

Carers UK: Spending Review Submission 2022-2025 – Spending Review 2021

Overview

The pandemic has tested families in a way that we have not seen before, particularly those providing unpaid care. It has resulted in some positive benefits to families, businesses, and public services – speeding up flexible working, accelerating the benefits of digital engagement, increasing joint working, increasing volunteering in local communities, and greater recognition for carers amongst the general public.

However, the overall impact for carers has been detrimental and, for many, harsh. The pandemic has increased health inequalities, increased costs for families and has made carers feel further away from the rest of society than before. As well as affecting millions of families' lives, these negative effects also impact on the core priorities for Government, including health and care, levelling up, and, in particular, a plan for growth.

Carers already contributed a huge amount to society, equivalent to the funding for the NHS. Every day of the pandemic, the value of this support has been £530 million – with an annual value of £193 billion.¹ The care they have provided has undoubtedly protected the NHS and our social care systems, which would have collapsed had carers not taken on additional care.

Our submission looks at measures which come under the Government's key priorities and principles, including:

- Health and care
- Levelling up
- Strong and innovative public services and communities
- Plans for growth

There were up to 9.1 million unpaid carers across the UK before the COVID-19 pandemic², providing everything from a few hours of support a week to intensive and complex round the clock care. The pandemic has resulted in millions of new carers – 4.5 million new to caring since the start of the pandemic, 2.8 million of whom are juggling work and care.³

¹ Carers UK (2020) 'Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic'

² Carers Week (2020) 'Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak'

³ Ibid.

Caring can come at great cost to families themselves, as the impact of caring without sufficient support takes its toll on their emotional and physical health, and their ability to work – which also has a knock effect on their long-term finances.

Carers have been hit particularly hard by the COVID-19 outbreak. Many have had to make extremely difficult decisions about work and family. Anxiety levels over risk and how to manage have increased. 81% of carers say they were providing more care. 35% said they were providing more care because services had closed or were not available because of lack of PPE, care staff self-isolating or having caring responsibilities themselves.⁴

In our first survey of carers during the pandemic (April 2020), 55% of carers said they were finding it hard to manage and were concerned they were going to burn out in the coming months. In subsequent surveys this trend continued as services continued to be closed or reduced.⁵ We warned that this would impact on social care and health systems. We have also now seen evidence of this through the Association of Directors of Social Services Budget Surveys, where they reported an increase in complex cases needing support due to carer exhaustion and breakdown.⁶ A system that doesn't provide sufficient support early and which lets carers reach this point of breakdown is a care system which needs fixing.

We are concerned that this stress will continue to have longer term impacts on carers – including on their work and their own health and wellbeing.

The Spending Review 2021, which will set out Government investment over the next three years, presents an important opportunity to ensure that unpaid carers are supported to rebuild their health and their lives. It is also an opportunity to recognise the vital role carers have played during the pandemic and continue to play in society. It's also an opportunity to fix social care according to the principles and goals set out by the Prime Minister in his statements.

Health and care

Government has made a bold step by introducing the new Health and Care Levy, which will bring additional funding into the NHS to speed up elective treatment. It also provides some funding for the Dilnot proposals and some elements of care, potentially through White Papers on social care and integration. These precise levels of funding have not yet been announced and so we are unable to comment further.

⁴ Carers UK (2020) 'Caring Behind Closed Doors'

⁵ Ibid.

⁶ ADASS (2021) 'ADASS Spring Survey 2021' and ADASS (2021) 'ADASS Activity Survey 2021'

During the COVID-19 pandemic, there has often been a rise in needs of the person being cared for. Indeed, a survey by Alzheimer's Society found 82% of people living with dementia having increased needs⁷, while our own research during the pandemic showed that 78% of carers reported that the needs of the person they care for have increased since the COVID-19 pandemic.⁸

As well as the needs of the person being cared for, we are seeing increased need of carers – particularly in terms of their mental wellbeing. Carers say that this is due to the effects and impact of lockdown and the reduction in services. Our own research found that almost two thirds of carers (64%) say that their mental health has worsened as a result of the COVID-19 pandemic, while 58% of carers say their physical health has worsened.⁹ This chimes with evidence from other major charities; a survey from Mencap found that two thirds (67%) of unpaid carers said their loved one's needs have increased during the COVID-19 pandemic¹⁰, while a survey of carers of disabled children for the Disabled Children Partnership found nearly 1 in 5 (18%) say their own general health has got a lot worse, a further 37% say their own general health has got a little worse¹¹.

