

Carers UK evidence – Module 2 – UK COVID-19 Public Inquiry

Reference: M2/CAUK/01

Overview of Carers UK's legal status and aims of the organisation. The work of the organisation is UK wide:

Carers UK is the UK's national membership charity for and of unpaid carers. Established in 1965 we were the first to national charity in the world to be set up. We work to represent and support people in the UK who provide unpaid care for ill, older or disabled family members or friends – campaigning for increased recognition and support for unpaid carers as well as providing information, advice and peer to peer support. As well as the UK office in London, we have offices in the three nations; Carers Northern Ireland, Carers Scotland and Carers Wales.

With over 46,000 members and over 1,000 volunteers, our vision is of a society that recognises, values and supports unpaid carers for the huge contribution they make to families and communities. As well as delivering public policy campaigns, we focus on good practice, provide peer to peer carers' support and provide specialist information and advice including a the only national UK helpline dedicated to unpaid carers. Last year this answered over 38,000 enquiries from over 25,000 carers across the UK. We run an Employers for Carers good practice forum with 2020 employer members covering 2.4 million employees.

Brief description of the people Carers UK represents:

Carers UK represents, advocates for and provides support to unpaid carers in the UK and specifically in Northern Ireland, Scotland and Wales. Unpaid carers are family members, partners, neighbours or close friends who provide unpaid care someone who is seriously ill, disabled or who needs extra help as they grow older and need help. We estimate that there are between 5.7 million and over 13 million unpaid carers.¹

¹ New Census 2021 results from England, Wales and Northern Ireland, plus Scotland from 2011. The figures are considered an undercount. [13 million is from analysis of Understanding Society: https://www.carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf](https://www.carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf)
Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

The reason why our submission is so important is because unpaid carers are more than just family or close friends. What they do is not “informal” as it often referred to; it is the backbone of care and support and without which, health and social care services would collapse. The number of unpaid carers outstrips both medical and social care staff 2:1 as a minimum, as a maximum around 4:1.

The role that they play include keeping people safe, maximising people’s independence, helping someone move around, bathing, personal care, help with dressing, being responsible for good nutrition, finances, arranging health and support, prompting, mental health support, medication, and so on. Some unpaid carers provide much more complex care which can involve nursing tasks, medical equipment. They care through someone’s life course, including end of life. A person might only provide a few hours a week through to people who provide 24 hour care and who often have not had a break even for a day or a week for years.

When someone starts their caring journey or has a change, they are not always experts, but still feel and are sometimes responsible for the person they support, as well as knowing them as a person. Over time unpaid carers can become real experts, some with more knowledge than medical or social care staff supporting them.

In this context, given the role that unpaid carers play the disproportionate impact that was felt by them, with additional pressure, no breaks, increased financial challenges and no choice but to provide unpaid care in a pandemic, it is very concerning to them and to us that that unpaid carers’ information, advice, support and welfare are overlooked, ignored and, at times non-existent. They are often considered less important than health and social care staff.

Brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and May 2022 as it relates to COVID-19 of the UK Government

Carers UK undertook extensive work to represent and support unpaid carers, including their views and experiences throughout the pandemic, with much of this activity seeking to ensure unpaid carers were properly supported by the UK Government, Parliament, health services, public bodies, local charities as well as supporting individual carers themselves. This included the following:

- **Providing significant policy expertise and intelligence input into senior level working groups** for the Government, Department for Health and Social Care and

NHS England. Carers UK also liaised with the Department for Work and Pensions, DEFRA, BEIS and the Department for Transport.

