

Written Evidence Submitted by Carers UK

(CLL0090)

1. About Carers UK

[Carers UK](#) is a charity set up to help the millions of people who care unpaid for family or friends. We are a membership organisation of carers, run by carers, for carers. We provide information and advice about caring alongside practical and emotional support for carers. We also campaign to make life better for carers and work to influence policy makers, employers, and service providers, to help them improve carers' lives.

2. Summary of lessons learnt – re unpaid carers:

In this submission, we have concentrated our evidence on the impact that the COVID-19 pandemic has had on unpaid carers¹ and those they care for, the lessons that need to be learnt, and what action we think needs to be taken by Government and others.

While some support measures have been put in place for unpaid carers through the course of the COVID-19 pandemic by Government, there are key lessons to be learnt with regard to how effective these measures have been / continue to be in supporting unpaid carers.

What has become clear as the pandemic has progressed is that unpaid carers need to be placed at the centre of planning by Government and others, along with other key support, and that disability needs to be clearly thought of early on in planning and exemptions included.

A summary of the key lessons that should be learnt regarding unpaid carers can be found below – these have been split into different categories depending on their effectiveness and timeliness:

A. Things that worked well:

- Including carers within the priority list for testing with key worker status for unpaid carers
- Producing early guidance for unpaid carers
- Extending furlough to those with caring responsibilities whilst shielding was in place
- Lockdown exemptions for people caring for vulnerable people
- Relaxing some of the rules associated with claiming Carer's Allowance – e.g. emotional support.

¹ By unpaid carers we mean people who provide unpaid care to their relatives or friends because of disability, illness or because they are older and need support. There are a potential 13.6 million carers across the UK – see *Carers Week (2020) 'The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak'*.

- The development and acceleration of digital support for carers
- Nation Governments also implemented a number of measures that successfully supported carers – including:
 - i. Providing an additional supplement for carers in receipt of Carer's Allowance in Scotland
 - ii. Providing Personal Protective Equipment to unpaid carers
 - iii. Giving carers priority access to a COVID-19 vaccine once available
 - iv. Producing ID for carers

B. Things that worked well, but didn't happen quickly enough:

- Gradual lockdown exemption improvements for unpaid carers e.g. respite care – allowing this to happen and to be clear. However, this only happened after 8 months of virtually no support. Positively, this has now been put in for all tiers, including the upper tiers.
- In England, trying to ensure that the Infection Control Fund supports the return of day and carers' services

C. Things that did not work well:

- Messaging for carers was not clear from the outset – and could have been more explicit, e.g. mentions of childcare could have had messages about unpaid carers as well. The NHS Responders included carers, but their core messaging did not mention them and therefore they thought they were not entitled to support. Carers quite often are an afterthought – however, when messages have been incorporated, they were well received.
- Recognition from leaders in daily briefings and national leadership has been almost non-existent when unpaid carers have been providing the bulk of care. Health and care workers were clapped. Unpaid carers remained unseen. They are providing £530 million worth of support every day and yet get too little recognition.
- The lack of PPE caused carers to withdraw from services, which have often not returned and caused immense anxiety as well as additional cost for families. Some have been paying for PPE out of their Carer's Allowance – e.g. a box of gloves costing £5 from their weekly Carer's Allowance of £67.25.
- No additional financial support for unpaid carers in England, Wales and Northern Ireland if on legacy benefits, particularly Carer's Allowance, when Scotland across the border has shown that this is possible (provided additional Carer's Allowance Supplement payment).
- Closure of care services and respite support has taken a huge toll on carers and this was not addressed quickly enough with sufficient flexibility in the Infection Control Fund. We welcomed the ICF when it was announced, but many services remain closed (ADASS evidence).
- Lack of understanding of carers, and the vital role they play, by the NHS as a system overall. There was a lack of identification of carers by the NHS, and a risk now of greater health inequalities as carers are more likely to have treatment cancelled, and less likely to have been supported by health professionals.