The Association of Directors of Adults Services (ADASS) said in response to their 2021 Spring Survey, "Many directors are saying they have never seen such an avalanche of need. Tens of thousands of people have lost their independence during the pandemic, suffered fresh distress or seen existing care and support arrangements break down. Many have delayed coming forward until now."

Sufficient funding is needed to continue essential services providing capacity and sustainability of the care and charity sector, provide sufficient breaks for carers - prevent carer breakdown of all ages, including young carers; improve carers' resilience, improve disabled and older people's health and wellbeing.

However, the Health and Care Levy funding, as it is currently configured, will not tackle the current crisis in social care with care services on the brink of collapse. The Health and Care Select Committee advised that £3.9 billion was needed just to deal with wage increases through the National Living Wage and ageing pressures.¹² We know that 8 out of 10 carers are also caring for someone whose condition has got worse during the pandemic, which means that the baseline for care has changed and increased.¹³ We strongly recommend a robust investment in social care which delivers a benefit to

⁷ Alzheimer's Society (2021) 'Moving forward stronger: Addressing deterioration in people with long-term conditions during the pandemic'

⁸ Carers UK (2020) 'Caring Behind Closed Doors: Six Months On'

⁹ Ibid.

¹⁰ www.mencap.org.uk/press-release/i-dont-know-what-day-it-or-what-weather-outside-social-care-cuts-people-learning

¹¹ Disabled Children Partnership (2020) 'Parent Carers' Experiences of Lockdown'

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¹³ Carers UK (2020) 'Caring Behind Closed Doors: Six Months On'

people who need care and their families. Without this investment, it is unlikely that the Prime Minister and Government will be able to deliver on their promise to “fix social care”.

The rationale for investment in care would be as follows:

- Improved health and wellbeing of people using care and their families supporting the ambitions of health prevention.
- New jobs, particularly those areas with high levels of disability or frailty.
- Sustainable care workforce setting strong foundations for the future of our ageing society. Families rely heavily on a well-trained, caring, consistent and motivated workforce to deliver good quality care in order to work, have a break, get a night's sleep, maintain family connections – things that other people take for granted.
- Stronger local economies.
- Business productivity – retaining skilled workers as care provides a strong foundation for unpaid carers to be able to juggle work and care. Pre-pandemic, 600 people a day were giving up work to care.¹⁴
- Stronger families – rather than undermine families pushed to the limit, social care helps to strengthen them.
- Faster and more successful delivery of the NHS plan for elective treatment to tackle the NHS waiting lists.
- A move from crisis operations between health and social care to managed integrated care, strengthening families and communities.

An investment in care is an investment in family and community. This investment in care should include:

- Investment in carers' breaks – at least £1.2 billion a year to allow those with the greatest caring responsibilities to benefit from a meaningful break.
- Investment overall in social care in line with Health and Care Select Committee to bring up the baseline, but also to increase the quantum of care.
- An additional focus on digital and data transformation across health and social care.
- Greater investment in a workforce plan.
- Rehabilitation and reablement funding to help people regain skills and abilities lost during the pandemic, helping them to live fuller and better lives and reducing the impact of caring on families.

As well as investment in care, we also see the following as critical:

- A new responsibility on the NHS to identify and promote carers' health and wellbeing – helping to support integration. Further detail is set out below on stronger and innovative public services.

¹⁴ Carers UK (2019) 'Juggling work and unpaid care: a growing issue'

A particular focus on carers' breaks is needed:

Many carers have had to care with very little support, and many are seeing the health, wellbeing and mobility of the person they care for deteriorate and feel powerless to do anything about it. This is having an impact on carers' own mental and physical health and their wellbeing. This includes all groups of carers – those caring at home, those caring at a distance, as well as people with relatives in care homes where they regularly provide support and have been unable to do so. The need for services to support carers and the person they are caring for is getting increasingly urgent.

Some people continue to receive care services into the home as self-funded services, through Continuing Healthcare services or through council funded services delivered through private, public or voluntary sector providers. Some people employ their own personal assistants using personal budgets, while others employ people directly. These services need to be rebuilt where services have been reduced or withdrawn.

Where face-to-face services have continued, carers have welcomed and praised the commitment and dedication of care workers and care services. This shows the value that families place on good quality services.

The Government should use the Spending Review to:

- Ensure sufficient funding is in place over Winter to help build breaks services back
- Deliver an investment programme in breaks for carers as part of social care.
- Introduce a three year Carers Strategy or Carers Action Plan as part of any forthcoming White Paper, to deliver the breadth and depth of support needed by carers. This could provide part of a broader New Deal for Carers.