- **Carers UK was part of a senior level working group on social care for the Department of Health and Social Care** chaired by the Director General of Social Care
- **Involved in liaising** with the NHSE vaccination team and across DHSC.
- **Carers UK was represented on the COVID-19 social care sector taskforce chaired by Sir David Pearson, we co-chaired and ran the Unpaid Carers Advisory Group to the Taskforce.**
- **Evidence and liaison with Parliamentarians** scrutinising the various steps of the Government response and including the Coronavirus Act 2020.
- **Advocating to all of these bodies** as well as local NHS organisations, GP practices, local authorities, local carers' organisations and employers about the needs of unpaid carers across health, social care, finances, travel, food, employment, ability to do exercise and schooling.
- **Significant advocacy around vaccination inclusion and then development of guidance and roll-out** for unpaid carers with the senior vaccine leadership team at NHSE.
- **Responsive real time listening exercises with unpaid carers** to ensure that feedback and input reflected issues that mattered most to unpaid carers.
- **Leading an evidence base by conducting swift research with carers**, that was maintained to ensure there was a robust evidence base for supporting them.
- **Addressing unpaid carers significant needs for information and advice**, communicating central Government policy, laws and regulations as they changed and developed and how this related to unpaid carers.

A list of articles or reports Carers UK has developed or contributed to regarding the impact on the groups that Carers UK supports and represents of the response to COVID-19 of the UK Government (links provided where possible):

Carers UK joint statement with Carers Trust: 11.3.2020

<https://www.carersuk.org/briefings/statement-on-covid-19-coronavirus/>

Carers UK briefing - The Coronavirus Bill and what it means for unpaid carers published – two briefings published 24.3.2020

<https://www.carersuk.org/media/wy0jacpu/carers-uk-briefing-1-the-coronavirus-bill-and-what-it-means-for-unpaid-carers.pdf> And 22.3.2020

<https://www.carersuk.org/media/wy0jacpu/carers-uk-briefing-1-the-coronavirus-bill-and-what-it-means-for-unpaid-carers.pdf>

Carers UK briefing on the statutory guidance for the Care Act 2014 easements and how it affects carers – published 2.4.2020.

<https://www.carersuk.org/reports/briefing-on-the-statutory-guidance-on-the-care-act-2014-easements/>

Caring Behind Closed Doors: Forgotten families in the Coronavirus outbreak. Carers UK research report using the views and experiences of 5,000 carers. Published 24.4.2020 - <https://www.carersuk.org/reports/caring-behind-closed-doors-forgotten-families-in-the-coronavirus-outbreak/>

Additional research and briefing for DEFRA (not published) 6 May 2020 – available on request.

Carers UK briefing – May 2020 - Improving Unpaid Carer access to food and Carer ID (practice based briefing based on the concerns of unpaid carers). Republished July 2020: <https://www.carersuk.org/reports/policy-and-practice-briefing-improving-carers-access-to-food-and-carer-id/>

Carers Week 2020: published 6.6.2020 - <https://www.carersuk.org/reports/carers-week-2020-research-report/> - gave first estimated numbers of unpaid carers since the start of the pandemic, new to caring, how much care provided, juggling work and care, etc.

Carers UK: a recovery plan for unpaid carers – published 24 July 2020 (proposed plan based on impact of the pandemic)
<https://www.carersuk.org/reports/a-recovery-plan-for-carers/>

Co-chaired the Unpaid Carers Advisory Group to the Adult Social Care Taskforce and provided a report to Government. Final Taskforce report is here: <https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/social-care-sector-covid-19-support-taskforce-final-report-advice-and-recommendations#key-themes-emerging-from-the-taskforce-advisory-groups>

Caring Behind Closed Doors six months on: The continued Impact of the Coronavirus (COVID-19) pandemic on unpaid carers, published 20.10.2020
<https://www.carersuk.org/media/cptbrdal/caring-behind-closed-doors-six-months-on.pdf>

Unpaid carers twice as likely to use a foodbank compared with non-carers – Carers UK and the University of Sheffield, 17 June 2020:
<https://www.carersuk.org/press-releases/unpaid-carers-twice-as-likely-to-have-used-a-food-bank-during-pandemic/>

Carers UK and University of Sheffield - Carers without physical and mental health treatment – 4 August 2020 <https://www.carersuk.org/press-releases/covid-19-leaves-unpaid-carers-without-physical-and-mental-health-treatment/>

Carers UK responds to formation of care bubbles: 22 September 2020 <https://www.carersuk.org/press-releases/carers-uk-responds-to-government-s-interhousehold-mixing-restrictions/> - unpaid carers could inter-mingle with other households in order care – seen as a positive move. This went alongside financial experiences of unpaid carers and loneliness.

