



**General
Election
2019**



#FixSocialCare

**The Care and Support
Alliance Manifesto**

**CARE &
SUPPORT
ALLIANCE**

Who we are:

The Care and Support Alliance is a coalition of 75 charities and organisations (including Age UK, Alzheimer's Society, Mencap, Scope and Carers UK). We campaign with people and their families who need care to ensure we all can get care we can rely on, without facing catastrophic care costs.

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Care and Support Alliance Manifesto 2019



We all deserve to know that if we needed care and support we would be able to get it.

Any of us could need care for many reasons – from setting out independently as a young autistic person, to becoming disabled in mid-life or getting dementia in our 80s. In all these circumstances and many more too we would want to know help will be there for us.

Everyone deserves the reassurance of knowing we wouldn't have to use all our savings or sell our home to pay for this vital support.

It would not be overstating it to describe social care as 'life support'. Care can be at home, in a home or in the community and can help with basics such as eating, communicating, and/or getting out of the house. For those that are able, it can mean the difference between getting to work and having to give up your job.

Today, more of us need care but fewer of us get it.

At least 1.5 million disabled and older people do not get the support they need¹ and the number of adults receiving care fell by at least a quarter between 2009/10 and 2013/14 alone². An estimated £6.3bn has been taken out of adult social care in real terms since 2010 and the cuts to budgets between 2010 and 2017 now total 49%.³

For over 20 years politicians have been promising to fix social care but with no action. Enough is enough, this needs to be the parliament that ensures we #FixSocialCare.

Yours,

Chairs of the CSA:

Caroline Abrahams, Age UK
Emily Holzhausen, Carers UK
Oonagh Smyth, Mencap

¹ Age, UK

² The Health Foundation, "Briefing: The social care funding gap", 2017

³ National Audit Office, "Financial sustainability of local authorities", 2018

A fair care system

We need a fair care system. Currently, very ill people miss out on what they need, and their dignity can be lost as a result. The lack of care is leaving people with woeful levels of support, or with none at all.



A recent survey by the Care and Support Alliance of nearly 4,000 people found⁴ that because of a lack of care:

- **1 in 5 people** have **gone without meals**
- **1 in 4 people** have **had to struggle without basic support**
- **1 in 5 people** feel **unsafe moving around their home** and **over a third can't leave it**
- **Over a third of people** have felt **lonely and isolated** because of a lack of support
- **Over a third of people** have **seen their health deteriorate** as a result of not getting the care they need
- **Over 1 in 5 people** have been **unable to work** because of a lack of care

1 in 5

have gone without meals because of a lack of care



Over

1 in 5

have been unable to work because of a lack of care



Over

1 in 3

have seen their health deteriorate because of a lack of care



It doesn't have to be this way.

As an alliance our 75 organisations recommend six key elements for reforming care:

1. Risk must be pooled on a compulsory whole (adult) population basis, funded through taxation
2. Care should be free at the point of use
3. There must be an independent, standardised national eligibility threshold and assessment process for social care
4. Eligibility should be set at a 'moderate' level to enable those in need of community and preventative support to access it. Eligibility criteria must be loosened and access to social care increased
5. Any proposed solution must include care and support for working-age sick and disabled adults as well as those of older people
6. Any proposed solution must ensure increased support for unpaid carers (such as family and friends), e.g. increased breaks and new financial and practical support to help them juggle work and care or increased Carer's Allowance for carers who can't work.

At this election all political parties must pledge to act urgently and ensure that care is available to adults of all ages who need it. Care costs must be shared across the population. Care needs to be free at the point of use. And family carers need proper support.

Elaine*, from Sheffield, said:

"Good care is a win, win situation, taking pressure off the NHS and other services and, most of all, good care should be an integral part of a humane society."

It needs to happen now...

Millions are suffering because nobody cares for them. It robs them of the dignity, their security and makes their health worse, putting extra pressure on the NHS.

There has been 20 years of Government promises but no action. Now there is a growing consensus that both urgent investment and long-term reform is required, including some form of compulsory, whole population risk pooling. This has been acknowledged by experts, politicians from all sides and the people who rely on care and it is a view the Care and Support Alliance strongly shares.

⁴ Care and Support Alliance survey of 3915 people who self-identified with care and support needs. Survey conducted Jan- March 2018

* People's names have been changed.