- Hospital discharge guidance published by NHS England failed to include carers' rights and assessments – overlooking their fundamental rights and entitlements to an assessment of need and a discharge process that expects them to collect their relative with almost no notice. This demonstrates a lack of understanding of carers, their rights and social care.
- Care homes with high death rates and a lack of visiting in care homes.

D. Things that still need to happen:

- Carers to be given priority for any COVID-19 vaccine - like they have for flu vaccine.
- Vital that Government urgently reviews carers' breaks services and invests in them to ensure carers can take a significant break – ADASS recently called for a £1.2 billion cash injection from Government in England
- Government needs to provide a supplementary payment of £20 a week to carers with an underlying entitlement to Carer's Allowance, to recognise the additional costs they currently face and to prevent financial hardship
- Any updated guidance released by Government should continue to recognise and support unpaid carers.
- Ensuring carers are supported to better enable them to juggle work and care.
- Targeted mental health support funding for unpaid carers
- Government to ensure that the social care system has sufficient funding for winter – the additional funding provided by the recent Spending Review is not sufficient.
- A new deal for carers needs to be brought forward by Government, with a tangible cross-cutting action plan
- Longer term, social care reform is vital. Any plans that the Government brings forward must place carers at heart of delivery – and they should be consulted openly on the plans as they are developed.

3. Carers UK's detailed response:

In this section, we provide our evidence that underpins the lessons learnt (see above). First we look at the research we have undertaken since the crisis began; second, we look at the distinct themes that are emerging regarding unpaid carers; finally, we detail the immediate, medium, and long-term responses that carers need to see from Government and others, to ensure they are properly supported at a time of national crisis.

A) Carers UK research into impact of COVID-19 pandemic

Carers UK has conducted various research over the past 9 months, looking into the impact that the COVID-19 pandemic has had on the lives of unpaid carers, and those that they care for. The key research we have undertaken are as follows:

- **Carers UK, (April 2020) '[Caring Behind Closed Doors: Forgotten families in the coronavirus outbreak](#)'** - based on survey responses from 5,047 people - 4,830 current carers, 217 former carers.

- **Carers UK, (October 2020)** [‘Caring behind closed doors: six months on - The continued impact of the coronavirus \(COVID-19\) pandemic on unpaid carers’](#) - based on survey responses from 5,583 current carers / 321 former carers.
- **Carers UK also carried out research in partnership with the Universities of Sheffield and Birmingham and produced two reports:**
 - [‘Caring and Covid: Loneliness and Use of Services’](#)
 - [‘Caring and Covid: Financial Wellbeing’](#)

Together, the findings from these pieces of research clearly show that the COVID-19 pandemic has had a devastating effect on the lives of carers and those they are caring for. A majority have had to provide extraordinary hours of care for loved ones with increasing needs during the crisis, often without the usual help from family and friends, and with limited or no support from local services.

As a result, many people providing care have been left exhausted, socially isolated and close to burnout. Adding to these considerable pressures, carers have also taken a financial hit, and seen their health and wellbeing decline. We explore these themes in more detail below.

B) Impact on unpaid carers – clear themes are beginning to emerge

Clear themes have emerged from our research, giving a clearer picture of how the pandemic has affected unpaid carers’ lives – we briefly explore each of these below and the lessons that need to be learnt:

I. The changing nature of care:

Firstly, it is clear that the amounts and types of care people are providing has changed. Before the COVID-19 pandemic, carers were providing substantial levels of care with many caring around the clock.² This has only increased since March. Our research in April 2020 showed 70% of carers were providing more care than normal.³ By October, this increased to 81% of carers who are providing more care since the start of the outbreak – an 11% rise in only six months.⁴ Only 5% of respondents reported providing less care.⁵

When asked for further details, two in five carers (40%) said they are providing more care because the needs of the person they care for have increased. Local services reducing or closing was another common reason for providing more care, with 38% of respondents selecting this option.⁶