Caring Behind Closed Doors: six months on – 20 October 2020 <https://www.carersuk.org/reports/caring-behind-closed-doors-six-months-on/>

Carer friendly employers better able to meet unpaid carers needs during the pandemic: 4 November 2020 <https://www.carersuk.org/press-releases/carers-friendly-employers-better-prepared-to-meet-changing-staff-needs-through-covid-19-pandemic/>

Unseen and Undervalued: The value of unpaid care provided to date during the COVID-19 pandemic: 26.11.2020 – established that carers provided support at £192 billion a year – higher than previously thought. [https://www.carersuk.org/images/News and campaigns/Unseen and undervalued.pdf](https://www.carersuk.org/images/News%20and%20campaigns/Unseen%20and%20undervalued.pdf)

Press release – 2.12.2020 – concern at unpaid carers being left out of JCVI's priority list for vaccinations. <https://www.carersuk.org/press-releases/carers-uk-responds-to-covid-19-vaccination-priority-list/>

Caring at Christmas: December 2020 - <https://www.carersuk.org/briefings/caring-at-christmas-research-briefing/>

Press release 31.12.2020 – unpaid carers included in the priority list for vaccinations under Priority 6. Subsequent updates and briefings for local Affiliates and local systems starting on 12 January and being updated as new information was released: <https://www.carersuk.org/media/q32m0ac0/covid-19-vaccination-and-unpaid-carers-briefing-for-affiliates-updated-on-4-march-2021-vfinal.pdf>

Breaks or breakdown: Carers Week 2021 report, published 07.06.21. <https://www.carersweek.org/media/u4jby32a/carers-week-2021-research-report.pdf>

Carers' experiences of hospital discharge – Discharge to Assess – 7 September 2021 <https://www.carersuk.org/reports/carers-experiences-of-hospital-discharge-discharge-to-assess-model/>

Unpaid carers at risk of being forced out of work without sufficient social care services: 20 October 2021 <https://www.carersuk.org/press-releases/unpaid-carers-pushed-to-breaking-point-and-may-be-forced-to-quit-work-warns-carers-uk-as-new-figures-reveal-devastating-impact-of-covid-19/>

State of Caring 2021: UK analysis – 3 November 2021
<https://www.carersuk.org/reports/state-of-caring-2021-report/>

Supporting working carers – return and recovery (based on employers experiences) – 11 November 2021 <https://www.carersuk.org/reports/supporting-working-carers-in-covid-19-return-and-recovery-report/>

Supporting working carers: opportunity and imperative – 25 November 2021
<https://www.carersuk.org/press-releases/employers-more-supportive-of-caring-but-carers-still-at-risk-of-leaving-work-unless-more-measures-adopted/>

Carers' health and experiences: data from the GP patient survey 2021 – 21 February 2022 <https://www.carersuk.org/media/shbb4c0s/carers-uk-gp-patient-survey-report-2021-web.pdf>

Brief view of Carers UK as to whether the groups it supports or represents (unpaid carers) was adequately considered when decisions about the response to COVID-19 were made by the UK Government. Reasons for Carers UK's views:

The UK Government was facing an unprecedented pandemic situation for which most governments around the world were ill-prepared, the needs of unpaid carers were not always adequately considered when decisions were taken in response to COVID-19 in the UK. There were clear instances of a lack of either action to support unpaid carers, or consideration of their role in policy and decision-making, despite being the backbone of care in the UK. There are some notable exceptions to this where Government did get decision-making right. Overall, the view of unpaid carers is that they did not feel visible, valued or listened to.