Levelling up

Carers would benefit significantly from a more robust levelling up agenda which recognises their needs. This encompasses:

- Reducing the negative financial impact of caring – putting carers and their families at a distinct disadvantage in the short and longer term.
- Raising the earnings limit on Carer's Allowance and aligning it with 16 hours at the Nation Living Wage.
- Health inequalities agendas recognising the impact caring can have on carers' health and wellbeing.
- A Winter Fuel Allowance for people receiving PIP or Carer's Allowance.
- Ensuring housing policy supports lifetime changes.
- Accelerating and improving digital inclusion.

- Greater recognition for unpaid carers – e.g. making caring a protected characteristic.

Reducing the negative financial impact of caring:

When people take on a caring role they often face a steep drop in income if they have to leave work or reduce their hours to care – sometimes a double loss of salary if they are caring for a partner who also has to give up work as a result of their illness or disability.

This is often coupled with a steep rise in expenditure as a result of the additional costs of caring and disability. Carers can face higher utility bills, higher transport costs, higher shopping bills, and have to spend their own money on care services and even for the cost of home adaptations.

Before COVID-19, almost 2 in 5 (39%) carers reported that they were struggling to make ends meet. Those that had been caring for 15 years or more and those who care for more than 35 hours a week were more likely to say that they were struggling to make ends meet, with 41% and 43% saying that respectively.¹⁵

81% of unpaid carers have seen an increase in the amount they have to spend as a result of COVID-19; this has been on additional equipment, more costly food (including food delivery), more heating, and increased costs of PPE.¹⁶ Many are struggling on low incomes. Whilst Universal Credit recipients have seen the equivalent of £20 increase per week, those in receipt of Carer's Allowance or who receive a premium as a result of entitlement, and people in receipt of 'legacy' disability benefits, have not seen an increase. Carers have also told us that costs are mounting up over time. It is essential that they receive parity of esteem.

Carers and others on low incomes also need to be considered during the winter as they are likely to face new household costs that come with colder temperatures. Working-age disabled people do not receive the Winter Fuel Allowance, nor do carers, but this could be a vital source of support over winter. We feel this is particularly important as we move into a period of higher energy prices.

The Scottish Government already provides carers with more income than the UK Government, with the Carer's Allowance Supplement paid every six months which effectively raises the level above the level of Jobseeker's Allowance. The Scottish Government have also recently doubled the six-month Carer's Allowance Supplement payment providing much needed additional income.

¹⁵ Carers UK (2019) 'State of Caring 2019'

¹⁶ Carers UK (2020) 'Caring Behind Closed Doors'

There are clear links between poverty, ill health and resilience. Financial hardship in these circumstances is even harder. It is essential that carers receive an increase in Carer's Allowance which takes them through to recovery and beyond with lasting improvements to the benefit.

Increasing the earnings limit for Carer's Allowance:

The earnings limit associated with Carer's Allowance is particularly challenging. The earnings limit has remained static over the last few years representing a real-terms cut in income for carers over time. This goes against the Government's work agenda and against the Government's agenda to support carers in their caring role. Set at £128 per week after deductions, at the current level of the National Living Wage of £8.91 per hour¹⁷, carers can only work 14.36 hours in any week in order to retain their vital benefit. The penalty for going even £1 over the earnings limit is to lose 100% of their Carer's Allowance worth £67.60 per week. This has been described as one of the harshest withdrawal rates within the benefits system. Whilst we welcome increases to the National Living Wage, unless the earnings limit is increased in line with this, carers will continue to lose out.

The Government should use the Comprehensive Spending Review to:

- Raise the level of carers' benefits – including the rate of Carer's Allowance and associated premia.
- Raise the earnings limit for Carer's Allowance and permanently link it to the level of the National Living Wage.
- Modernise the ability for carers to keep up to date with any earnings and how it affects Carer's Allowance.
- Write off any overpayments debts for carers that have may have occurred during this time where the carer has made a mistake.
- Extend the Winter Fuel Allowance to carers entitled to Carer's Allowance as well as people in receipt of Personal Independence Payment (PIP).

A plan for growth: strengthening business, supporting families

Prior to the COVID-19 outbreak there were up to an estimated 5 million people juggling work and care.¹⁸ Data collected since the outbreak suggests that 2.8 million more people are now juggling work and care, making nearly 1 in 4 of the working population a working carer.¹⁹

¹⁷ 2021/22 rate for people aged over 23.