26% of carers said they are providing more care because someone they rely on for breaks was no longer available and 15% said they were providing more care because they were worried about paid health and social care staff having contact with the person they care for.⁷

² Carers UK (2019) ‘State of Caring 2019’

³ Carers UK (2020) ‘Caring Behind Closed Doors’

⁴ Carers UK (2020) ‘Caring Behind Closed Doors: six months on’

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

Our research indicates that carers are providing an average of 10 hours more care, with respondents providing 55 hours a week on average before the start of the pandemic and 65 hours a week since. Many were caring around the clock for more than 90 hours per week.⁸

Carers also reported changes in care needs of the people they care for. 8 out of 10 (78%) carers reported that the needs of the person they care for have increased since the COVID-19 pandemic.⁹

Just 2% of carers reported that the needs of the person they care for have decreased since the start of the COVID-19 pandemic.¹⁰

This increase in care has had a severe impact on many carers, in a number of ways:¹¹

- 58% of carers reported that this increase has made them more stressed.
- Half (51%) of carers report that this had an impact on their health and wellbeing.
- Half (50%) of carers also reported that the increased needs of the person they care for had impacted their ability to take a break, and 41% said the increase in care needs had impacted their relationship with the person they care for.
- Almost half (49%) of working carers said that this increase had impacted on their ability to juggle paid work with caring.

II. Access to breaks and services

Many carers continue to face severe challenges in accessing breaks or other care and support services.

Carers have a right to a life beyond their caring responsibilities, but prior to the COVID-19 pandemic, research showed that 40% hadn't had a day off for more than a year, and a quarter (25%) for more than five years.¹²

Care and support services provide many carers with a break from caring, however, our research shows that large numbers of these services have been unavailable in recent months.

Almost two thirds of respondents (64%) said that they had not been able to take any breaks from their caring role during the COVID-19 pandemic, while one in five (19%) said that they had not been able to take as many breaks as they felt they needed.¹³

A clear majority of carers (79%) selected at least one of these two options indicating that they had not been able to take any, or sufficient, breaks during the pandemic.¹⁴

The reasons given by carers for why they had not been able to take a break were wide ranging, with many pointing to lockdown or shielding restrictions, or not being able to rely as much on friends and family. This has had a severe impact on them.

⁸ Carers UK (2020) 'Caring Behind Closed Doors'

⁹ Carers UK (2020) 'Caring Behind Closed Doors: six months on'

¹⁰ Ibid.

¹¹ Ibid.

¹² Carers UK (2017) 'State of Caring 2017'

¹³ Carers UK (2020) 'Caring Behind Closed Doors: six months on'

¹⁴ Ibid.

Carers were also asked about their experiences of accessing different support services during the COVID-19 pandemic and the impact this has had.

The responses show that many carers are still unable to access services which they previously relied on, as many of these have not reopened or returned yet, in their area.¹⁵

III. Health, wellbeing and emotional impact

Caring during lockdown has taken an immense physical, mental and emotional toll on carers.

Pre-crisis, we knew that carers were more likely than non-carers to have poor health, as demonstrated by the 2011 Census and the more recent GP patient survey by NHS England.¹⁶ Given the huge increase in caring being provided in recent months, and the fact that this is often without any breaks, it is unsurprising that carers are feeling the pressure and seeing an additional impact on their own health and wellbeing.

The key findings from our research show:

Almost two thirds of carers (64%) say that their mental health has worsened as a result of the COVID-19 pandemic. This was significantly higher for carers who were struggling financially (74%). 65% of women said their mental health had suffered compared to 58% of men.¹⁷

58% of carers say their physical health has worsened as a result of the COVID-19 pandemic. This was slightly lower for men (54%) compared with (58%) of women, but carers who were struggling financially had seen a higher impact on their physical health with 70% having seen it worsen as a result of the pandemic.¹⁸