- **Reduction and closure of social care support.** Overnight support that unpaid carers relied on, if they got help, shut down - effectively leaving many to cope on their own. Families did not feel able to give each other breaks because of the rules and this was only resolved later on with care bubbles (see list of responses). Vital

services such as day centres had to close leaving some older and disabled people distressed at not having their regular support. Voluntary sector services often changed to telephone or online support. Domiciliary care remained as the most likely support to continue, but many unpaid carers refused these services out of concern about infection. 23% refused homecare services and 43% refused sitting services (a break in the home) by late 2021.² This has had devastating effects on unpaid carers, with services. At this same point, 55% of day services had not returned compared with pre-pandemic levels and we continue to measure poor returns of services.³ Carers are effectively telling us that they have lower levels of support now than compared to pre-pandemic and, of course, during the pandemic. Pre-pandemic the level of social care support was already considered to be low and this has now got worse. This, coupled with the extreme toll on their health and wellbeing during the pandemic, is unacceptable.

- **Continued lack of breaks and support.** In 2021, 72% of unpaid carers said they had not had a break since the start of the pandemic.⁴ 74% of unpaid carers said they were exhausted and 35% felt that they could not carry on. Unlike a paid care worker or healthworker, unpaid carers say they cannot resign from their roles. We continue to see the underfunding of breaks as a key issue for unpaid carers in 2022 in our State of Caring 2022 survey of 13,000 carers across the UK with nearly half not having had a break in the last year because it was too difficult.⁵
- **Intensifying the amount of care over time.** Worryingly, there is an upward trend in the number of unpaid carers providing over 20 hours and 50 hours of care, effectively providing round the clock care. The recent Census 2021 shows that the number of unpaid carers providing over 20 hours increased by 260,000 and 50 hours by 152,000.⁶ Our research conducted with unpaid carers saw a huge increase in the number of unpaid carers at the start of the pandemic i.e. 4.5 million extra people taking on care.⁷ Whilst some people stopped providing unpaid care (9%), a huge number took on responsibilities and our later research showed the number of hours provide intensifying. In our State of Caring 2021 survey 81% of unpaid carers said they were providing more care.⁸ This is a significant issue since the more care provided, the more likely it is that someone will have to give up work to care, the more likely they are to have ill-health (up to twice as likely if providing 50+ hours of care), increased loneliness and isolation as well as financial hardship and poverty.
- **Toll and pressure on carers' health and wellbeing.** As a result of isolation, care became concentrated on some individuals, at home, without any breaks. As well as

² State of Caring 2021, Carers UK, November 2021

³ State of Caring 2021, Carers UK, November 2021 and State of Caring 2022, Carers UK, November 2022

⁴ Breaks or Breakdown, Carers Week 2021, Carers UK

⁵ State of Caring 2022, op cit

⁶ Census 2021 results - <https://www.carersuk.org/press-releases/census-2021-data-shows-increase-in-substantial-unpaid-care-in-england-and-wales/>

⁷ Carers Week 2020, Carers UK.

⁸ 81% of

Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

the additional financial pressures some unpaid carers were reporting experiencing, the isolation, worry, lack of information, advice and support overall has had a long term effect on their health, with one quarter of unpaid carers providing over 50 hours of care per week rating their physical health as 'bad' or 'very bad' and 37% of carers rating their mental health in a similar way.⁹ Equally, of the 81% of carers who said they were providing more care, 78% said it was due to the condition of the person they were caring for deteriorating and carers described loss of abilities such as walking, talking, eating themselves, cognitive decline that was faster than expected, more challenging behaviour, poorer mental health. Having worked so hard to maximise the independence and health of relatives and friends, this has been devastating for unpaid carers and has placed additional caring responsibilities on unpaid carers.

“Responsibility of my son is massive. No one can appreciate the impact this has on my mental health.” Unpaid Carer, 2020.

