Witness Name: Emily Holzhausen
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UK COVID-19 INQUIRY - MODULE 6

WITNESS STATEMENT OF EMILY HOLZHAUSEN CBE

I, **Emily Holzhausen CBE**, Director of Policy and Public Affairs of Carers UK, 20 Great Dover Street, London SE1 4LX will say as follows: -

Overview of Carers UK and its role

1 Carers UK is a registered charity in England and Wales (charity no. 246329) and in Scotland (SC039307) Scotland) and a company limited by guarantee registered in England and Wales number 864097. First established in 1965, we were the first national charity for unpaid carers to be set up and, indeed, the first globally. The charity's objects are, in summary, to make life better for unpaid carers, looking after older, ill, disabled relatives or close friends, as well as those for whom they care. Our dual responsibility is to alleviate the conditions of life for carers, or those at risk of facing "necessitous circumstances" as well as promoting education of caring with carers and the public.

2 With over nearly 50,000 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 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.

3 We campaign on behalf of unpaid carers and their families to make life better for them, provide information, advice and support and raise awareness of their needs. We are a UK wide organization, with offices in Northern Ireland, Scotland and Wales; Carers NI, Carers Scotland and Carers Wales. Each of these offices works directly with their relevant Governments and administrations in their nations.

4 Our membership of nearly 50,000 carers includes 38,750 in England (78% of membership), 4,633 members in Wales or 9% of membership, 3,245 members in Scotland or 6% of membership and 1,556 members in Northern Ireland, 3% of membership. Carers UK also works through our 230 employers who are part of Carers UK's Employers for Carers forum, covering 2.7 million employees (this could include between 378,000 and 540,000 depending on the rate of carers in the working population – varies by sector). Finally, our Affiliate network of local carers' organisations covers many millions of unpaid carers across the UK.

5 The carers we are in touch with tend to provide very substantial care for people with significant needs, often multiple and complex conditions. This includes unpaid care for children with disabilities and chronic illnesses, and adult relatives and friends with learning disabilities, mental health issues, long term health conditions, neurological conditions, cancer, diabetes, stroke, dementia, autism and ADHD, and more. These are people who have been hardest hit during the pandemic in many ways – carers and their families. Our State of Caring survey is the most in-depth survey of our members and it also includes other carers (around 3 out of 10 are non-members). 48% care for 90 or more hours per week, 14% care for 50-89 hours , 23% for 20-49 hours and 13% for 1-19 hours per week. 76% care for one person, 18% for two and 6% for three or more people. 34% are in paid work; 46% full time and 39% part-time. The majority of respondents are of working age; 20% of aged 65-74 and 7% are 75 and over.

6 Whilst we represent our members, who have voting rights within the organization, our charitable objects also mean that they act on behalf of the UK's wider population of unpaid carers – data on which is set out below.

Definitions

7 Unpaid carers are, at times, referred to as a "workforce" or a "sector" – but this can be misleading. They are individuals who are not formalized, not paid by the state, and are not protected like paid workers by employment legislation in relation to their unpaid caring responsibilities. Very often families do not have a choice about caring and our recent research for Carers Week 2024 showed that 62% of unpaid carers said they did not have a choice about taking on a caring role because there were insufficient care options available. Please see **EXHIBIT EH/01** The 'No choice but to care' report, published on the first day of Carers Week 2024 exhibited at **[INQ000588633]** Whilst this most recent research is outside of the pandemic, it demonstrates the level of choice that unpaid carers don't have about caring and this was even more evident in carers' comments during the pandemic. Some families chose to reduce external care in order to protect the person they cared for.

8 Pre-pandemic and during the early days of the pandemic we would refer to "carers" i.e. people who provide unpaid care to older, disabled or ill relatives or friends who cannot manage without support. This is, effectively, the definition used in the Care Act 2014 and related earlier legislation around unpaid carers' rights and entitlements. However, during the pandemic, the rise in visibility of the care workforce, the word "carer" was then used very frequently to mean someone who was paid for care work, rather than a family or friend. This is not the primary legal definition of a "carer" in law. For Carers UK, Carers Wales, Carers Scotland, Carers NI, practitioners and for unpaid carers, this caused problems of awareness and interpretation of legal texts, guidance, and official communications, causing delays, confusion, and disappointment, for unpaid carers which impacted negatively on their mental health and negatively affected their practical support. In our evidence work and policy briefings in the early days of the pandemic you will see us refer to "carers" as in the Care Act 2014. This is a similar challenge in Wales, Scotland and Northern Ireland where language has also shifted and where definitions of carers were in relevant legislation. We have now amended our language to "unpaid carers" in each nation to make this distinction and to avoid confusion, even though this is not the definition in law. We do not use the word "informal carers" as this term "informal" is disliked by carers. **Our recommendation is that there is clarity of definition around the use of the term "carer" to be clear whether we are talking about the paid workforce or unpaid carers i.e. family and friends.**

Overview of representation and support

9 At the UK and nation levels we liaised with a large number of advisory bodies, government departments and agencies, arms length bodies, local authorities and local charities as well as employers within our forum.

At a UK level liaison included the following:

10 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. The evidence supplied by Carers Wales, Carers Scotland and Carers Northern Ireland **(EXHIBITS EH/02 [INQ000499481]; EH/03 [INQ000499482] and EH/04 [INQ000099677])** set out the relevant representation in those nations and is similar to the UK. 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 e.g. NHS England (VCSE Group on volunteering). Carers UK also liaised with the carers team within the DHSC, 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 – National Adult Social Care (COVID-19) Group – NACG.
- **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.
- **Supporting our Affiliate network of local carers support organisations, largely charities which numbered around 230 across the UK** but mainly based in England with information, advice and change.
- **Supporting the wider group of local carers' charities** who were not part of our Affiliate network, particularly in Scotland, Wales and Northern Ireland.
- **Responding to queries from local carers' charities and local authorities** wanting to know good practice, as well as interpretation of guidance and the law across the UK.
- **Addressing unpaid carers significant needs for information and advice,** communicating Government policy, laws and regulations as they changed and developed and how this related to unpaid carers through our helpline and advice services, membership communications and social media.