1

Risk must be pooled on a compulsory whole (adult) population basis, funded through taxation

Currently, how much you pay for support is down to chance – how much money you have, what type of care you need and for how long. Any of us could need care and what we need will vary depending on the condition/s, disabilities, or accident you have, or if you live into old age. It is impossible for anyone to predict and therefore impossible for anyone to save for.

If you have an unpredictable health condition, you are protected by the NHS. But if you have a disability or long-term condition that means you need care, you receive little to no protection and you may find yourself on your own. Sharing the risk of developing care needs through taxation would take away the worry from individuals and families; which already happens with the NHS. It shouldn't matter whether you require social care or health care to stay alive and live decently: after all, the worry, uncertainty and need are the same. It's not fair that for now the financial burden of paying for care often rests on the person who needs care and care bills can be enormous.

At the moment, many people who pay for their own care are subsidising the care of those who rely on council funding. Councils don't have enough money to cover the real cost of care, so they pay care homes and providers less than the actual cost. This means care homes and providers have to charge self-funders a lot more to make up the difference.



Julie, from Barnsley, said:

"Good social care would mean that my 86 year old mother who has Alzheimer's and has paid into the system all her life would receive free care. We recently had a fee rise, which we were openly told was to counterbalance the 'free' places for other residents."

2

Care should be free at the point of use

Care should be free at the point of use, just like the NHS. Many people assume this is already how it works, and how it should work. However, currently care is means-tested, and those with assets over £23,250 will have to pay for all their care. Anyone could need care, so any of us could face care costs and 1 in 10 of over 65s face costs of over £100,000⁵.

In practice this would mean when you need support you wouldn't be subject to financial assessments and seemingly endless form filling. The focus could instead be on caring.

People describe it as a 'fight' to get what they need, as they face a bureaucratic system, where what you get, how you get it and how much you will have to pay are not clear, even for those who are really familiar with the system.

Mark, from Leamington Spa, said:

"The care, at times, becomes as big a problem as the condition itself, which can't be right. Social care is not just feeding and cleaning. It should enable people to live the best life they can despite the challenges they face."

Care being free at the point of use would mean a lot more taxpayers' money would go on the actual care for people who need it, rather than on lots of bureaucracy.



Rosalind, from Northampton, said:

"My sister is in a care home for which she self-funds. Her bill every month is approximately £4,300. This would be equivalent to sailing around the world first-class. It cannot be beyond the wit of man to come up with a social plan that will make care fair."

⁵ Commission on Funding Care and Support

3

There must be an independent, standardised national eligibility threshold and assessment process for social care

The support you get should be the same across the country. This would end the current postcode lottery and make the system more transparent and easier to understand.

Sarah, from Hampshire, said:

"Good social care would mean that I wouldn't have needed to be assessed (for the umpteenth time) by 13 different social workers. If I had got the care I needed, maybe I could have stayed at home a little longer."

"If I had got the care I needed, maybe I could have stayed at home a little longer."



4

Eligibility should be set at a 'moderate' level to enable those in need of community and preventative support to access it. Eligibility criteria must be loosened and access to social care increased

Currently, care is only given to people in the most desperate need, but this doesn't make sense. Given at the right time, care can prevent further illness or delay decline. Without it people often need more expensive help from other services, including the NHS.

Good care allows people to do what is important to them, such as getting out to see friends, joining clubs and for those that can, getting to work.

Jane, from Wiltshire, said:

"Good social care means less time in hospital and not having to reach a crisis point before help arrives."

Given at the right time, care can prevent further illness or delay decline.



5

Any proposed solution must include care and support for working-age sick and disabled adults as well as those of older people

Everyone should be able to get the care they need, regardless of age or condition. The type of care may vary but it should be available – whether you’re a 20 year-old blind woman needing support to learn her route to work, a 40 year-old man recovering from a stroke needing support to eat breakfast, or a 90 year-old woman with dementia requiring help taking her medication.

As a country we must acknowledge that our care needs are increasing. Current spending on working-age adults makes up 48% of local authority expenditure on social care⁶. In addition, public spending on young adults is set to increase from around £8.4bn (0.53% of GDP) in 2015 to £18.4bn (0.73%) in 2035 (at 2015 prices)⁷.

The Office of National Statistics population projections show that the number of people aged 65 or over is expected to rise from 12.2 million in 2018 (18% of the population) to 16.7 million in 2033.

The Government must put forward a long-term funding solution for social care that works for working-age adults, older people and carers, while recognising the differences between these groups in terms of their needs and, in some cases, their ability to contribute towards the cost of care.