- **Access to healthcare and treatment was worse for unpaid carers.** One of the research reports found that nearly six in ten unpaid carers were unable to get through to 111 health services and 89% of unpaid carers had health treatment cancelled compared to 77% of the general public. This is a shocking outcome for this group of people and the backlog is discussed below.
- **Insufficient and sporadic short-term funding for social care and an ongoing lack of workforce plan hindered and continues to hinder recovery of the social care sector.** Part of the challenge facing social care is decades of underfunding with sporadic funding released late into the health and care systems meaning that services are almost impossible to plan for longer term. The pandemic then placed this fragile system under more pressure. Social care services are a lifeline for many carers, not just providing support to the person cared for, but their own health and wellbeing, ability to work and connection with others.
- **Decisions around hospital discharge unpaid carers and their rights were not considered, carers' legal rights absent from national guidance.** Discharge to assess procedures were effectively in place long for an unnecessary amount of time. Guidance issued by the NHS England did not contain any mention of carers' rights to assessments or involvement, despite the law and this continued with later iterations of guidance up to the summer of 2021. The Health and Care Bill which was then introduced effectively removed a key right of unpaid carers to be involved at the point of hospital discharge. Evidence from unpaid carers between 2020 and 2021 found that 61% of them were not given sufficient support to enable them to care safely and well, putting their health and wellbeing at risk.¹⁰ One year later, whilst that rate had improved to 49%, covering the period June 2021 to June 2022, it still shows a worrying lack of involvement for carers providing substantial care.¹¹

⁹ Ibid

¹⁰ Carers and hospital discharge: discharge to assess, Carers UK, September 2021

¹¹ State of Caring 2022, op cit

Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

After a significant campaign to restore unpaid carers' rights, a new provision to involve unpaid carers at the point of hospital discharge was included in the Health and Care Act 2022 in its last stages and implemented. However, some local health and care systems not including carers have now become entrenched in our view.

- **Decisions around visiting/supporting as essential caregivers either in hospital or in care homes failed to take account of the needs of unpaid carers and disabled and older people.** The Inquiry will be receiving a lot of evidence from families about this and we will not repeat it here. Unpaid carers have raised the same issues through Carers UK that will be covered by the Alzheimer's Society, Relatives and Residents Association and the John's Campaign.
- **Decisions about vaccinations where unpaid carers were left out in the major announcement of vaccination priority groups on 2 December, but included on 31 December. They were then left out of each iteration of interim advice by JCVI but included in the final guidance.** The fact carers were first left out and then included three times, is extremely worrying that the JCVI, NHSE and DHSC are not learning from each exercise. Each time, this has caused carers' distress and worry each time until the outcome is confirmed. The first time that they were left out, they were staggered since the flu vaccination programme has recognised the role of unpaid carers for years in ensuring that infections are not passed on to relatives as well as ensuring that they remain in good health and able to care. There were times when core communications on vaccination failed to include unpaid carers as a group even though they were part of the vaccination programme.

“My savings that I have spent 30 years trying to build up for retirement are now vanishing to pay the bills.” Unpaid carer, April 2020

- **Additional financial pressures on unpaid carers that were not recognised has weakened carers' financial situation and made them even more vulnerable during this Cost of Living crisis.** Our first pandemic research showed carers reporting an increase in costs – heating, food as they were unable to shop around or had to get deliveries, activities for the person they cared for, cleaning and hygiene products, etc. 81% of unpaid carers saw an increase in spending in April 2020, with 72% spending more on food.¹² In the early days of the pandemic, 100,000 unpaid carers were using foodbanks and 226,000 were cutting back on food just to get by.¹³ By November 2021 in our State of Caring 2021 survey, 56% of unpaid carers providing substantial care (over 35 hours per week) were struggling to pay bills and were cutting back on heating, food, and other expenses. 77% of carers 2022 said that the cost of living would be a key issue for them over the coming year.¹⁴
- **Financial support for unpaid carers in receipt of Carer's Allowance, but not Universal Credit did not take place in England.** Scotland already has a Carer Supplement payment (worth around £500 per year made in two six monthly

¹² Caring Behind Closed Doors – April 2020, Carers UK

¹³ <https://www.carersuk.org/press-releases/unpaid-carers-twice-as-likely-to-have-used-a-food-bank-during-pandemic/>

¹⁴ Heading for Crisis, Carers UK, October 2022.

Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

payments), and this was quickly doubled. Wales introduced a £500 payment for carers in receipt of Carer's Allowance. Northern Ireland announced that a payment of £500 would be made but it was not possible to deliver due to outdated and unresponsive administrative systems. England did not promise any additional payments for unpaid carers in receipt of Carer's Allowance specifically to recognise their increased costs. We are deeply concerned about the inequity across the different nations for unpaid carers.

- **Carer's Allowance** is currently worth £69.70 per week, for providing over 35 hours of earning and earning less than £132 per week. It is the lowest benefit of its kind.
- **Carer's Allowance recipients in England (non-UC claimants) did not receive any additional financial support.** The uplift of £20 per week to call recipients of Universal Credit was welcome, however all benefits recipients on "legacy" benefits did not receive the same payment. This left unpaid carers in receipt of Carer's Allowance in England significantly worse off than carers in some other nations. These benefits are built on outdated and unresponsive systems which do not allow in-year changes or updates. There is an urgent need to modernise the benefits platform for Carer's Allowance.
- **Access to food was an issue for unpaid carers:** As set out above, however, DEFRA included a disability and carer working group to look at food access which met regularly and carers were included as a group who could get support.
- **Lack of ID when travelling to provide care, accompanying the person needing care, or needing to access food:** Lack of ID was an issue for some carers, being stopped by the police, questioned by neighbours, or unable to access food quickly because of the lack of ID. Some local authorities or charities quickly implemented ID systems but this was not universal. Areas with ID systems in place, e.g. Hertfordshire's Carer Passport, already had a simple system that could be utilised. However, these ID systems tend to be very localised.
- **PPE shortages for care staff caused huge anxiety for families.** One carer described health workers coming into support his wife dressed from head to foot in PPE, whereas the care workers had aprons and a small mask. Unpaid carers were unable to access PPE because of cost or shortages. One carer in receipt of In February 2021 for unpaid carers in England was provided which was welcome, but this had been delivered much earlier in Scotland. Some local authorities provided PPE to unpaid carers recognising their need.
- **A lack of local administrative data shared across health, social care and the voluntary sector hindered opportunities to identify and support unpaid carers.** Some areas did this better than others in identifying unpaid carers and pooling data.
- **Some GP practices refused to flag people as unpaid carers effectively blocking their ability to access the COVID-19 vaccination under Priority 6.** Even though identifying unpaid carers is supposed to be good practice, some practices were refusing to identify unpaid carers or got the definition wrong because of an incorrect definition on the NHS website. This needs to be urgently changed.

Relatively timely positive actions included:

- **As soon as lockdown started, there were exemptions for unpaid carers to leave the house to travel to care for someone.** This was absolutely critical and we know mirrored in other countries such as Italy. Not all unpaid carers live with the

Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

person needing care and, without this rule, those people would have been made very vulnerable. Some carers didn't know that they could continue to travel. There was not huge clarity on how far this travel could be. In one family, two sisters were sharing the care by taking turns, caring for their mother with cancer, but needed to drive 80 miles to get there. Another unpaid carer over 70 years old was stopped by the police and questioned whilst out with her son. She had to provide evidence that her 50 year old son had a learning disability and needed to be accompanied.

- **Guidance for unpaid carers was published at the end of March 2020** – as this was one of their key concerns – the lack of information and advice which was tailored specifically for them.
- **Support through volunteers was considered early through the NHS Responders scheme and unpaid carers included which was positive.** However, the communications often failed to mention unpaid carers as a group who could be supported. Bespoke communications were created, but this was a real missed opportunity.
- **Rules for Carer's Allowance were relatively quickly clarified to accommodate the fact that the nature of caring would change and to explain that support at a distance still qualifies as "caring"** . Clarified on 30 March 2020.
- **Furlough for unpaid carers was a significant and positive decision on 4 April 2020** by Government and a good example of how unpaid carers can and should be included early in policy. The communications around furlough relating to unpaid carers who were unable to work because of caring were not extensive, but good practice employers took this on board as our work with employers demonstrated.¹⁵
- **Vaccination roll-out for unpaid carers was successful for the first rollout and booster.** However, for this third round, it has been less successful because of a change in approach.
- **Unpaid carers were included in a list of essential workers who could get tested for the virus on 4 May 2020.** Again the inclusion of unpaid carers at this point was critically important, although access to the tests was challenging at the time.