The following is a key list of submissions to Government and bodies mentioned above in the UK:

- Carers UK joint statement with Carers Trust: 11.3.2020 **EXHIBIT EH/05 [INQ000239455]**
- Carers UK briefing - The Coronavirus Bill and what it means for unpaid carers published – two briefings published 24.3.2020 **EXHIBIT EH/06 [INQ000577432]** and 22.03.2020 **EXHIBIT EH/07 [INQ000587273]**
- Carers UK briefing on the statutory guidance for the Care Act 2014 easements and how it affects carers – published 2.4.2020. **EXHIBIT EH/08 [INQ000577428]**
- 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 - **EXHIBIT EH/09 [INQ000176237]**
- Additional research and briefing for DEFRA (not published) 1 May 2020 – a draft copy of this is **EXHIBIT EH/10 [INQ000499484]**

- 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: **EXHIBIT EH/11 [INQ000577448]**
- Carers Week 2020: published 6.6.2020 - gave first estimated numbers of unpaid carers since the start of the pandemic, new to caring, how much care provided, juggling work and care, and further areas **EXHIBIT EH/12 [INQ000577442]**
- Carers UK: a recovery plan for unpaid carers – published 24 July 2020 (proposed plan based on impact of the pandemic) **EXHIBIT EH/13 [INQ000577434]**
- Co-chaired the Unpaid Carers Advisory Group to the Adult Social Care Taskforce and provided a report to Government. Final Taskforce report is here: **EXHIBIT EH/14 [INQ000588638]**
- Comprehensive Spending Review submission 2020 – **EXHIBIT EH/15 [INQ000499485]**
- Caring Behind Closed Doors six months on: The continued Impact of the Coronavirus pandemic on unpaid carers - we shared this with key officials. **EXHIBIT EH/16** **[INQ000239455]**
- Unpaid carers twice as likely to use a foodbank compared with non-carers – Carers UK and the University of Sheffield, 17 June 2020: **EXHIBIT EH/17 [INQ000588643]**
- Caring and COVID-19 – loneliness and the use of services: Bennett, Zhang and Yeandle, August 2020. Published in partnership with Carers UK and University of Sheffield **EXHIBIT EH/18 [INQ000588634]**
- Caring and COVID-19 Financial wellbeing – Bennett, Zhang and Yeandle, in partnership with Carers UK August 2020 -**EXHIBIT EH/19 [INQ000588631]**
- Briefing for DHSC on unpaid carers and PPE – 11 November 2020 – unpublished **EXHIBIT EH/20 [INQ000499486]**
- Unseen and undervalued The value of unpaid care provided to date during the COVID-19 pandemic, November 2020, Carers UKEXHIBIT **EH/21** **[INQ000239451]**
- Unpaid carers at risk of being forced out of work without sufficient social care services: 20 October 2021 **EXHIBIT EH/22 [INQ000588642]**
- State of Caring 2021: UK analysis – 3 November 2021Supporting working carers – return and recovery (based on employers experiences) – 11 November 2021 **EXHIBIT EH/23 [INQ000577440]**

- Supporting working carers: opportunity and imperative – 25 November 2021 Carers' health and experiences: data from the GP patient survey 2021 – 21 February 2022 **EXHIBIT EH/24 [INQ000577433]**

A list of evidence provided by Carers UK to Parliamentary Select Committees in relation to matters which are within the Provisional Outline of Scope for Module6

- Evidence submitted to Health and Care Select Committee for Inquiry on PPE – 9 April 2020. **EXHIBIT EH/25 [INQ000499487]**
- Evidence submitted to Health and Care Select Committee for Inquiry on social care funding. July 2020 **EXHIBIT EH/26 [INQ000499488]**
- Evidence submitted to Health and Care Select Committee for Inquiry on lessons learned from COVID-19 – November 2020 **EXHIBIT EH/27 [INQ000499489]**

Unpaid care

11 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.

12 The role that they play include keeping people safe, maximising people's independence, helping someone move, 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 and 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.

13 Carers may not be experts in the condition or situation when they are first starting to care, but they will know the person better than health and care professionals. Over time, they become real condition experts, some with more knowledge than medical or social care staff supporting them. They feel and very often are, responsible for the person for whom they care. They are often not given the information, advice and

support to care safely and well by either health or social care which is well evidenced by all our research.

14 In this context, given the role that unpaid carers play, they experienced a disproportionate impact, with what was often extremely stressful responsibility for the safety and wellbeing of their family or friends with disability and illness, with additional pressure that comes with that responsibility, very few or no breaks, increased financial challenges and no choice but to provide unpaid care in a pandemic. Carers regularly talked about being terrified of COVID-19 affecting them and not being able to care, or affecting the person they cared for. At times there were not considered by Government at all and, if they are, this often comes a long time after health and social care paid staff.

15 Unpaid care encompasses a whole range of activities and tasks. It is essentially the provision of any unpaid care for a person who is chronically ill, disabled or is older and needs support. It might be prompting and supervision for someone with dementia, learning disability or mental illness, it could be support due to mental illness, autism, ADHD, financial management such managing financial affairs, practical tasks such as shopping, housework or gardening if they cannot manage it, laundry, it also includes administrative tasks, booking of appointments, form filling, accompanying to appointments, to physical care such as helping dressing, eating, cooking meals for someone who is unable to, taking care of meal planning or nutrition. It increasingly includes medical tasks – injections, dressings, wound care, health monitoring, complex drugs and medicines administration. It can be as little as 1 hour per week. It can be as much as 24 hours a day, 7 days a week. Some carers talk about getting up several times in the night even if they are in their 80s or 90s, and many say they have very few breaks. Caring often goes unrecognised by society and carers often say that they feel taken for granted. According to the Census 2021, there are 1.5 million unpaid carers who provide over 50 hours of care per week across England and Wales i.e. full-time care.

16 Caring can start gradually as someone finds it harder to manage, or can happen overnight – if your partner has a stroke or a son a major accident. With certain conditions there can be periods of more intense care. Disability and caring can often

be a lifetime for parents of disabled children into adulthood, where a child has complex health needs or a learning disability.

17 The role of unpaid carers within adult social care is incredibly important to society and the economy. Health and social care would collapse without their support. The value of their support is estimated as equivalent to the NHS. They outnumber health and care workers by 2:1 as a minimum and 4:1 as a maximum. In terms of the value of their support, where we have up to date Census 2021 figures we have estimated this as: £152 billion in England, £10.7 billion in Wales and £5.8 billion in Northern Ireland. In each nation, this is equivalent to NHS spending. As already set out, the vast majority of unpaid carers don't have a choice about caring. Where care falls short, families often have to step in. **EXHIBIT EH/28 [INQ000577457] and EXHIBIT EH/29 [INQ000577456].**

18 The impacts of this are discussed below. We called our two key reports using their voices during the pandemic: Caring Behind Closed Doors because this is what carers feel – that their work and their care is invisible.

19 The number of estimates of unpaid carers vary from around 5.7 million through the Census 2021 and 13 million but this includes care for disabled children as well as disabled, older or ill adults across the UK. Broken down by nation, the Census 2021 shows the number of unpaid carers at 4.7 million for England and 310,000 for Wales, 220,200 for Northern Ireland and for Census 2011, 490,000 for Scotland. The Census does identify for whom the care is provided. The most comprehensive survey official survey on carers, from 2010, suggests that 8% of unpaid carers look after a disabled child under the age of 18 suggesting that 92% of unpaid carers provide support to an adult needing care and support. Please see **EXHIBIT EH/30 [INQ000588639]** Carers UK does not often disaggregate our surveys to focus solely on carers of adults because our remit is for carers of all ages. Carers UK has not used other data sets to look at carers of adults only. Since 92% of carers look after adults in need of care and support, we would like the Inquiry to consider our Carers UK statistics in this light unless otherwise specified.

