

Voices from the social care crisis

**An opportunity to end a broken
system, once and for all**

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A Care and Support Alliance report on how the social care crisis is affecting the day to day lives of older people, working aged disabled people and unpaid carers across the country.

Who are we?

The Care and Support Alliance (CSA) is a coalition of more than 80 of the country's leading charities who are calling for a properly funded care system. We include Age UK, MS Society, Alzheimer's Society, Scope and many more.

See careandsupportalliance.com/membership for a full list of members.

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Our Big Social Care Survey

3,915 older people, disabled people and unpaid carers with self-identified care and support needs took part in our survey, from every region of England.

The survey ran between January and March 2018 and was completed by 3,915 self-selecting people who identified as having experience of adult social care. We had a broad range of respondents from a wide range of ages, locations and financial backgrounds. Of these, 36% were aged under 65 and 64% were over 65, which broadly mirrors the profile of the population relying on adult social care in England.

Care at crisis point

Social care is essential in meeting the needs of disabled people, older people and their unpaid carers in enabling them to live healthy and fulfilling lives.

As well as relying on care and support for help with everyday tasks like washing, dressing and eating, social care plays a vital role in supporting people to work, volunteer and take part in social activities and it can prevent avoidable expenditure, particularly on health services. It can also help people to stay in their own homes and be independent. Paid-for social care is generally provided by care workers in someone's home or in residential settings such as care homes and nursing homes, but the reality is that the majority receive informal, unpaid support from 7 million families and friends across the UK¹.

Although our social care system is supposed to help people to live full and fulfilling lives, growing numbers are unable to access it. Currently at least 1.2

million older people and disabled people do not receive the care they require, a number which has almost doubled since 2010². And despite more of us needing care, the number of adults receiving it has fallen by at least a quarter between 2009/10 and 2013/14 alone³. An estimated £6.3bn will have been taken out of adult social care in real terms since 2010 and the cuts to budgets between 2010 and 2017 now total 49%⁴. These cuts have ratcheted up the pressure on unpaid carers – generally families and friends – who currently provide care worth a massive £132bn, almost equivalent to the UK's total annual spend on healthcare. 2 million people have already given up work to care⁵.

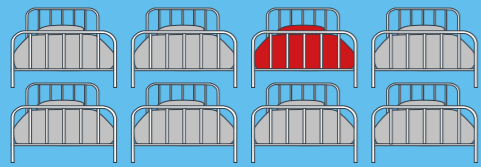
Being without basic care has a damaging effect and creates unseen crises in people's homes, as so many of the stories in this report demonstrate.

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CARE & SUPPORT ALLIANCE

Ahead of the Government's plans to bring forward proposals to improve the social care system we spoke to nearly 4,000 of those with care needs and those providing unpaid care. They told us the effect of a broken system and highlighted the areas desperately in need of change.

Impact on the health service



1 in 8 had to stay longer in hospital



1 in 4 have needed hospital treatment



Over 1 in 6 missed crucial medical appointments

Waste to wider society

1 in 5 are unable to work



I'm so sorry to ask ...

Nearly half are relying more on family and friends

Shocking experiences people endure



1 in 5 have gone without meals



Over a third have not been able to leave the house

Over a quarter have not been able to maintain basics like washing, dressing or visiting the toilet



1 | The shocking experiences people endure

1 in 5 told us they've gone without meals due to a lack of care and support

For people with health problems and disabilities inadequate nutrition can have devastating health consequences. It can interfere with medications (which often need to be taken with food) and can also lead to people being malnourished, which we know drastically increases their vulnerability to ill health⁸.



W I can't prepare meals so don't eat properly and haven't taken my medication properly in years. I'm very depressed and have no social life. Also [the local authority] only offer me 30 minutes per week domestic help so after 10 years of this my home is just too embarrassingly messy and dusty to invite people around. Apparently two meals a day of porridge is eating properly... Also they refused to give me help with shopping so I regularly run out of perishables."

W Although I am in a care home, I receive no attention other than being washed and dressed. I am left to walk myself to the toilet even though I've had falls in this care home before. I have food put in front of me that I can't see, can't cut, and can't balance on cutlery. Staff take it away again saying: "oh you must not be hungry today." I prefer a sandwich, but even though my family have specified this, I'm served a hot meal that I can't be independent with, and give up after struggling with a couple of mouthfuls."

1 in 4 told us they had to struggle without basic support

Too many struggle with the basics, such as getting out of bed in the morning, getting dressed or going to the toilet - because they lack vital care and support.

If people receive visits from paid carers they often barely have the time to make a cup of tea, let alone help someone get to the toilet in the morning.