Anne, from Nottinghamshire, said:

"The care, at times, becomes as big a problem as the condition itself, which can't be right. Social care is not just feeding and cleaning. It should enable people to live the best life they can despite the challenges they face."

Ilana, from South London, said:

"Good care would mean that I could stop worrying about how my son will be looked after once his dad and I are gone. Good care would mean he could continue to have a safe and happy life, although he's dependent on others to live."

⁶ Personal Social Services: Expenditure and Unit Costs, England – 2015 – 16 [NS], NHS Digital October 2016

⁷ Personal Social Services Research Unit, Projections of Demand for and Costs of Social Care for Older People and Younger Adults in England, 2015 to 2035, Economics of Health and Social Care Systems Policy Research Unit, 2015

6

Any proposed solution must ensure increased support for unpaid carers (such as family and friends), e.g. increased breaks and new financial and practical support to help them juggle work and care or increased Carer's Allowance for carers who can't work

Care has either been taken away or denied to hundreds of thousands of people. This has led to increased pressure on unpaid carers, who currently provide care worth a massive £132bn, almost equivalent to the UK's total annual spend on healthcare. Research into caring showed that around 7.6 million people over 16 are caring across the UK, an increase of approximately 500,000 over 10 years⁸.

Many are pushed to breaking point: mentally, physically and/or financially. Supporting carers is not only the right thing to do, it also makes good policy sense because it reduces the risks of carers 'burning out'.

Angela, from Stockton-on-Tees, said:

"Good social care would mean my mum could have a real rest before it's too late. She has cared for my sister since she was 15 - that's 32 years without a day off. They both have been totally failed and neglected."



Frances, from Harrogate, said:

"Dad has now passed away but his needs, with two broken hips and pneumonia were not met in the slightest by either the NHS or social services. I feel if care had been better he would still be alive. Mum is in a care home and I have had to give up my job to care for them and have received very little acknowledgment of this."

Catherine, from Epsom, said:

"Good care would mean I don't have to rely on my family to help with everything. They could become my family again rather than my carers."

⁸ The Social Market Foundation, 'Caring for Carers', 2018

When it works

Recently the CSA asked people to share what good care meant to them. Their answers show why this matters.



Susan, from Chelmsford, said:

"Good social care means that both my deafblind sons can lead interesting and fulfilling lives, free from mental health problems caused by isolation and fear of not knowing what is happening around them from day-to-day. With the appropriate support they are both happy, confident men who are able to make day to day decisions and take a full part in activities in and out of their homes."



Janice, from Northamptonshire, said:

"Good care means I can employ staff to support me with things I find difficult and they enable me to be a parent to my 12-year-old daughter. I also have the flexibility to have longer support where needed i.e. to take my daughter on holiday."



Rebecca, from Redditch, said:

"Having carers has totally changed my life so I can now live instead of lying in a dirty bed all day. I cannot tell you how much having the help has improved my life, and my outlook on life has improved."



Ian, from Worthing, said:

"Good care means that my father-in-law experiences a network of people who express their care by investing their time, interest and skills in making him feel known, valued, respected and empowered as a person in a community, not a challenge."

Pat, from Surrey, said:

"Without the care for our 45-year-old son with learning disabilities, at our age of 70 and 80 years respectively, we just could not cope. He lives independently, but he is only able to do this with care being able to assist him. Otherwise, he would have to give up his independence and come back home to live, which would be disastrous."



Susan, from South Shields, said:

"Good social care means that my husband can continue to regain his confidence and feel he is not useless. Plus it gives me time as a carer on my own with free time for myself which I value so much as it gives me the strength to carry on as a carer."



Jamie, from Kent, said:

"Good care means that my adult son can live a fulfilling and useful life away from the parental home, allowing his parents to work full time, just like a normal family."



Pat, from Liverpool, said:

"Getting the support we needed was an absolute godsend. It means so much to us all: Laura can get the help she needs. Also, Laura's partner Jay can continue to work, which is much better for him than being a full-time carer. The family can have a better standard of living than they would if they were on benefits."



What can candidates do to #FixSocialCare?



Get informed about the issues in your area, if you don't know how contact us and we will advise.



Put #FixingSocialCare on the local political agenda: raise it at party and council meetings and talk about it with your local media if you get the chance.

If you are elected to Parliament, congratulations, get the Government to publish their plan to #FixSocialCare by March 31st 2020.

Talk to us about the things you can do to help make this happen - from asking Parliamentary Questions that hold Government to account, to writing to new Secretaries of State and Ministers to get their commitment.





Contact us

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