

Comprehensive Spending Review

Carers UK Submission 2020

Overview

There were up to 9.1 million unpaid carers across the UK before the COVID-19 pandemic, 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.¹

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

Carers have been hit particularly hard as a result of 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. 70% 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.²

Worryingly, 55% of carers said they were finding it hard to manage and were concerned they were going to burn out in the coming months. With many breaks services not available or closed, there is a really urgent need to ensure that the most vulnerable carers are supported now.³

We are concerned that as a result of the stress and challenges during this time, many carers will not be able to provide the same level of caring through the winter or in response to a second wave of COVID-19 or local lockdowns. If this results in carer breakdown from mental and physical health issues, we could see substantial increases

¹ Carers Week (2020) 'The rise in the number of carers during the coronavirus (COVID-19) pandemic'

² Carers UK (2020) 'Caring Behind Closed Doors'

³ Carers UK (2020) 'Caring Behind Closed Doors'

in demand on social care and the NHS as well as individuals going without essential care.

The Comprehensive Spending Review 2020 presents an important opportunity to ensure that unpaid carers are supported to enable them to continue to care during any further outbreaks of Covid-19. It is also an opportunity to look ahead to recovery and to how unpaid carers are supported and recognised for the vital role they have played during the pandemic.

The Comprehensive Spending Review must provide additional financial support for carers, ensure sufficient funding for care services to enable carers to take breaks and there must be an urgent re-assessment of social care need.

Financial support

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, spending on care services and even 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.⁴

81% of unpaid carers have seen an increase in the amount they have to spend as a result of COVID-19 on additional equipment, more costly food (including food delivery), more heating, and increased costs of PPE.⁵ 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

⁴ Carers UK (2019) 'State of Caring 2019'

⁵ Carers UK (2020) 'Caring Behind Closed Doors'
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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 needs 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.

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. They have also doubled the six-month Carer's Allowance Supplement payment providing much needed additional income.

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.

The Government should use the Comprehensive Spending Review to:

- Introduce an equivalent payment to Universal Credit to those in receipt of Carer's Allowance or receive a premium due to underlying entitlement. This would also help older carers who are on low incomes.
- Provide continued flexibility in the claiming conditions for Carer's Allowance.
- Raise the earnings limit for Carer's Allowance and permanently link it to the level of the National Living Wage.
- Write off any overpayments debts for carers that have may have occurred during this time where the carer has made a mistake.
- Increase the level of Carer's Allowance and associated premia, to at least the level of Jobseeker's Allowance.
- Extend the Winter Fuel Allowance for those entitled to Carer's Allowance.

Breaks

Carers UK welcomes the additional funding of the Infection Control Fund until March 2021 and the Government's Winter Plan which recognises the importance of breaks for carers. We consider this to be a key priority for funding in the year ahead.

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' mental and physical health and their wellbeing. This includes all groups of carers - those caring at home, those caring at a distance and 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 through personal budgets, or 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 Comprehensive Spending Review to:

- Announce an urgent review of breaks provision by Government to delve deeper into solutions for carers and providing sufficient capacity for the sector.
- Ensure the Infection Control Fund and other capacity funding is provides sufficient investment for day and evening service providers to increase face-to-face support to comply with social distancing and infection control measures. This funding should be continued beyond March 2021 to provide the surety for carers that they will be able to get a break and provide stability of the market.

Increased social care need

Prior to the crisis, there was evidence of rising unmet need as funding for social care was not keeping pace with need, and that Directors of Adult Social Services were increasingly concerned they would not be able to meet their statutory duties.

During the COVID-19 pandemic, there has often been a rise in needs of the person being cared for. 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. This chimes with evidence from other major charities, a survey from Mencap found, two

thirds (67%) of unpaid carers said their loved one's needs have increased during the COVID-19 pandemic⁶. 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 worse⁷. A survey by Alzheimer's society found 82% of people living with dementia having increased needs⁸.

The Association of Directors of Adults Social Services (ADASS) said in their budget survey, "Overall, the onset of the pandemic has led to an increase in the number of people presenting adult social care needs to local authorities and unmet need." ADASS and the Local Government Association suggested that providers and other care costs would rise to £6.6 billion by the end of September.⁹

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. In addition, good social care services help carers to juggle work and care. In a survey with employers through Employers for Carers, two thirds of employers said good social care services were important for staff wellbeing when they were carers.¹⁰

We welcome the Infection Control Fund, but are naturally concerned about winter and the potential impact on need as we move into Spring. Local authorities must be equipped with sufficient funding to meet these increased levels of need. Much of the prevention work that would normally be undertaken by many organisations is hindered or prevented by social distancing. Healthcare that has been delayed or cancelled is also likely to add to these issues. We urge you to recalculate the baseline on which adult social care funding is allocated reflecting the picture of increased need that we are seeing for adults of all ages and all conditions.

This Government should Comprehensive Spending Review should:

⁶ www.mencap.org.uk/press-release/i-dont-know-what-day-it-or-what-weather-outside-social-care-cuts-people-learning

⁷ Disabled Children Partnership (2020) 'Parent Carers' Experiences of Lockdown'

⁸ Carers UK (2020) 'Supporting carers health and wellbeing in the workplace'

⁹ ADASS (2020) 'ADASS Budget Survey 2020'

¹⁰ Alzheimer's Society (2020) 'The Fog of Support'

- Conduct a rapid re-assessment and re-appraisal of the level of need for social care and housing.
- Conduct an urgent re-appraisal of the baseline need in local authorities, and provide sufficient resource allocation for winter, and subsequently for the 2021/22 budgets for local authorities.

Working carers

Prior to the COVID-19 outbreak there were up to an estimated 5 million people juggling work and care. 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.

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.¹¹

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.

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 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, many carers will be unable to return to an office or workplace. We are concerned that some carers will have no choice but to give up work to care.

The Government should use the Comprehensive Spending Review to:

- Extend the furlough scheme past November to those who are unable to work due to care services running at reduced capacity.

¹¹ Carers UK (2020) 'Juggling work and unpaid care: a growing issue' September 2020| Comprehensive Spending Review 2020

- Bring forward a timeline for the introduction of the right to 5 days Carer's Leave.
- Consider introducing paid Carer's Leave, ideally paid by the Government at a level that recompense employers.

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 is £132 billion per year – roughly the same as the budget of the NHS.¹² 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.¹³

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 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 by identifying people who need to shield and are extremely clinically vulnerable, those who are clinically vulnerable. Identification of carers in GP practices helps with a number of

¹² Carers UK, Increasing Value of Carers Support, S. Yeandle, L. Buckner, University of Sheffield, University of Leeds, 2015.

¹³ 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

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, 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 Comprehensive Spending Review to:

- 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.

Long Term Funding for Social Care

The Government needs to set out plans for a long term, sustainable, solution to funding social care that has carers at its heart. A failure to do so will only see social care continue to be in crisis, with knock on effects on hospitals, the economy, families, carers and people who need access to care.

A reformed system and funding solution must guarantee stability and sustainability, and deliver improvements to care and be well funded, with resources to enable the delivery of consistent high-quality care. We want to see care free at the point of delivery under a system of pooled risk, ideally funded through taxation. The plans need to include working age disabled people and older people, and it needs specific measures to support carers.

The Government should use the Comprehensive Spending Review to:

- Ensure that there is an urgent increase in funding for the care sector that recognises the challenges presented by the COVID-19 pandemic.
- To set out a timeline for long term reform of the social care system, ensuring that any plans have carers contribution both financial and practical, at its heart.

Contact us

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