The impact of the pandemic on carers' health is far reaching with 70% of carers having reduced the amount of physical activity they are taking part in since the start of the pandemic. This rises to 74% of BAME carers and 74% of carers who said that they are struggling financially. Only 29% of carers feel that they have been able to maintain their health and wellbeing during the pandemic and only 43% have been able to maintain a healthy diet.¹⁹

Only 30% of respondents reported having a network of people around them to support them, and 48% reported feeling lonely and cut off from people. This is perhaps due to the fact that less than half (48%) of carers feel they are able to keep in contact with neighbours, family or members of their local community.²⁰

Carers who were struggling financially were more likely to be facing loneliness with 19% saying they had a network of people around them and 62% saying they feel lonely and cut off from people.²¹

IV. Financial pressures

¹⁵ Ibid.

¹⁶ <https://www.england.nhs.uk/statistics/2019/07/11/gp-patient-survey-2019/>

¹⁷ Carers UK (2020) 'Caring Behind Closed Doors: six months on'

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Ibid.

²¹ Ibid.

Pre—crisis, 1.2 million carers were living in poverty²² and during the earlier stages of lockdown, carers were twice as likely as the general public to have used a foodbank.²³

Our research confirms that the financial pressures carers were facing six months ago are still an issue.

Over a quarter of respondents (28%) reported that they were “struggling to make ends meet”.²⁴ While more than one in ten respondents (11%) revealed they “were/had been in debt as a result of caring”.²⁵

This research shows that certain groups of carers were more likely to be struggling with their finances than others. 30% of carers caring for more than 35 hours a week reported that they were struggling to make ends meet compared to 20% of carers providing less than 35 hours of care a week.²⁶

Over a quarter of carers (26%) reported that they are spending more due to COVID-19.²⁷ This is lower than in our previous Caring behind closed doors research in April, but there remains a significant proportion of people seeing an increase in costs

36% of those who are in receipt of Carer’s Allowance reported that they are struggling to make ends meet.²⁸ 15% of carers in receipt of Carer’s Allowance also reported being in debt currently or in the past as a result of caring.²⁹

V. Impact on working carers

Working carers were already struggling before the COVID-19 pandemic, trying hard to balance providing practical and emotional support, managing appointments, and keeping an eye on the person they care for – all alongside paid work.

The events of recent months have had a significant impact on work, with both employers and employees having to adapt quickly to new circumstances.

Our previous research in April showed the immediate impact of the pandemic with 9% of working carers unable to work due to social distancing measures, and 13% on the furlough scheme.³⁰

Of the 1,374 carers who reported to our October survey that they were in paid work before the pandemic, 40% reported that they were working from home, 14% had returned to their normal workplace and 27% were key workers who had been going to work as normal.³¹

The furlough scheme was a significant intervention that supported many carers to manage their caring responsibilities when services were shut and particularly for

²² New Policy Institute (2016) ‘Informal carers & poverty in the UK An analysis of the Family Resources Survey’

²³ Matthew R. Bennett, Yanan Zhang & Sue Yeandle, Universities of Sheffield, and Birmingham (2020) ‘Caring and COVID-19: Hunger and mental wellbeing’ – in partnership with Carers UK

²⁴ Carers UK (2020) ‘Caring Behind Closed Doors: six months on’

²⁵ Ibid.

²⁶ Ibid.

²⁷ Ibid.

²⁸ Ibid.

²⁹ Ibid.

³⁰ Carers UK (2020) ‘Caring Behind Closed Doors’

³¹ Carers UK (2020) ‘Caring Behind Closed Doors: Six months on’

those caring for someone who was shielding. 5% of working carers remained on the furlough scheme, with 2% of those working part-time on the scheme.³²

Despite the intervention in the labour market, 11% of carers reported that they had reduced their hours to manage their caring responsibilities and 9% had given up work because of caring.³³

Services being closed or reduced during the COVID-19 pandemic often meant that some carers felt they had no choice but to reduce their hours or give up work. The limited return of services continued to have an impact.