W I haven't been washed for over two months. My bedroom floor has only been vacuumed once in three years. My sheets have not been changed in about six months, and my pyjamas haven't been changed this year. My care workers don't have time for cleaning, washing or changing me."



1 in 5 feel unsafe moving around their home and over a third can't leave it

Feeling unsafe or stranded at home are all too common consequences of not being able to afford care, or of not having access to the right care.

Some people told us that they couldn't leave their own homes because they don't have carers to support them to get out and about.

W There have been times when the carer could not turn up because of illness, staff shortages etc. I feel particularly unsafe because I don't have any family."

W I cannot afford to pay a private carer more than one visit a day, which means I have to rely on two neighbors to help since I feel unsafe with carers provided by the council, as they were too rough with me and rushed me and had no compassion."



Lorraine, 47, from Lincoln, looked after her mum Margaret who recently passed away. She said:

"The carers hadn't been feeding her lunch, they had just been leaving cold soup by her bed."

"Mum had been battling with MS for over 40 years and used to live at home and get care from people coming round twice a day to help her. They just didn't understand her care needs and the issues that people with MS have.

One day, dad found out the carers hadn't been feeding her lunch, they had just been leaving cold soup by her bed but hadn't been helping her to eat it - they just left. So he had to complain to social services, who stopped the carers from coming over. We found there were no other carers willing to help mum who has complex needs - we had no choice but to put her in a care home.

Initially she was placed in a care home with only people with dementia, and this made her feel isolated. She was only 64 at the time. On visits we noticed her health was getting worse.

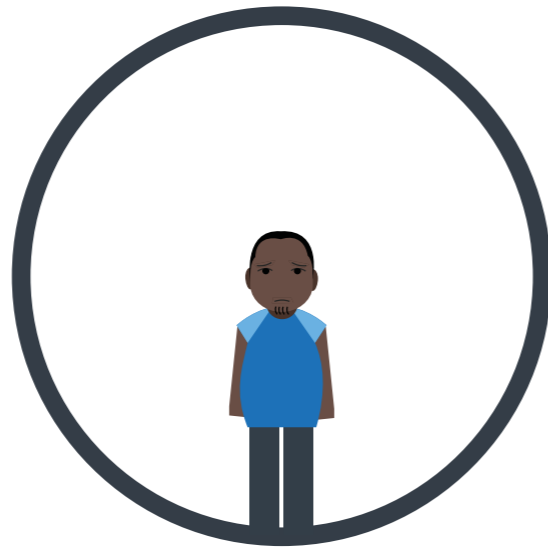
As a result she ended up in a nursing home in Herefordshire, but again it wasn't equipped to support someone with MS. The food was disgraceful, which was hard for her because she was a chef - she lost weight because of it. She was bedbound and the carers hadn't been moving her, which meant she developed bed sores and led to her being hospitalised.

We tried to keep the family together for as long as we could, but nobody was ready to look after her. It affected all of us, and we never wanted Mum to go into a home but we weren't given a choice."

Over a third told us they have felt lonely and isolated because of a lack of support

The serious impact that loneliness has on peoples' wider health and wellbeing is increasingly recognised.

Because people aren't getting the help they need, their independence suffers. Many disabled adults who could work are prevented from doing so. Older people and disabled people struggle to get out and take part in leisure or social activities. This leads to loneliness and social isolation⁷.



W I cannot walk any further than my lounge to kitchen anymore and am almost totally confined to my home, as I have to use a wheelchair to get outside now.

My daughter and carers prepare my meals, do my housework, change the bedding, help me shower, do my shopping etc. I pretty much have to just watch TV or fall asleep in my chair. I am very lonely and would love some company.

As I fall on a regular basis, I would love to go into residential care, but I'm not able to pay the fees so I am at the mercy of social services."

W Carers give me a meal a day but it has to be a simple microwaveable meal as there's no time to make a healthy meal. They rush in and out as quickly as possible. I feel there is no understanding or training in dementia.

If there is clearly a need [and] it's not in their remit it doesn't get met."



KEITH

Keith, 58, from Norwich, is living with MS. He told us:

"We're worried about our situation in the long-term, and can't see how it can go on like this. We just can't do this anymore, we've spent over £28,000 in five years on social care, and we don't know what's going to happen in the future."

"I was diagnosed with MS in my thirties and now have severe MS. I rely on a hoist and can't get up or go to the toilet on my own anymore. About five years ago, I managed to get a personal budget for my care, and it worked well at the beginning. All of that suddenly ended, because in spite of being assessed as needing care, they did a financial reassessment last year.