Whether Carers UK raised any concerns being given to unpaid carers with the UK Government, when they were making decisions about their response to COVID-19. Please provide a list of such

¹⁵ See list of employer related reports and November 2021 report on Carers and Work: Opportunity and Imperative.
Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

correspondence or meetings, when they were held and any response from the UK Government.

Carers UK regularly raised concerns in key forums, with evidence using our listening exercises, our evidence from local services, queries generated through our helpline and through our responsive and extensive research with unpaid carers.

Carers UK engaged in several working groups around:

- Social care response regularly meeting with the Director General of Social Care, Director of Public Health, and social care sector leaders.
- Regular meetings with social care sector leaders and another with unpaid carers and people with lived experience with the Ministers, Helen Whatley MP and then latterly Rt Hon Gillian Keegan MP.
- Working group around the Winter Plan.
- Adult social care sector COVID-19 Taskforce.
- Working groups on Government guidance in relation to the Coronavirus Act 2020.
- DEFRA working groups around disability, unpaid carers and food security
- A working group specifically around unpaid carers looking at Government guidance, support, including information at the point of hospital discharge.
- Specific meetings around hospital discharge, Discharge to Assess guidance, which was later amended.
- Working group on vaccination specific to unpaid carers – concerns here were addressed well.

All of these groups included raising concerns about:

- Huge demand in need for information and advice.
- Clarity of language around unpaid carers (muddling “carer” between paid and unpaid – we now use unpaid for clarity).
- Infection control and lack of PPE for workers, but then also for carers.
- Testing, including carers.
- Huge pressure on unpaid carers as a result of the closure of services and increased caring because of the impact of the person being cared for.
- Engagement with health services.
- Impact on social care sector, workers, re-opening of settings, investment overall in the sector to promote recovery and the ability to re-engage with services.
- Overall levels of carers’ needs and health and wellbeing issues and isolation.
- Ability to juggle work and care and employers responses, including the implications for long term policy goals e.g. Carer’s Leave.
- Financial issues and challenges for carers and the need for additional support.
- Lack of carer ID causing issues when travelling or “proving” need.
- Ability to get food and shopping i.e. (not being able to queue, but not being a priority for delivery).
- Ability of family members to travel to provide care.

Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

- Some relaxation of rules to enable household mixing and breaks away from home.
- Digital poverty and lack of digital skills.
- Contact with relatives in closed settings i.e. hospital or care homes.

Brief summary of the lessons learned about the consideration given to the UK Government of unpaid carers when they were making decisions about COVID-19

The lessons learned are largely set out in our Recovery Plan published in 2020 but we look at them here one by one:

1. Including support for unpaid carers is central to any decision-making regarding health and social care workers/the health and social care system.

- The general lack of awareness of unpaid carers and the key role they play which led, at times, to them being left out, or not considered. Awareness of unpaid carers needs to be improved overall.
- Clarity over terms used. Although “carer” is enshrined in legislation e.g. Care Act 2014 as being an unpaid carer, it was used to describe health and care workers. We have now changed our terms to ensure that it’s clear in policy. Confusion was problematic, left carers feeling under-valued and invisible.
- The importance of emergency and contingency planning which was very high on unpaid carers’ list of priorities¹⁶. This type of planning activity should be standard within health and care planning, not just because of the pandemic, but also because it remains a key concern of unpaid carers.
- Where carers were included, it transformed their feelings of being identified and valued, in a very stressful and challenging situation.