20 Given the huge shift in people's lives, Carers UK undertook polling to look at the public's own experiences of providing unpaid care. This was carried out by YouGov in a poll of 4,700 adults in May 2020 and published in June 2020. This showed that:

- UK - 9.1 million people said they were already caring pre-pandemic and 13.6 million since the pandemic had started, a rise of 4.5 million people. A rise to 26% of the population or one in four adults.
- Wales - 487,000 people said they were caring pre-pandemic and 683,000 since the pandemic had started, a rise of 196,000 people. It was a rise from 19% of adults in Wales to 25% of the population.
- Northern Ireland – 212,000 people said they were caring pre-pandemic and 310,000 since the pandemic had started, a rise of 98,000 people. It was a rise from 15% of the population to 22%.
- Scotland – 729,000 people said they were caring pre-pandemic and 1.1 million since the pandemic had started, a rise of 392,000 people. This was a rise from 16% of people to 25% of the population.

21 We re-measured the value of carers' support and published this work in 2020. This was a staggering £111 billion for England, £4.8 billion for Northern Ireland, £10.9 billion for Scotland and £8.4 billion for Wales in only 8 months. This was equivalent to £530 million every day in the pandemic or £193 billion over a full calendar year. This reflects the intense level of care provided by unpaid carers during the pandemic. **EXHIBIT EH/21 [INQ000239451].**

22 In 2021, the Census 2021 was undertaken in England, Wales and Northern Ireland (nearly 1 year later compared with the survey above). This found a reduced number of unpaid carers compared to 10 years previously. There were a number of reasons for this, in particular changes to the question which Carers UK, Carers Wales and Carers Northern Ireland felt become more impersonal. It also suggested that there were fewer disabled people. One suggestion, as well as the question change and a suggestion that care had become more concentrated within families during the pandemic was that more people had died during the pandemic (therefore fewer carers). Despite the lower numbers, there was a rise in amount of very significant care being provided i.e. a rise in the number of carers providing over 20 and 50 hours of care per week. Carers UK's own research with those who were providing more

substantial care, that their care intensified significantly during the pandemic to very stressful levels.

Employment

23 The numbers of carers in paid employment on top of unpaid caring responsibilities vary according to the source and type of survey. The Census 2021 suggests that there are 3 million unpaid carers in paid employment taking England, Wales, Northern Ireland (2021 Census) and Scotland (2011 Census).

24 When Carers UK carried out its polling for Carers Week 2020 in May 2020, this found higher numbers of unpaid carers in paid work – two thirds (62%) of those new to caring in the pandemic were in paid work.[1] **EXHIBIT EH/31 [INQ000577442].**

25 In the UK, 4.9 million unpaid carers were juggling work and care pre-pandemic, 7 million during the early pandemic a rise of 2.8 million. In Wales, 50% of unpaid carers in paid work; 31% of unpaid carers in full time work and 19% in part time work. In Northern Ireland, 53% of unpaid carers in paid work; 36% in full time work and 17% in part-time work. In Scotland, 58% of unpaid carers in paid work; 42% in full time work and 16% in part time work.

Disability and caring

26 All of those being cared for have a disability, whether caused by illness and a long term condition which then requires support, such as a learning disability, mental illness, cancer, dementia, chronic fatigue and so on. According to the Census 2021, around 28% of carers are also disabled themselves (England and Wales, 1,390,355) Carers were more likely than non-carers to be disabled. 28% of carers in England and Wales were disabled, compared with 18% of non-carers. These findings are roughly similar in all nations and we find roughly similar proportions in our State of Caring surveys.

Ethnicity and caring

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27 According to the Census 2021, over half a million carers are from an Asian, Black, Mixed or Arab background (626,985). 4 million (4,088,340) are White English/Scottish/Welsh/Northern Irish British. Over 200,000 (211,785) are from another White background (Irish, Gypsy or Irish Traveller, Other White). Over 60,000 (61,875) are from another ethnic group. Carers UK undertook additional work to identify the needs of unpaid carers from ethnic minority communities which showed that they were more likely to say that services did not meet their needs, more likely to be worried about their finances and less likely to have their vaccinations. **EXHIBITS EH/31 [INQ000577442] and EH/32 [INQ000577455].**

Carers' experiences overall

Through our engagement with unpaid carers we found a devastating intensity of caring along with extremely stressful responsibility that often went without recognition or support:

- An intensity of caring that was already high pre-pandemic became significantly worse during the pandemic. This was caused by a combination of the closure of day care and other activities for disabled and older people and the fact the guidance didn't clearly allow wider family members to help or provide breaks (it did later with care bubbles).
- Families concentrating care with a smaller number of people to reduce risk e.g. a younger student cared for her grandmother whilst her father and mother, both health professionals continued to work for the NHS.
- A choice made by families to reduce risk by cancelling care and doing it all themselves.
- Increased illness and disability as a result of isolation (see later section) and lack of stimulation, activities, or outlets for people with disabilities and illnesses. For some, this was exacerbated by challenges in accessing healthcare (see later section).

"My son has a severe learning disability and isn't capable of understanding what is happening as time passes and his routine has vanished and he has become increasingly dependent on me and seeking my presence beside him at all times as though he senses anxiety and fear but can't make sense of it and feels the need for more comfort and reassurance than usual."

In terms of employment, the NHS Staff survey suggests that 1 in 3 workers is also an unpaid carer. It's equally possible that the same rate exists amongst adult social care workers.

Pre-pandemic structure and capacity of the adult social care sector in the UK

28 Adult social care is a devolved matter across the UK; to England, Wales, Scotland and Northern Ireland. In each of our nations, our concerns are similar:

* A shortage of accessible and affordable adult social care to provide choices for carers around caring, vital breaks, etc. Pre-pandemic around 600 people a day across the UK gave up work in order to care for disabled or older family members or close friends.
* A difficulty in finding appropriate care even if carers are able to afford it or have direct payments (self-directed care payments) to pay for it.
* Waiting times for assessments and care.
* Costs of care which make it unaffordable for many carers.

29 Whilst each nation has slightly different legislation and adult social care is organised differently, each nation shares the common problem that adult social care has under-investment. Unpaid carers tell us that they feel invisible and undervalued in each nation. **EXHIBIT EH/33 [INQ000588637].**

9. 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.

30 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.

31 The structure and capacity of the adult care sector in England, along with how the sector is acknowledged and understood within the whole care economy, has had a considerable impact on its capacity to respond to the pandemic. Whilst good care was provided in many areas, it was already a sector under strain; under-funded and under-

recognised. Local authorities had experienced cuts since 2010 to their budgets at a time when demographic changes and a shift of care closer to home (i.e. NHS shifting to more care in the community) meant greater need in communities. Age UK's work has shown that unmet need for people aged over 50 alone affects 2.6 million people. This left the social care sector under even more challenges to provide the vital care and support that they do. Social care is a core service and vital for people's lives and needs better recognition, support and funding.