When the council increased the contributions I would have to make for my care from £125

a week to £179 a week, we couldn't afford care anymore. We'd already been struggling before that, and now we had to make all the carers redundant; we felt terrible. All I have now to support and care for me is one carer coming in for one hour a day, and that's not even enough to help me get showered; but it's all we can afford.

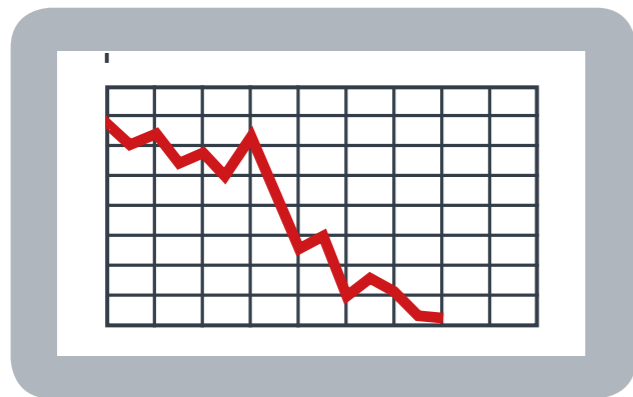
My wife is unwell herself. She's got heart problems and isn't meant to do any strenuous lifting, but has no choice but to help me in and out of bed now.

Part of me wishes we'd never gone for the personal budget, because we've seen what life could look like for us with the right support in place. For a while, we had the freedom and ability to do more, but it's also been taken away."

2 | The impact on the health service

A lack of social care means worrying numbers of people are reaching crisis point because they are going without what they need and have nowhere to turn to but the NHS. This adds up to a huge unnecessary cost for the NHS, due to people having no choice but to rely on services, such as their GP and A&E.

This is also a very inefficient way to provide people with care. A hospital bed alone costs around £2,800 a week while a bed in a residential care home costs on average £600 a week and it can be even cheaper to provide care at home⁸.



Over a third have told us they have seen their health deteriorate as a result of not getting the care they needed

Every day, people across the country are feeling the physical and emotional consequences of struggling without proper meals, personal care and the effect this has on their ability to live independently.

W My budget has been cut and I no longer receive what I need. My mental health is suffering as a result. It also aggravates my physical disabilities."

W I am struggling and this is impacting on my physical health, not being able to do anything at all that would be beneficial to my health and well-being. The struggle gets worse as I'm now no longer able to access transport to hospital. Not given support for anything else and so it is a constant struggle."

CSA research last year revealed almost 90% of GPs think reductions in social care are leading to extra pressures in their surgeries. In addition, 93% think that the lack of social care is leading to extra pressure on A&Es and contributing to increased delayed discharges from hospital. Not only is this having a detrimental effect on the health service, it's often not the best way to look after people, and it is certainly not a long-term solution to the care crisis⁹.



Howard, 44, from West Sussex, has paraplegia and needs to rely on his 18-year-old son for some of his care. He said:

"I don't have the money to go to medical appointments, and I haven't been able to see my diabetes nurse since last September."

"I've needed social care since 2007. I have three carers at the moment, and I choose to arrange my own carers, because I get direct payments. But the money I get isn't enough to give me the support I need on a daily basis; it leaves me with only the very basics.

The carers are great, but everything is done in a rush because they don't have enough time. That means I often have to rely on my son, especially when I'm feeling worse than I usually do, and there's no one there to provide me with extra support. He's 18 and really shouldn't have to take on so much, I

do worry a lot about him. He supports me if the carers don't show up, or if they need holidays, and he sometimes has to help me during the night too because I don't get funding for care during the night. I really worry about what would happen if my son wasn't around because I'm also diabetic and it could get bad if I'm left alone.

As a single parent I struggle financially. All the worry and the lack of support has impacted my physical health, as well as mental health. It's got so bad that I don't have the money to go to medical appointments, and I haven't been able to see my diabetes nurse since last September. To be able to go to the doctor's I have to give up hours for my personal care so I can afford transport, which means I have to choose between my personal care needs and managing my overall health."

1 in 6 told us they have missed crucial medical appointments

The lack of funding in social care has also meant that more and more local authorities have rationed care. As a result, people often don't get the support they need to get to and from medical appointments.

Missed medical appointments are a major concern for the NHS as every missed outpatient hospital appointment costs around £120¹⁰. However, they can also have a detrimental impact on people's health, as small health issues can develop into bigger problems requiring more urgent and/or costly intervention.

W I will soon be going into hospital to have cataracts removed but so far I've been unable to find someone to accompany me. I don't have any family support, as most of my friends are either elderly or deceased."



