house. I also have “Take a Break” for four hours a week, where someone comes and sits with him while I take the dogs for a walk or just go out.

‘My health has suffered. I have back, neck and shoulder pain that is probably from having to move him manually. I am also getting osteoarthritis in my hands and my knuckles are swollen. It’s double wear and tear – from getting older and helping someone else all the time. I’ve been advised to rest for two months but it’s not possible. You tend to put the other person first. You can’t be sick yourself.

‘I think the main thing is that I don’t have a life of my own. I can’t come and go as I choose. I have no social life.

‘Reggie also has vascular dementia. It’s a very lonely life. You can’t have a conversation with the person you are caring for. It’s very distressing – he’s a shadow of the person I’ve known.’
Seven building blocks for social care reform

Those in need of social care should be able to agree with the following seven statements.

1. I receive the care and support I need and there’s no chance I’ll be left without it.

For many people, care is literally a matter of life and death. However, local authorities in England have recently begun squeezing funding for older people’s social care in order to balance the books. As a result, in some areas only those who are considered to have ‘critical’ or ‘substantial’ needs are able to get support and care. Moreover, others who own their home or have some savings are left to fend for themselves.

There should be a single national eligibility threshold for adult social care, which is set at ‘moderate’ needs so that those who require care do not slip through the net until they get worse and become ‘substantial’ or ‘critical’. Assessments must also consider all individual needs (as recommended by the Law Commission) and be applicable wherever you live. Furthermore, no one should ever be refused care without full consideration of their needs.

2. I receive high-quality care and support.

The care system has to be fit for purpose – it should meet the needs and support the aspirations of the person using it – and has to be of high quality. All too often, care services meet neither of these two conditions. A high-quality care system should also include the choice to arrange the support people want.

Regulation of care needs to be much more effective and transparent to ensure high levels of quality and consumer choice in arranging care. This is not simply about increased inspections by regulators, but having the tools for people to be able to judge the quality of a care service. Local authorities should also involve service users and the public in the planning of services.

Dignity should be a key focus for the care system
The care and support I receive enables me to live safely and with self-respect.

Social care is too often seen as an emergency, task-orientated service, only offering support on the narrow front of providing meals, getting people up or putting them to bed, helping with toileting or administering drugs. This narrow vision means that other needs which improve people’s quality of life, such as support to leave the house or meet other people, are often forgotten. Older people needing care are usually adjusting to a new way of life and the system must reflect this.

How people are treated is just as important as what is provided. Dignity should be a key focus for the care system. Local authorities must not just provide care to keep people safe while neglecting dignity, quality of life and social interaction. People should be able to choose where they live and where they receive care, with support provided to deal with major life changes. Fundamentally, this must never result in pushing people into poverty. To help achieve this, people should know more about the care and support they receive and what it is going to mean for them.

I am able to plan in advance before I need care.

Most people seeking care have either an urgent need as a result of a crisis, such as a fall or stroke, or slowly experience a reduction in physical or mental capacity. In either situation, it is currently largely impossible to plan ahead for care needs. This is because people who need care, and their families and carers, are unlikely to know where to start looking for information, or know the support they could access. A reformed care and support system should allow people to plan ahead for possible care needs and understand what the state will provide. It is critical that information and advice is available to support people through the process and enable them to plan in advance.

On a financial level, there are few opportunities to insure oneself against the catastrophic effect that needing care can have. People need to know what their financial responsibilities might be and what support they can expect from the state. Any financial advice should be appropriate, adequately independent and regulated.
I am able to pay for my care in a fair and transparent way.

The current system of paying for care is unfair, complex and lacking in transparency. There is financial support available for people on low incomes, or for those who have low asset wealth, but the large majority of people have to pay the full cost of their care. As a result, some people are forced to sell their homes. Someone could end up sacrificing up to 80 per cent of their wealth under the current system.

The Dilnot Commission recommendations should be implemented. This would see a cap on the cost of care to £35,000, while raising the threshold for means-tested support for people in residential care to £100,000. This would mean that no one would need to sacrifice more than 30 per cent of their assets. It would also provide an opportunity for the financial services market to offer packages to enable people to plan for their care.

The Law Commission’s recommendations should be implemented in full to create a clearer and more transparent system. There should be support to help guide people through the process, which must be free. The system also needs to be much more transparent, so people are clear who is responsible for particular areas of their care.

If I have a family member or friend who acts as a carer they have the support they need and are not expected to sacrifice health, career, social life or future economic security.

It is important to recognise that much of the care provided in this country is given by the 6.4 million people who care for spouses, family and friends without payment. Often, this is at a cost to their own health. Some struggle to stay in work, have poor mental and physical health and become isolated. These ‘informal’ carers save the state an estimated £119 billion – more than the cost of the professional NHS. As a result, 70 per cent of carers feel their physical or mental health has been damaged by caring.

More support must be provided for carers. The Law Commission recommendations, giving carers a right to assessment, should be implemented. The benefits system should be reformed to provide adequate support for carers.
Conclusion

Care is in crisis. There are significant problems with the current system, which leads to people being forced to sacrifice what they have worked for all their lives and not being treated with the respect they deserve. As the examples in this report have shown (and these are not isolated cases), there is a tremendous cost attached to a failing care system.

There has been a lot of talk about reforming adult social care. But now is the time for urgently-needed reform. In spring 2012, the Government is publishing a White Paper to reveal its policy on adult social care in the future. Despite numerous commissions laying out the strategy for reforming care, and promises that this time care reform will not be kicked into the long grass, we are worried that this once-in-a-generation opportunity to improve the social care system will not be seized.

If you agree with what you have read, or have experienced a similar care situation, please sign Age UK’s petition to the Government, calling for reform of the system. We are looking for 100,000 people to demonstrate that enough is enough in this way. The time for reform is now.

Sign Age UK’s petition, calling for the Government to reform the adult social care system at [www.ageuk.org.uk/careincrisis](http://www.ageuk.org.uk/careincrisis) or contact your local Age UK or Age Concern.