32 The lack of recognition for social care then caused huge issues for unpaid carers and support for families who relied on social care. The NHS was primarily in the minds of decision-makers and this did not feel like the case for social care; which was slower to get PPE than the NHS. A carer described this situation with NHS workers coming with full visors, full PPE, whereas care workers performing similar tasks relating to risk of COVID-19 had very low levels of PPE, if at all. The unpaid carer had no PPE. The numbers of providers, the complexity i.e. part private, part public, commissioned by local authorities, lack of data on the sector, lack of wider public understanding of social care all added to these challenges, lack of definition compared with a strong single NHS brand. The social care sector includes many dedicated people doing valuable and important work, providing valuable support for unpaid carers. The challenges in the social care sector, in turn, impacted on families who bore the brunt of the shortages of social care and health care in taking on more unpaid caring responsibilities with significant impacts on their health, wellbeing and work.

Impact of the pandemic on unpaid carers

33 **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. Vital services such as day centres and day time activities had to close leaving many older and disabled people distressed at not having their regular support particularly for people with dementia and people with learning disabilities. Carers described an increase in challenging behaviour for people they cared for where they did not understand the changes. As well as being distressing for the person with the disability or condition, it was increased stress and

pressure for unpaid carers that some described as unrelenting. Voluntary sector services often changed to telephone or online support, which was valuable but many carers missed the face-to-face contact. 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. Please see **EXHIBIT EH/01 [INQ000588633].** . 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. Please see **EXHIBIT EH/01 [INQ000588633].** Carers were 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.

Toll and pressure on carers' health and wellbeing.

34 As a result of isolation, care became concentrated on some individuals, at home, without any breaks. As well as 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. 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 without support, they described cognitive decline that was faster than expected, more challenging behaviour some of it physically challenging, poorer and bad mental health. Having worked so hard to maximise the independence and health of relatives and friends, this was emotionally and physically devastating for unpaid carers and placed additional caring responsibilities on them. **EXHIBIT EH/16 [INQ000239445].**

Access to healthcare and treatment was worse for unpaid carers.

35 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 who arguably need this help most. **EXHIBIT EH/34 [INQ000588641].**

Nature of caring

36 The nature of caring, an explanation of which starts at paragraph 11, changed because care was concentrated in the home. Whereas families could find activities for the person they cared for outside of the home beforehand, they then had to occupy the person they cared for during the day. Carers of people with learning disabilities or dementia seemed to find this particularly challenging. Many carers found this exhausting. Six months on (October 2020) (**EXHIBIT EH/16 [INQ000239445]**), as already stated, 81% of carers in our survey said that they were providing more care, 78% said that the needs of the person cared for had increased.

37 Our Caring Behind Closed Doors April 2020 contained early important data on the changes of carers' care at the time, 70% said their were providing more care. Six months on and this had increased to 85% providing more care. In April 2020, carers were providing more care in the following areas – 69% were providing more emotional support, motivation, etc. 53% were doing more practical help in person e.g. shopping, laundry, housework, etc. 40% were providing practice help at a distance, 34% were doing more personal care, 26% were doing more care coordination, 25% more help with moving around, 25% doing more with paperwork and financial matters, 24% helping with medication and 11% doing more by helping with medical care e.g. giving injections, changing dressings, etc. Comments from carers suggest that this is largely due to either voluntary withdrawal from services, or services not being delivered to them. Exhaustion is a common theme from all of our touchpoints with carers, and not knowing when the pandemic would end.

"My son has a severe learning disability and isn't capable of understanding what is happening, as time passes and his routine has vanished he has become increasingly dependant on me and seeking my presence beside him at all times as though he senses anxiety and fear but can't make sense of it and feels the need for more comfort and reassurance than normal."

Ability of unpaid carers to take breaks from caring

38 In our Caring Behind Closed Doors: six months on (October 2020) report exhibited at **EXHIBIT EH/16** **[INQ000239445]** 64% of carers said that they had not been able to take any breaks from caring. Only 27% of unpaid carers aid they had been able to take a break in the first six months of the pandemic. Considering the extremely high levels of care provided, this was a worry. Only 15% of family or friends were providing breaks, 3% had a care bubble, 4% had a break through day centre support, 4% through home care support breaks.

"I have struggled hugely being with my husband 24/7 unable to have a break from caring. There are times I think I can't go on, but of course I have to. Sometimes I don't want to wake up in the morning." Six months on (Oct 2020)
"I'm doing at least 14 hours of intense caring a day. I get an average of 5.5 hours sleep and eat most of my meals 'on the move'. Never get to relax or read a book. With increasing restrictions, I can't see my extended family at home or visit a friend who is my main support." Six months on (Oct 2020)

39 We looked at this a year later in 2021 in our Breaks or Breakdown report. By May 2021, carers were telling us that they had lost, on average, 25 hours of support per month that they previously had (pre-pandemic) from services, or family or friends. 72% of carers had not had any breaks from their caring role at all. Of those who got a break, one third, 33% used it to complete practical tasks and a quarter (26%) to attend their own medical appointments. In other words, they were not getting time to recharge their batteries and look after their own health and wellbeing. As a result, three quarters of carers, 74% reported being exhausted as a result of caring during the pandemic and 35% felt unable to manage their caring role. **EXHIBIT EH/35** **[INQ000239456].**

40 One fifth said that they hadn't taken a break because they were worried about COVID-19 and infection. One quarter (24%) felt it was too difficult during the pandemic.

"When the pandemic broke out, I cancelled services because of the risks. There could have been 30 carers coming in per week which was worrying. I was told if I didn't keep the services going I would lose them. This caused great stress. I kept the services but lost

the showering calls and still haven't had them back. I pay someone once a week so at least the family member gets a shower or I have to do it on my own. At 68 years old it is quite demanding physically on me." Breaks or Breakdown, June 2021.

"Our paid PA refused to work during the pandemic and left us high and dry. All charity support stopped in person and I was completely alone. Still am over a year later with no active in-person support." Breaks or Breakdown, June 2021

"My son's day services all closed. His support worker could only offer a few hours here and there (instead of daily support) because of shortage of staff in the provider organisation. I had to move in with my son because of the collapse in support." Breaks or Breakdown, June 2021

"My husband has Parkinson's disease, it's hard work sometimes 24/7 and without three hours' respite per week supplied by Crossroads because of COVID, I am exhausted, my home is also my place of work caring for him. I haven't been able to take that break away from him & home/ work since February 2020." Breaks or Breakdown, June 2021.

41 Many carers said they were worried for the future and post-pandemic about whether support would return.

Excess deaths in unpaid carers

42 We do not know whether there have been any excess deaths in unpaid carers or whether they were more or less likely to die from COVID-19. There are very few administrative data relating to unpaid carers and we do not think that this has been collected.

Whether we feel that unpaid carers were disproportionately affected by COVID

43 We feel that unpaid carers have been disproportionately affected in each of the nations; England, Wales, Scotland and Northern Ireland – just as people with disabilities or illnesses were affected, because they have borne a level of stress, worry and responsibility for someone as well as the physical and mental toll of providing caring tasks, at times in a vacuum of knowledge or where systems and processes acted against them. When health and care staff were given priority in shopping

queues, some unpaid carers unable to queue because they could not leave the person they cared for at home for long enough, were deeply frustrated. Equally queuing for vaccinations could be an issue for some unpaid carers who were not a priority, whereas health and care staff were given priority. There is one positive recommendation that we set out below where NHS England tried to resolve this for the vaccination queues later on.