1 in 4 told us they needed hospital treatment and 1 in 8 told us they've been delayed leaving hospital because of not getting the care they need

This is happening because people are being left without basic support and are having to struggle to manage health conditions on their own. Consequently people's health can deteriorate to such an extent that they need to go to A&E. And then when they are ready to leave, the right kind of support often isn't available, so people get stuck, using up a hospital bed.

In 2016-2017 alone, patients were delayed from being discharged from hospital for the equivalent of around 1 million days due to a lack of social care, which adds to pressure on the NHS¹¹. Staying in bed for long periods or not receiving proper help to rehabilitate can seriously undermine people's mobility and capacity to stay independent, especially for older people.



W My wife is confined to her bed and she's just not getting the help she needs. The longer it goes on the worse it will get. She recently broke her leg and got stuck in hospital for over 19 weeks - she was in bed the whole time. The hospital transferred her to a nursing home to wait for her care package and as a result of inactivity her muscles have now deteriorated so much."

W I broke my hip before Christmas. I was very confused in hospital and was discharged back to a care home after one week. But no physiotherapist was provided once back at the care home and my health deteriorated rapidly."



Glyn, 58, and Kristin, 46, are married and live in West Sussex. Glyn told us:

"I'm completely falling apart - I check and double check everything that's done."

"My wife Kristin was diagnosed with Relapsing Remitting MS 16 years ago and has had Secondary Progressive MS for four or five years now. She is also a type 1 diabetic and is on a diabetic pump.

She should have left hospital much quicker than three months, but it took that long to get a care package in place. That was just to have someone to help get her up in the morning and put her to bed in the evening - I did all the rest. During her time in hospital she caught sepsis and had another lung infection, which I'm sure she wouldn't have got if she'd been sent home earlier.

Because the care home she's now in has limited staff she's sometimes left in bed until after 11am. Sometimes she's left on her own, and if her catheter bypasses she's left sitting in wet. Because of limited staff they frequently have to rely on agency nurses who've got no idea how to use Kristin's pump and/or insulin. She once ate dinner at 7pm the night before, they forgot her breakfast and then the lunch feed was late so it was 1.45pm the next day before she got anything to eat.

I'm completely falling apart - I check and double check everything that's done."

3 | The waste to wider society

The current social care system is leaving many people with disabilities, as well as older people and their carers, locked out of society. People are unable to contribute their skills, talents and unique perspectives to the paid or volunteer workforce. It also impacts on our economy, as people aren't working or are struggling to meet care costs.

Over 1 in 5 told us they have been unable to work because of a lack of care

Because the care system is broken, people are unable to work, volunteer and contribute to the economy, and many have also reported they've had to reduce the hours they work.

This is backed up by other evidence which shows that disabled people are more than twice as likely to be unemployed as non-disabled people¹².

As the system has increasingly broken down and local authorities have had to withdraw all but the most basic care and support, fewer people have been able to access the high quality and affordable care they need.

W I have reduced my working hours and eventually my husband will need to be my carer so he will need to stop work too. We have our own business with debts and a dependent child of 14. We will not be able to fund this all ourselves."



W To be able to work, I need help with getting up in the mornings and getting dressed. So I tried to arrange for carers to come in beforehand to help me get ready, but they don't come on time and sometimes I end up stuck having to give lessons in my pyjamas. I really want to be independent, I want to do as much as I can on my own - but it's just not manageable. I don't know where I'm going to find £8000, with a mortgage to pay and a family to look after. I don't know where the extra money is going to come from, and we're down to the last £100 every month."



and go to college which she enjoyed. It helped her flourish, and her confidence really grew as a result. In 2017 a new assessment resulted in her direct payments being cut by

Ildi, 64, from the South West, lives with arthritis and looks after her daughter Sarah-Jane, 27, who has Down's syndrome. Ildi told us:

"We're having to live on an overdraft that we both had to take out."

"I am 64 and a full time carer for my daughter, Sarah-Jane, who has Down's syndrome. We moved from Staffordshire to enable my daughter to gain more independence and hopefully to expand her social and leisure activities. We really wanted to make our own choices, taking her strengths and abilities into account. When we moved, Sarah-Jane was assessed for her care and support package. Although it was accepted that she had care needs, we were also told that due to lack of funding they could not provide any support.

Eventually, we were able to get her direct payments and this unlocked everything for Sarah-Jane. She was able to go swimming

two thirds without any change of her needs - a difference of £500 and now her transport costs are no longer paid.