¹⁸ Carers UK (2020) 'Juggling work and unpaid care: a growing issue'

¹⁹ Carers Week (2020) 'Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak'

Working carers can struggle to balance their caring responsibilities and paid work. Pre-COVID-19, around 2.6 million people had given up work to care, the equivalent of 600 people a day.²⁰

With a national shift to predominantly working from home, and some families losing key care services, both employees and employers have had to adjust quickly and have gained a great deal of learning in the process. Many working carers have been working from home. For some this has been beneficial, making caring easier to juggle, others have found it more challenging because there are no day services to support them and because they are unable to take a break.

We are delighted that the Government has responded positively to the consultation on the Carer's Leave and intends to bring this forward, delivering on their commitment in their 2019 manifesto. We believe that it will not only help to support families juggling work and care, and we also know it will help businesses retain key staff. We also welcome the consultation on flexible working as another measure which we believe will have the same outcome, keeping businesses competitive and thriving, supporting families, and laying the right foundations for a diverse economy in an ageing society.

However, we are concerned that the lack of available social care services will put a break on this growth. Furlough has been a critical measure supporting business, but also carers – where they have been unable to work because of supporting someone who is shielding. As the furlough scheme comes to an end, day services continue to remain closed or at significantly reduced capacity. Until social care services, holiday play schemes and specialist services are fully restored to their former levels (and increased), many carers will be unable to return to an office or workplace. We are therefore concerned that some carers will have no choice but to give up work to care. This may hit key sectors such as the NHS – where one in three workers also has an unpaid caring responsibility for someone who is older, ill or disabled.²¹

The Government should use the Spending Review to:

- Set out a timeline for the introduction of Carer's Leave and other work measures, including flexible working.
- Ensure that investment in social care is seen as part of the Government's plan for growth.
- Invest in the digital and data infrastructure and reduce digital exclusion (levelling up).
- Consider introducing paid Carer's Leave, ideally paid by the Government at a level that recompenses employers.

²⁰ Carers UK (2020) 'Juggling work and unpaid care: a growing issue'

²¹ <https://www.carersuk.org/news-and-campaigns/press-releases/one-in-three-nhs-employees-juggle-job-with-caring-unpaid-for-a-loved-one>

NHS identification of carers

The NHS depends heavily on the role and input of people who care, unpaid, usually family and friends but also neighbours, in supporting people with long term conditions and disabilities in the community. The value of this support (prior to the pandemic) is £132 billion per year – roughly the same as the budget of the NHS.²² Most are caring for people with multiple conditions and throughout many stages of their illness or disability. 1.4 million people in the UK provide over 50 hours of unpaid care per week.²³

Carers are not a workforce. They are partners, husbands and wives, sons and daughters, nieces and nephews, who have little choice about caring, although many wish to continue.

The NHS focusses primary on the patient, as the 1946 NHS Act clearly sets out, and this defines the approach throughout the NHS, which has since continued including training and learning of staff through to planning, service design and delivery. This approach misses out a core cohort of support, i.e. unpaid carers. Carers have their own health and wellbeing needs, as well as being key partners in the delivery of care.

Carers postpone and delay their own medical treatment because they cannot make alternative caring arrangements for the person they care for while they are undertaking treatment. This normal effect in everyday caring in the UK will be amplified and extended if there is a shortage of care, and if shielding groups have to continue to remain under more restricted conditions.

The GP practice has been at the heart of the pandemic response for many, including by identifying people who need to shield and are extremely clinically vulnerable, and those who are clinically vulnerable. Identification of carers in GP practices helps with several prevention response measures for COVID-19 – to flu, any COVID-19 vaccination programme, advice for carers managing conditions at home, more with fewer health visits, risk stratification, and prioritisation of any treatment.

The identification of carers through a GP Quality Marker Scheme is good practice identified in the Long Term Plan but there needs to be greater take up. Identification of carers is not widespread in GP practices, and we believe it would be beneficial to the COVID-19 winter response if this were accelerated.

The Government should use the Spending Review to:

²² Carers UK, Increasing Value of Carers Support, S. Yeandle, L. Buckner, University of Sheffield, University of Leeds, 2015.

²³ Census 2011, figures for UK, published in Facts About Carers. Increased figures from Understanding Society suggests that this has increased since 2011 in Carers, Social Market Foundation, 2018

- Introduce a new duty is needed on the NHS in England to put in place policies to identify carers and promote their health and wellbeing, including their own employees who are juggling work and care.

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