44 One of the major positive decisions, which could have been better communicated, was the decision by Treasury and the Department for Business and Trade to include unpaid carers in furlough. Although it was not well communicated, this, combined with working from home meant that vast numbers of unpaid carers did not fall out of work and were not thrown into poverty by a reliance on the benefits system.

Key decisions made by UK Government and Devolved Administrations.

45 Attached are several exhibits with evidence from Wales, Scotland and Northern Ireland in relation to Modules 2 and 3 which refer to the decisions made in those nations.

Decision to discharge residents to social care settings without testing

46 This was extremely distressing for families, that they could effectively receive someone back home and not know whether they had COVID-19 or not, particularly when there was someone else in the household who was extremely or clinically vulnerable. This was raised by Carers UK in the NASCG. Most of the discussion was understandably around the discharge of hospital patients into residential care settings without testing which was catastrophic for some care homes. Our Caring Behind Closed Doors report also raised this issue and concern of families and discharge home or into a residential care home.

47 We welcomed testing for anyone who needed one in social care settings on 15 April. Nearly two thirds of unpaid carers had said that more testing would really help them in terms of managing risk (Caring Behind Closed Doors, April 2020). We welcomed later expansion of testing. When the English Government announced testing on 5 May for essential workers, they included unpaid carers. This was very warmly welcomed by

unpaid carers, who until then, did not feel that they'd been treated as essential workers. Testing at this time, however, was not widespread.

Impact of shielding on recipients of domiciliary care and/or those with learning or other disabilities.

48 We have substantial comments and evidence from some carers that shielding provided, on the one hand, a feeling some control that they needed to be away from the source of infection as much as possible. For others, shielding took them away from networks, activities, wellbeing support. For many this meant loneliness and isolation. Carers provided clear evidence of the difficulties of people with learning disabilities, dementia or some types of mental illness to understand the situation.

"Lack of clear guidance regarding caring for someone in the shielded category has caused significant stress and anxiety due to the potential impact on my son. I work in health and want to redeploy to frontline clinical practice. The guidance has been very unclear and not supportive of my carer role." Carer view - Caring behind closed doors, April 2020."

49 We collected distressing evidence from carers in October 2020 – six months on – where carers told us that there had been cognitive decline in the person they cared for, reduced abilities that they had worked hard to develop for people with learning disabilities or retain for people with dementia and mental illness - **EXHIBIT EH/16 [INQ000239445].**

50 When shielding rules began to relax in July 2020, many carers felt that they could not do so because they felt that the risks were too great for the person they cared for and themselves i.e. fear of getting it or passing it on. We still hear from unpaid carers who are effectively continuing to shield and have restricted contact, or that the person they care for has done so now.

Impact of lockdowns

51 The timing of communications gave unpaid carers very little time to prepare for them. Our evidence from carers shows that lockdowns provided reassurance for some in measures to reduce risk of infection, but for others, caused many negative issues.

52 The lockdown rules restricted travel and contact but allowed essential care to be provided. This was common across Europe and was critical to the operation of care for professionals but also for families. Whilst this was clearly understood for professionals, the rules were not always well understood by unpaid carers themselves, by the police or by neighbours who reported unpaid carers for going out more frequently, even though they were providing unpaid care to someone who didn't live with them. For Carers UK as a significant information and advice provider, the lack of definition of "essential care" made our advice to unpaid carers more difficult – e.g. a carer concerned about driving 40 miles to share care with her sister for 4 days per week to care for her mother with cancer. They would share the care over the week to try to remain in paid employment as well.

53 Carers were often confused by varying lockdown rules about what was and what was not allowed. As time went on there, were increasing adjustments for people with disabilities that were welcome e.g. when people with disabilities could be accompanied outside by two people in order to remain safe. The pandemic demonstrated that the public and decision-makers were initially unaware of the impact of key disabilities and reasonable adjustments that needed to be made. Over time this learning and adjustments improved. In the future, these need to be implemented immediately.

54 We many sections of this evidence we set out the impact of lockdowns on carers' levels of care, health and wellbeing and ability to work. In the Association of Directors of Adult Social Services survey on 12 June 2020, 53% of Directors had seen an increase in people presenting to the council with adult social care needs as a result of carer breakdown, sickness or lack of availability. The most recent survey found that 88% of Directors agreed that unpaid carers have come forward with increased levels of need in their local area over the past 12 months. Whilst this is outside of the time period considered, this is part of an ongoing decline in social care which has not recovered since the pandemic. **EXHIBIT EH/36 [INQ000577427]**

Impact of social distancing measures

55 The impact of social distancing measures were problematic for some unpaid carers, who effectively went without additional support that would normally be provided by households. Although theoretically unpaid carers were allowed to continue to provide

essential care, such as a daughter giving her mother a break from caring 24 hours a day, 7 days a week for her 85 year old husband, there was not sufficient confidence with unpaid carers or the interpretation of the guidance to be able to do this. The stress of caring alone, as a single parent, for non-disabled children was recognised and acted on quicker than it was for unpaid carers.

56 Many carers found it very difficult in situations where the person they cared for didn't understand social distancing measures when out in the community. This caused huge stress for unpaid carers because the public's reaction was obviously alarm. Social distancing for people with dementia and learning disabilities was most difficult for people to understand. For closed settings such as hospitals and care homes, the lack of an ability to have direct contact and to accompany someone was extremely distressing for the unpaid carer, but also others. For some, it will have been harmful to their health and wellbeing. One carer told me that his wife with dementia would be unable to communicate with staff during her treatment for cancer and would be extremely frightened in hospital as a result of her condition. He was distraught not to be with her to reassure her and communicate on her behalf.

"Waving at my terminally ill husband through the hospital window was devastating for both of us. To be allowed to be with him for only the last 40 minutes of his life was useless to both of us leaving me torn apart with inconsolable guilt and grief."

Whether core political and administrative decision-makers adequately understood the role and/or importance of unpaid carers and/or gave them due consideration when key decisions relevant to the adult care sector were made during the pandemic?

57 There was a mix of awareness between political and administrative decision-makers understanding the role and/or importance of unpaid carers. There are instances where where they were completely ignored and others where they gave them due consideration with good outcomes.

Consideration in:

- Unpaid carers ability to provide essential care and therefore to travel to another household (within the first few days).

- Carers UK's inclusion in the National Adult Care (COVID-19) Group (NACG group).
- Reviewing legislation and implications of the Care Act 2014 easements April 2020.
- Furlough provisions by Her Majesty's Treasury and the Department for Business, Enterprise and Innovation which included unpaid carers. 4 April 2020.
- Clarification of Carer's Allowance rules – provision of caring including mental health support. 30 March 2020
- Inclusion in NHS Volunteer Responders – as a group that could be supported by volunteers.
- At a policy administrative level across DHSC carers' team, DWP carers, BEIS flexible working team and NHS England in relation to the Commitment to Carers team, there was very good understanding of carers' issues.
- Once agreed that unpaid carers were a priority for the vaccine, the roll-out programme included very positive work by officials within the Department for Work and Pensions to ensure the maximum number of unpaid carers were identified from their records to be eligible for the vaccine.
- Overall positive collaboration to retrieve lists of unpaid carers for the vaccine.