Carers highlighted the importance of having a supportive employer and being able to work flexibly and access Carer's Leave in supporting them to remain in work. However, many others struggled to access the leave and flexibility they need.³⁴

For those carers who have given up work or reduced their hours to care during the COVID-19 pandemic, almost half (48%) said affordable and accessible replacement care, or access to quality day and support services, would help them to stay in or to return to work.³⁵

Without services returning, and the introduction of measures to support flexible working and paid leave, more carers will have no choice but to give up work to care

VI. The support carers are calling for

Many carers already faced significant pressures prior to the COVID-19 pandemic, which have now been compounded further by the current crisis. It is clear from survey responses that there is a need for increased support in a wide number of areas.

Carers were asked what additional support they would like to receive in the future:³⁶

- Over half of carers (52%) said they wanted clearer and more specific guidance from the government for unpaid carers, showing that carers are clearly still anxious to ensure they are providing care as safely as possible and taking the correct steps to protect those they care for.
- Many carers also stated that they needed clearer and more specific guidance in certain areas, for example when the people they care for have to go to hospital, or when accessing care homes.
- Almost half (49%) of carers who responded selected 'prioritised access to vaccinations for carers and people they care for' as support they wanted in future.
- Half (48%) of carers who responded said they wanted more help with contingency planning in case they aren't able to provide care. This was a significant worry for many pre-COVID-19, and clearly many carers are very worried about the future, and fear that they won't be able to continue providing care for the people they currently support.

³² Ibid.

³³ Ibid.

³⁴ Ibid.

³⁵ Ibid.

³⁶ Ibid.

- Just under half (47%) of carers selected ‘more government funding for social care’, with many carers noting that the current system does not work for them or the people they care for.
- More than two in five carers (44%) also wanted better access to breaks and replacement care.
- A rise in Carer’s Allowance was the next most popular choice.

C) The need for increased support for unpaid carers – the immediate, medium and long-term response carers need to see from Government

It is clear is that without the support of families and friends caring, the response to COVID-19 could have been very different with health and care services becoming quickly overwhelmed.

Carers have gone above and beyond to ensure that the people they care for are safe – but our research clearly shows that carers are struggling to cope with the levels of care they are providing.

We think it is clear that carers need, and deserve, more support – on an immediate, medium-term, and longer-term basis.

That’s why we are calling for immediate action by government, local government, health bodies, and local organisations, to give back to carers now and are calling for nine key measures to support carers in lockdown:

- 1. Clear tailored guidance for carers** during lockdown, including the support available if someone is deemed to be clinically vulnerable for caring for someone in this group.
- 2. Clarity around exemptions allowing caring for vulnerable people**, so that caring can continue and families are able to get breaks. Provisions to allow people needing care and carers to get breaks and respite.
- 3. Continued opening up of care services** – finding solutions so that carers are able to get support and get a break
- 4. Visiting in care homes to be enabled safely**
- 5. Volunteer support for carers** needs to be rebooted
- 6. A boosted payment for carers in receipt of Carer’s Allowance** and associated means-tested benefits such as Carer Addition and Carer Premium – making sure they don’t lose out due to additional costs during COVID-19
- 7. Clarifying continued furlough arrangements for carers** and continued support from employers
- 8. Unpaid carers must get the PPE** they need to care
- 9. Ensuring carers have a form of ID**, e.g. Carer Passport, Carer Emergency Card, or a letter from the local authority/carers’ organisation

Longer term, we are also calling for Government to commit to a New Deal for Carers – with medium term tangible action. This New Deal for Carers needs to start with a tangible cross-cutting Government Action Plan, and move to strong and robust delivery of support as part of the government plans for the future of social care reform in each of the nations.

Finally, any future reform of the social care system must have strong, clear and defined benefits and support for carers. It is vital that carers are involved in the development of these plans as well as in delivery. It is the collective nation governments responsibility to see that this is delivered as a priority; as longer-term social care reform is long overdue and extremely urgent.

(November 2020)