I was diagnosed with osteoarthritis in 2015, and since then it's now affecting my hands. It impacts my ability to do things like drive, cook, clean and dress. I used to run a bistro and it was really great because I was also able to give my daughter work and we did that together. But after my diagnosis, we had to give up my dream, because I just couldn't do it anymore with my arthritis. It was so painful, it was too much. It did affect my mental health, as well. I am not eligible for support for my arthritis or my anxiety and stress, exacerbated by the council's attitude to both me and my daughter. We're having to live on an overdraft that we both had to take out."

Sarah Jane said: **"I'm not happy and feel upset and I will fight it."**

Nearly half told us they had to rely on family and friends

Today, unpaid carers are often filling the gap in care provision and shouldering more and more responsibility. Because support isn't available for their family members or friends, many unpaid carers are unable to work or have to reduce the hours they work to care.

I'm so sorry to ask ...

When I was caring for my mother at home getting respite care was very hard - in fact for a long time I didn't know I was entitled. It's a lottery as to whether social services give you the information you need about what you are entitled to as a carer."

I've had to shut off because it breaks me sometimes. Everyday tasks like shopping and preparing meals are impossible for me because of the stabbing pain and burning sensation I experience in my hands and other joints. My granddaughter stays with me four nights a week to help me with day to day life, including making meals, and I feel that without her support I'd be lost."

My sunny nature has been lost - I care for my mum but have no other life."



FAY & AIDAN

It's awful. I would have thought they'd want to keep someone healthy when they care for someone else.

Fay, 74, from Oxfordshire, has diabetes and is a carer for her husband Aidan, 81. She told us:

"It seems like you have to be a prisoner and wait until you die."

"My husband has had primary progressive MS for 15 years. I'm 74 and have a heart condition, arthritis and also diabetes which is affecting my feet a lot.

We get no care at all. We couldn't afford any of that. They've assessed us - I think they come once a year - but they've never offered us any actual help. So we do whatever we can for each other.

It's hard. Someone came out to assess me, and my health because I keep falling - I keep falling because my foot is so bad because of the diabetes. No one listens to me. It makes it difficult to care for someone else when you're in such pain. And it's very difficult to get somebody to listen and take notice.

He can't do anything without me. He can't do much for himself although he tries. He does like to be in the bathroom by himself but he has to be monitored because he does fall off the toilet. It's quite devastating. When he stopped working about 10-11 years ago, we had some savings, and I thought they would keep us going. But we've had to eat into them and he gets worse all the time.

They don't see the day to day difficulties with the wheelchair trying to fit into doors and all of that. It seems like you have to be a prisoner and wait until you die.

The system is so alien to people who are not able to control anything. You can't control it and your income is always low. Sometimes I'm just too tired to have a bath or shower, too worn out to get dressed. You end up neglecting yourself a bit to keep up with everything else."

Conclusion

The voices in this report reveal the impact of the failing social care system on people and their ability to go about their daily lives. People are frankly neglected - unable to eat, get washed and leave the house because the help isn't there to enable them to live dignified and healthy lives. In addition to this being appalling for the individuals affected it's resulting in people relying more on the health service; often getting stuck in endless cycles of having to go to hospital and not being able to leave because the right care isn't available, and putting enormous pressure on family and loved ones who are under increasing pressure.

To make matters worse, the lack of support available - whether that's in terms of quantity or quality - also means that it is generally impossible for paid care staff to do more than just the basics, with the result that people are missing out on working, volunteering or taking part in their communities.

In the upcoming Green Paper on social care, the Government must put forward proposals for how to put social care on a sustainable footing and ensure that people who rely on care and support and their families don't continue to bear the brunt of the current crisis.

The Government must also recognise the urgent need to fill the current funding gap and invest the £2.5bn required now to keep the system afloat while we wait for a better model in the future¹³. Only by doing this will the Government address the significant harm the current system is causing; the waste to peoples' lives, the waste to our NHS and the wider waste to society.

Action is needed now; for too long politicians have promised action but we've seen very little improvement and in most respects things are getting worse. The result is a care system that is failing many of those who need it today.

The Government must:

Put a stop to older people, disabled people and their carers being locked out of our society. We need a social care system that ensures they'll not only get the basics, but also have access to the care and support they need to lead fulfilling and healthy lives. We need a social care system that enables independence and makes sure that people can access all the support they need to lead fulfilling and healthy lives.

Put a stop to the NHS having to save the day when there's no other support on offer. We need a system that provides people with the preventative, high quality and person-centered care and support they need. This is crucial to preventing so many from needing intervention at the point of crisis and to reducing the pressures on our health service.

We would like to thank everyone who took the time to share their personal experiences.

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The Care and Support Alliance
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