There was a lack of consideration of:

- Easily identifiable definition of "essential care" readily understood by the police and others advising carers. Definition most pointed to in carers' guidance, published early April 2020.
- Infection control, PPE and carers' inability to get PPE even though it was informally recommended by Government guidance.
- Carers' concerns about people coming into the home without adequate PPE.
- JCVI and the decisions around the lack of inclusion of unpaid carers in the list of priorities on 2 December 2020 even though they were a priority for flu vaccinations. This was changed on 31 December when they were part of Priority 6. However, with the next 2 booster waves, each time carers were left out of the interim guidance and then included later on.
- The need for contact in closed settings e.g. hospitals in particular to advocate for learning disability or dementia
- The need for contact in care homes
- Financial support for unpaid carers

- Initially around a lack of identification for unpaid carers i.e. ID for unpaid carers to allow for mitigations and support. Identifying unpaid carers was even more difficult than identifying social care staff.

Where unpaid carers are involved, in relation to the guidance published by the UK Government and/or the Devolved Administrations, relevant to the adult social care sector, our concerns centre around:

- Guidance not considering their needs or providing them with advice even though they were a major source of care.
- Some of these clarifications came later on.
- As above, the guidance did not always apply to unpaid carers.

58 The Government pulled together a cross-departmental meeting of officials to review unpaid carers' needs from 11 March 2024 which agreed to our recommendation for central government guidance on unpaid carers. This arose from the multiple clarifications being sought by carers and local organisations supporting unpaid carers, including local authorities. They worked on this quickly, pulling together Government guidance and publishing this on 8 April 2020. Carers UK was involved in reviewing the guidance and our points were taken on board where this was possible. The publication has been updated 18 times since publication and was withdrawn on 1 April 2022. The Government involved us in the development of this guidance appropriately and considerately. **EXHIBIT EH/37 [INQ000577459].**

A summary of key concerns about the support provided to unpaid carers during the pandemic by the UK Government and/or the Devolved Administrations, including (but not limited to):

59 **The ability to travel to provide "essential care" was vital but not well understood by professionals, by carers or the general public.** The UK Government said that "essential care" could still continue as soon as lockdowns started. This was essential and it would have been catastrophic if this had not been in place. However, this was not defined which, on the one hand, allowed a wide interpretation and which, on the other hand, made advice very difficult to provide to carers. People were being fined and stopped by the police for providing care outside of the home. 22% of unpaid carers provide personal care to a relative or friend and don't live with that person.

Essential care can extend beyond personal care to other types of care as well e.g. sharing the care of someone with dementia. Our helpline had a case of two sisters caring for their mother with advanced stage cancer and other conditions and who shared the care – 3 days and 4 days each whether driving 40 miles to start the visit to provide this care could be deemed "essential care". They were extremely concerned that they would be fined and potentially prosecuted. Were they stopped by police, they had nothing to prove that they were providing essential care or that someone relied on them for their basic needs. The homecare guidance that was published we saw a definition of "essential care" such as washing, dressing and preparing meals. **EH/38 [INQ000588644].**

60 Carers UK published guidance for unpaid carers on the same day that there were announcements, updating with further information as it developed. We had developed a quick reaction system where policy would share any announcements, information or developments, this would be considered quickly against carers' concerns/issues or questions that had already arisen, information would be published on our website and then communicated often before the end of the day. Any further clarifications or updates would then be applied after that.

61 **Guidance for unpaid carers by Government –** This was first announced at the end of March.

62 **Contingency planning** – was a key issue for unpaid carers and came out very quickly after the pandemic started. ***What happens if I cannot care?*** Carers UK already had contingency planning advice for unpaid carers prior to the pandemic and we updated and refreshed this in the light of the pandemic. Government then referred to this in their guidance.

Financial support;

63 In our survey, *Caring Behind Closed Doors: Forgotten Families in the Coronavirus pandemic* (**EXHIBIT EH/09 [INQ000176237])**, only 19% of respondents were not spending any more on anything; 81% said they had seen an increase in household bills. 72% were spending more on food because of lack of choice on where to buy or what, the cost of deliveries. 50% were spending more on household bills. 19% were

spending more to keep in touch with tech, 11% spending more on equipment. Only 6% spending more on social care support.

" My savings that I have spent 30 years trying to build up for retirement are now vanishing to pay the bills."

" Everything is more expensive. Trying to get medical help unconnected with the virus is all but impossible. Phone bills horrendous trying to chase medical, medicines or orders."

64 When we asked carers six months on, in October 2020, 26% of respondents said their still had increased costs (this is before the cost of living crisis, high inflation and energy prices). Carers providing over 35 hours of care per week were significantly more likely to be struggling to make ends meet. Comments from carers showed that they continued to be deeply financially stressed:

"With my [disabled] son home full-time my household bills have trebled."

"Food shopping has gone up and I don't eat most nights so, bills have gone up with the children being at home more."

65 Work carried out by the University of Sheffield in partnership with Carers UK found that carers were twice as likely to be using a food bank during the pandemic.

66 There are clear reasons for carers' financial stress. Carer's Allowance was worth only £66.15 per week (for a minimum of 35 hours unpaid care earning under £120 per week) and £67.25 (2020/21 rates with earnings limit of £123 per week) and £67.70 (2021/22) and £69.70 (2022/23). There was already substantial evidence to show that unpaid carers struggled financially pre-pandemic. **EXHIBIT EH/39 [INQ000577450]** In March 2020, Government announced that people in receipt of Universal Credit (which includes some carers) and Tax Credits would receive an additional payment which was equivalent to £20 per week or £1,000 per year. In the March 2021 budget, it was extended for another six months. **EXHIBIT EH/40 [INQ000577452]**

67 However, groups of carers missed out:

- Carers in England and Northern Ireland who were in receipt of Carer's Allowance, but not Universal Credit. This is because older benefits, such as Carer's Allowance and Income Support did not receive an uplift. This group was £1500 worse off over 18 months and did not receive any additional payments. Those in receipt of Income Support are just as deserving as those in receipt of Universal Credit and are, by definition, with the lowest incomes. With a cost of living crisis following the pandemic, financial issues for unpaid carers have deepened and worsened. Carers UK will be publishing new evidence on carers' poverty rates later this year.
- For carers in Northern Ireland, it was even more frustrating when in 2021, it was announced that there would be a £500 payment for unpaid carers, similar to Wales. However, the administration then received legal advice that their powers did not extend this far to make additional payments and it did not materialise.
- Legacy benefits, such as Income Support and Carer's Allowance did not and currently still do not have a sufficiently responsive administrative systems to allow the Government to respond quickly and flexibly in a pandemic or emergency situation.
- The Welsh Government made a single additional payment for carers in receipt of Carer's Allowance which was very welcome, but could not extend this to carers in receipt of means-tested benefits e.g. Income Support. This was due to benefits rules, which would have meant the funding would simply have been reclaimed by the UK Government as it would have been treated as income. Combined with the problems of an outdated benefits system, it was not possible to deliver all carers a payment.