2. Stronger clearer rights base for unpaid carers:

- Duty on the NHS to have regard to unpaid carers and to promote their health and wellbeing.
- Make caring a protected characteristic within the Equality Act 2010 to increase public sector equality duties and to prevent discrimination. This would encourage systems and practice including public services, goods and services and employers to appropriately identify unpaid carers. It would help to mitigate some of the issues faced by carers.
- Introduce a new right to breaks for unpaid carers.

¹⁶ Caring Behind Closed Doors April 2020 and October 2020.
Carers UK, Module 2 evidence, COVID-19 Inquiry/M2CAUK01

- Introduce the concept of an “essential caregiver” into legislation in relation to healthcare.
- 3. Communication using the term “carer” and unpaid carers needs to be clear, consistent and visible.**
- Clarity over terms used. Although the term “carer” is enshrined in legislation (Care Act 2014) as being an unpaid carer, it was used to describe health and care workers. We have now changed our terms to ensure that it’s clear in policy. Confusion was problematic, left carers feeling under-valued and invisible.
 - Carer awareness should be mandatory in workplaces.
- 4. Social care profile and support, including breaks, needs to be a priority – including longer term investment to aid recovery.**
- Social care needs to be considered at the same time as the NHS during a pandemic and be of equal priority.
 - Significant longer term investment in social care is needed with security of funding. This is to re-stabilise the social care system, provide vital support and give home to families and disabled and older people for the future.
 - A workforce plan is needed to redress some of the issues the sector faced.
 - Carers UK has called for a £1.4 billion carers breaks fund to aid carers’ recovery.
 - Having an emergency plan in place for unpaid carers is a key priority for them, as well as critical during a pandemic when many felt abandoned.
- 5. Financial support for unpaid carers needs to be made a priority.**
- Financial support for unpaid carers is critical and is needed both early and fast.
 - Platforms such as Carer’s Allowance need to be modernised digitally to improve carers’ experience of the benefit and to enable the Department for Work and Pensions to be more responsive.
 - In pandemic situations, urgent action is needed from Government to increase carers’ benefits.
 - Longer term significant reform of the benefit is needed, including raising carers’ incomes. This is an urgent priority.
- 6. Vaccination programmes need to start with including carers clearly at the outset.**
- 7. Information, advice and guidance is essential for unpaid carers is essential.**
- National Government guidance was important although outstanding policy issues made decisions in some areas difficult.
 - Boosting Carers UK’s information and advice capacity made a difference.
- 8. Identification of unpaid carers and improvement of data is essential.**
- There is a lack of local administrative data around carers leading to challenging ways of identifying them across health, social care and voluntary sector support systems.

- There need to be clear national targets around identifying unpaid carers within GP practices on their own patient record and that of the people they care for.
- Permissions to flag unpaid carers on their own patient records once identified need to be automatically included in any system, or to free up mechanisms for carers doing it themselves e.g. through the NHS App. Not doing this meant that there were opportunities which were lost to include carers each time.
- Local data systems need to flag unpaid carers with clear data sharing protocols set up locally.
- Data pooling nationally, including the DWP, needs to be a priority in any pandemic situation.

9. Carer's rights base at work and in society needs to improve in order to change and shape responses, but provide unpaid carers with some redress:

- Furlough including unpaid carers was essential.
- When making decisions about employer support for parents, we recommend specific consideration of unpaid carers who are juggling work and care at the same time.
- Making caring a protected characteristic would help support carers at work where they face discrimination (as discrimination by association is poorly understood).
- Passing the Carer's Leave Bill and the Employment Relations (Flexible working) Bill would both provide good architectures to enable employers to be more responsive and supportive as employers.
- Working from home made continuing working possible for the majority of unpaid carers. For a minority, it was impossible to juggle work and caring.
- Providing paid Carer's Leave of up to 10 days would also give employers and unpaid carers additional flexibility without having to put someone on furlough. This is also a positive policy during non-pandemic times.

PPE and testing

- As well as sufficient PPE for workers, free PPE needs to be provided to unpaid carers.
- Testing MUST be mandatory for all people coming out of hospital or a care setting.
- Tests should be freely available to unpaid carers at the same time as workers.

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