68 The Scottish Government had already brought in an enhanced payment for unpaid carers – the Carer's Allowance Supplement which people who received Carer's Allowance on qualifying dates were entitled to receive in two six monthly payments. This single six monthly payment of £230.10 (2020) was doubled to £460.20 as the Coronavirus Carer's Allowance Supplement. This additional payment ran for three payments, giving unpaid carers an additional £694.20 over 18 months in Scotland. This means that eligible carers received an additional £1,388 over 18 months compared with carers in England and Northern Ireland. The Scottish Government estimates that 82,000 unpaid carers benefited from this uplift. Please see **EXHIBIT EH/41 [INQ000577444].** For those in receipt of Universal Credit in Scotland, they will

have received £2,888 over 18 months including the UC uplift, the Carer's Allowance Supplement and the Coronavirus addition. This largest amount is £37 per week over 18 months – roughly half the value of Carer's Allowance per week. Carers Scotland welcomed the Scottish Government for taking this action to improve carers' lives during the pandemic.

69 Our conclusion from this is that the DWP must modernise its benefit systems in every nation so that they are able to provide financial support quickly. This needs to be done purely because of an efficiency point of view, but it would also allow Governments to be more responsive in the pandemic. The Wales Government and NI Assembly need the ability to make additional payments and for this not to be clawed back by Westminster. Legislation needs to be brought into this effect.

70 Carers who were struggling financially had additional pressure on top of unpaid caring which was already stressful and, for some, unrelenting. Our strong recommendation to the UK Government is to ensure that a better solution is found to ensure that payments can be made swiftly and equitably and that all nation Governments are able to make the same decisions, as Scotland, to retain any material benefit for the people of their nation. Legacy and older benefits operating systems need to be upgraded and made more efficient. Unpaid carers' support worth £193 billion a year during the pandemic ensured that health and care services continued to function and yet some received the least recompense of all. This is unacceptable in our modern society.

71 The other area, indirectly, of financial support, is in relation to furlough announced on 4 April 2020. The furlough definition in relation to unpaid carers was, "unable to work, including from home or working reduced hours because…they are caring for a vulnerable adult in the household." **EXHIBIT EH/42 [INQ000577458]** We do not know whether any national data established the rate of unpaid carers who took furlough. From our own State of Caring 2021 data, 13% of respondents (largely providing substantial care) were on furlough in April 2020, 5% in October 2020 and 1% in September 2021 as the scheme came to an end. We know from our helpline that some employers were not aware that people could be furloughed as a result of unpaid caring responsibilities and this is something that we think could be made clearer.

72 Caring six months on (**EXHIBIT EH/16 [INQ000239445]**) found that 20% of unpaid carers had left their employment, reduced working hours or lost work if self-employed to caring and COVID-19. 47% of respondents to our 2021 survey said that they were working from home all or part of the time. For many, this was essential with services closed or unavailable. However, many working carers said that they did not get a break at all. Carers UK saw a very clear response from employers who saw, for the first time, caring firsthand for those working and juggling care at home.

"Our daughter was home for 12 weeks because her care home wouldn't have her back. We went from having her home five days every three weeks to caring for her 24.7. I had to give up paid work." Six months on (Oct 2020)

"Less time for work or anything because of the lack of day services and cut back in hours from my son's support workers (because of shortages of staff from the provider organisation". Six months on (Oct 2020)

"My employer has been supportive in allowing me to stay furloughed until shielding finished which allowed me to care for my parents and keep them safe, but they have also allowed me to work just one day during local lockdown." Six months on (Oct 2020)

"I have explained to my manager how my Mum's health is deteriorating, and they have not been very understanding. If this continues to happen, I will have no choice but to leave work." Six months on (Oct 2020)

Support through training e.g. on infection prevention control

73 Carers were faced with an incredibly difficult situation with infection prevention control. The overwhelming concern from carers, is that they would get COVID-19 and that there would be no one to care for their family member/friend. The evidence that we supplied to the Health and Care Select Committee on advice, to isolate within the household and not have contact was simply not possible when you are providing care. We communicated information to carers provided by Government e.g. in the guidance for unpaid carers, but in reality there was very little carers could do. Domiciliary care

services were stretched and without adequate and consistent supplies of PPE, leaving carers feeling helpless. Public access to PPE was even worse.

74 Scotland was the first nation to provide PPE to unpaid carers which we have set out in **EXHIBIT EH/02 [INQ000499481].** England introduced this considerably later. The need and evidence we set out in our evidence from the Unpaid Carers Advisory Group.

Wellbeing support

75 Wellbeing support is very commonly delivered through the voluntary sector, particularly local carers' and older people's, dementia and learning disability services and support for families. Local authorities have direct payments for unpaid carers to be able to provide themselves with self-directed wellbeing support. We have not collected any evidence on whether these were used more widely in England. In terms of wellbeing support, this was largely delivered through online means or by telephone support. Like many local organisations, as an organisation of carers, we developed a new suite of online support services and online get togethers for unpaid carers.

76 Carers have told us that this wellbeing support was helpful, but given the poor mental health of unpaid carers, we feel that this should be a greater focus in any future pandemic.

A brief description of the impact of easements to the Care Act 2014 (if any) on unpaid carers.

77 The impact of easements on unpaid carers in England is less clear. There was a distinct concern at the time that the new legislation would mean that carers' needs would not be considered at all. We provided detailed briefings to the sector and to carers to be clear about the correct legal position (see list). Whilst the legislation stipulated that full assessments did not need to take place, it did not mean that needs could be completely ignored, but that risk and need still had to be considered. One of our concerns was that if easements were officially utilised, the suspension of financial assessments and the ability to retrospectively apply costs to families would be financially catastrophic. We do not have any evidence of this happening, fortunately. Few authorities officially applied for easements.

78 Official statistics provided through local authority sources are not recording a significant drop in assessments during 2020/2021 and 2021/2022. In 2021/22, 380,7215 carers were either supported, assessed or reviewed, 2.15% down since 2020/21. NHS Digital, also noted that there was increased demand during the first year of the COVID-19 pandemic with the role of unpaid carers increasing due to lockdowns and shielding in 2020-21 in England.

79 The total number of carers that local councils in England assessed for support across the six years has a very slight increase from 386,605 in 2015/16 to 388,730 in 2020/21. **EXHIBIT EH/43 [INQ000587272].** This increase is not considered to be significant, or even too low, given the ageing population and increase in care provided by unpaid carers. However, whilst more assessments might be taking place, there is a worrying downward trend of carers not getting practical support following an assessment and a sharp increase in information and advice only. **EXHIBIT EH/44 [INQ000588632].**

80 In Northern Ireland, there was a distinct fall in the number of assessments of around 18% over the first year or so, and a 32% reduction in Scotland. In England, carers' assessments can be delegated to local carers' organisation who might provide a full assessment or one which is very light touch, depending on their contract with the local authority. This could have had a bearing on the differences in the figures between the different nations where carers' assessments (or their term for them) are done solely by local authorities or health and care trusts in Northern Ireland.

81 In our evidence for the Unpaid Carers Advisory Group, we note that some local authorities were describing few carers' assessments whereas others had significant numbers. We raised a concern in that report and these differing rates.

82 Several local authorities spoke to us in 2022/23 about the waiting lists for carers' assessments which they said was a result of a backlog building up during the pandemic but also due to increased need post-pandemic.

Matters relating to end of life care and deaths

83 Many of our members raised significant concerns about DNACPRs which had been added to their relatives' records without consultation or consideration. Many of these

unpaid carers were parents of adults with learning disabilities. We supported the excellent campaigns of other key organisations such as Mencap, challenging concerns through others' already leading in these areas.

84 We did not collect any data on end of life care from our members.

85 We are unaware of any data relating to COVID-related deaths of unpaid carers.

Changes to the regulatory inspection regime

86 We did not collect any information in relation to this area.

Access to PPE for unpaid carers

87 Carers UK supplied a number of different pieces of evidence from unpaid carers about PPE which was a key concern for them. They were not provided with any PPE and it was impossible to buy on the open market. This was particularly challenging for unpaid carers who would normally use PPE prior to the pandemic e.g. use of gloves or plastic aprons.

88 We supplied evidence on the Health and Care Select Committee on 9 April 2020 setting out our concerns:

- Lack of PPE for workers, particularly care workers.
- Ambiguous guidance which suggested that unpaid carers should have PPE, but when there was no route for accessing this on the open market.
- Inability of unpaid carers to purchase PPE

89 In our evidence as part of the Unpaid Carers Advisory Group, we set out the huge costs of PPE for unpaid carers; the cost of £5 for gloves out of an income through Carer's Allowance of £67 per week.

90 Scotland provided PPE to unpaid carers through Local Resource Hubs and a screening process from the end of April 2020. Free PPE was delivered on 26 January 2021 through local authority Local Resilience Forums. The evidence from Scotland was that take-up from unpaid carers was reasonable and manageable. Despite this and evidence from unpaid carers, delivery took far longer in England.

Matters specific to Carers UK

91 The senior level working group was the National Adult Social Care Group on which we were represented. It met at times twice per week e.g. 18 March 2020 and 20 March 2020 and other times every 2 weeks. I was invited on 10 March 2020. Its purpose was to assess the additional guidance support needed for the adult social care sector in the light of the Government's plan for COVID-19 (published on 3 March 2020), to provide advice on specific areas such as guidance to the sector in the event of a reasonable worst case scenario, emergency legislation and financial support for the sector and finally, a route of communication and rapid insight from providers.

92 Because of the situation, there were significant issues raised by care providers in relation to many key issues such as PPE, infection control, guidance to the sector, testing, etc. and the Inquiry will have received detailed evidence from care providers on this. I raised issues such as PPE for unpaid carers, testing, concern about infection control. On 29 April, I presented the findings from our Caring Behind Closed Doors research. **EXHIBIT EH/09 [INQ000176237].**

93 On 6 May 2020, the workstream on unpaid carers reported on the unpaid carers guidance, PPE advice to carers, young carers advice being developed, hospital discharge identification and breaks.

94 The presentation raised a number of really large issues, some of which were not able to be resolved at that point such as the reinstatement of services that were stopped during the pandemic.

95 The Department was responsive in terms of carers' guidance, and relatively responsive advice for carers at the point of hospital discharge. Given the shortages of PPE, testing, concern about Infection Control, those issues were discussed more frequently in relation to professionals working in adult social care. Some of our issues were, therefore, not resolved.

COVID-19 social care taskforce

96 The taskforce and its membership is all documented and within the public domain. I was asked to chair the Unpaid Carers Advisory Group to feed into the overall Taskforce report alongside other taskforce group. I asked Dame Philippa Russell a carer for her adult son with learning disabilities to Co Chair the group. We had a mixture of experience including unpaid carers, learning disability representatives, Healthwatch, Carers Trust, ADASS Carers Policy Group joint chairs, LGA, Children's Society, key academics, UKHCA, NHS England Commitment to Carers team and local commissioning NHS representatives.

97 The Unpaid Carers Advisory Group produced a thorough and considered paper **EXHIBIT EH/14 [INQ000588638]** with evidence. This was delivered to the Taskforce chair on 7 August 2020. It explains the COVID-19 pandemic several months in and ahead of winter planning. We divided the report up into:

- Overarching recommendations
- Action that needs to be taken for any future lockdowns/waves
- Immediate and urgent actions to be taken pre-September 2020
- Action for the first phase of winter – up to October 2020
- Action required for the second phase of winter.

98 We raised a number of concerns:

- Increased risk of different communities e.g. Gypsy Roma Traveller or /BAME communities.
- Increased vulnerability of different groups e.g. dementia, learning disability, autism and mental illness; carers with conditions themselves and older carers; young carers and working carers.
- PPE
- Testing coming out of hospital into the community (still an issue)
- Visiting in care homes
- Test and trace identifying unpaid carers
- Lack of a benchmarking tool/plan for carers should there be another wave
- Lack of ID
- Rising need
- The need for contact e.g. care bubbles and contact with those in hospital.
- Young carers and education

- Mental health issues for unpaid carers
- Concern about carers ability to return to work (if it meant back to the office)
- Carers' breaks and day services being reopened and reinstated.
- Assessments and contingency planning
- Hospital discharge and support for carers
- Role of NHS in identifying carers
- Low incomes and the effect of winter
- Vaccinations programme with flu and then for COVID-19 itself – the need to ensure that carers were a priority along with key workers.
- Data collection

99 A number of our recommendations were outside of our terms of reference e.g. fundamental baseline funding for social care, but we included it as we felt it was extremely important.

The key outcomes that Carers UK campaigned for during the pandemic:

100 We have set these out clearly in this evidence and the successes are threaded throughout this evidence.

Lessons learned:

101 The Unpaid Carers Advisory Group report notes that key areas that can be adopted in non-pandemic times can be health and wellbeing positive for carers and are highly effective during the pandemic. Carers support across the UK is valued at £184 billion per year and it's essential that they are valued and supported. The social care sector was under-supported compared with the NHS.

Measures that need to be adopted for unpaid carers specifically;

- Carer identification, particularly through GP practices is critical.
- Understanding that unpaid carers status should be equivalent to key workers.
- Furlough and the ability to work from home.
- Tech and digital support for families (taking note of digital poverty which needs to be tackled).
- Financial hardship during the pandemic.
- Mental health and wellbeing support for unpaid carers.
- Breaks and physical services.

- PPE and infection control.
- Testing being critical.
- The need for adjustments for disabled and older people and their families e.g. care bubbles, additional exercise, etc.
- Visiting
- Vaccinations where carers are considered a priority – because of the care they are providing.
- Emergency and contingency planning.
- Support for young carers.

102 The Unpaid Carers Advisory Group report, the Carers UK reports and other evidence essentially sum up the lessons learned. We consider that we have a blueprint for the future.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: **Personal Data**

Dated: 19 May 2025