Caring behind closed doors

Forgotten families in the coronavirus outbreak

April 2020
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About this research

Carers UK carried out an online survey between 3rd April and 14th April 2020. A total of 5,047 carers and former carers responded to the survey. This included 4,830 current carers and 217 former carers. Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week. As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented here, are based upon responses from fewer than 5,047 carers.

Of current carers responding to the survey:
- 67% live in England, 19% live in Scotland, 9% live in Northern Ireland, and 6% live in Wales.
- 81% identify as female and 18% identify as male.
- 23% consider themselves to have a disability.
- 1% are aged 0–24, 4% are aged 25–34, 13% are aged 35–44, 27% are aged 45–54, 32% are aged 55–64, 17% are aged 65–74, and 5% are aged 75 and over.
- 4% identified as lesbian, gay or bisexual.
- 4% described their ethnicity as black or minority ethnic.
- 18% also have childcare responsibilities for a non-disabled child under 18.
- 36% have been caring for 15 years or more, 17% for between 10–14 years, 24% for 5–9 years, 20% for 1–4 years, 2% for less than one year and just 1% have been caring since the beginning of the coronavirus outbreak.
- Most (71%) care for one person, 20% care for two people, 6% for three people, and 2% care for four or more people.
Introduction

Whilst the current crisis has come as a shock to so many aspects of our society, it has created a particularly frightening reality for the UK’s 6.5 million1 carers – those who provide unpaid care to family or friends who are elderly, disabled or who have a long term health condition. The essential support provided by family and friends has been valued at £132 billion a year2 and without these people our health and social care system simply wouldn’t survive, whether in a time of crisis or not. Families are caring for people with a variety of conditions, and sometimes several conditions, which may mean they need to be shielded in the current context. The vast majority of the time, care is provided behind closed doors, in people’s homes and is largely invisible to the general public.

This new research report, released in the midst of the coronavirus crisis, provides powerful evidence of the difficulties carers are facing and their worries for the future.

The majority of carers are now providing more care than before, and the need for self-isolation or shielding closure of local services and reduced support from social care providers have had a particularly powerful knock on effect for carers, many of whom were already providing substantial hours of care every week, and were already frustrated, anxious or exhausted. This research also shows that the impact of coronavirus on carers’ lives is far-reaching with many facing difficulties accessing food and other supplies necessary for caring, increased costs on supplies and bills, and changes to working patterns for those who are juggling paid work and care.

Before the coronavirus outbreak, many carers already found it challenging to put in place a plan for the future – our previous research found that only one in six carers (17%) had taken part in a conversation with an NHS professional about what to do if the condition of the person they care for deteriorates, or they are no longer able or willing to provide care for them3. These concerns have only been exacerbated by the current crisis, with more carers worried about getting ill themselves with coronavirus, and the impact this could have on their caring role.

This current crisis has shone a light on what so many do every day to care for friends and family, and we want to ensure that carers are recognised for their huge contribution. Whilst many of us take part in weekly claps to recognise the important work done by the health and social care workforce, the vital unpaid work done by family and friends to care for their vulnerable loved ones is being forgotten about.

This crisis needs to be a turning point in how we as a society treat carers. It has never been more important that both national and local government, as well as employers and policy makers, take action to support them and the people they care for.

Carers UK will continue to fight for carers’ rights, now and in the future.

Helen Walker, Chief Executive, Carers UK

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1 Census 2011
Executive summary

Carers UK’s survey into the experiences of over 5,000 current and former carers has found that the coronavirus crisis is having a profound impact on carers’ lives. Many of those who responded were providing very high levels of care, or juggling care in complex lives. They are those most in need.

Not only are many providing more care than before, they are suffering financially and are worried about the future.

• 70% of carers are providing more care due to the coronavirus outbreak.
• Over a third (35%) of carers are providing more care as a result of local services reducing or closing.
• Carers are, on average, providing 10 additional hours of care a week.
• 69% of all carers are providing more help with emotional support, motivation, or keeping an eye/checking in on the person they care for.
• 81% of carers are spending more money at the moment. 72% are spending more on food and 50% are spending more on household bills.
• 38% of carers agreed or strongly agreed with the statement “I am worried about my financial situation”.
• The majority (55%) of carers agreed or strongly agreed with the statement “I feel overwhelmed and I am worried that I’m going to burnout in the coming weeks”.
• 87% of carers agreed/strongly agreed with the statement “I am worried about what will happen to the people I care for if I have to self-isolate or become ill”.

Carers UK is calling on every Government across the nations of the UK to take action to support carers, both in the short and longer term. In particular, we are calling for an urgent increase in the level of Carer’s Allowance, ensuring access to food and necessary supplies, additional guidance for unpaid carers, increased levels of testing, and increased access to personal protective equipment (PPE). 
Rising levels of care

Before the coronavirus outbreak, carers across the UK were already providing substantial amounts of care, valued at £132 billion a year.\(^1\) The increased pressures carers are currently facing means many have changed the amount and type of care they are providing.

**Changes in the amount of care provided**

The results show that on average, carers are providing 10 hours more care per week than they were before the coronavirus outbreak. The average figure is now 65 hours per week, compared to 55 hours before. Respondents were asked if their caring levels had changed and were able to select multiple reasons for this. Overall, 70% of carers said that they had increased the amount of care for one or more reasons.

Looking at the reasons why more care is being provided in detail, shockingly over a third (35%) of people said they were providing more care as a result of local services reducing or closing. This figure rose to 39% in Scotland, 36% in Wales and 45% in Northern Ireland. It’s worth noting that by no means all carers received services before the coronavirus outbreak.

**Has the amount of care you are providing changed since the start of the coronavirus outbreak?**

(Extract of carers who said they are providing more care)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am providing more care than before because local services have been reduced/closed (e.g. day care)</td>
<td>35%</td>
</tr>
<tr>
<td>I am providing more care because I am worried about paid health and social care staff having contact with the person I care for</td>
<td>22%</td>
</tr>
<tr>
<td>I am providing more care because the paid health and social care staff have reduced personal care</td>
<td>10%</td>
</tr>
<tr>
<td>I am providing more care because my paid working arrangements have changed so I have more time</td>
<td>10%</td>
</tr>
<tr>
<td>I am providing more care for another reason</td>
<td>27%</td>
</tr>
</tbody>
</table>

100% of my husband’s care is on me. He is in a wheelchair so I have a lot of heavy lifting to do. Before coronavirus I had two care workers three times daily. It makes a difference.

Day centre twice a week is closed and my brother can no longer take my Dad out one day at the weekend. I am providing three full days more than I used to. 24 hours a day 7 days a week.

Despite having an Education Health and Care Plan my son is at home full time as the specialist provision he attends has closed and his school do not feel able to manage his needs due to the reduced staff they are operating on.

Other reasons shared by carers as to why they were providing more care included the fact that other family and friends are less available to provide care, and that some people had temporarily moved in with the person they care for.

I have cancelled Mum’s care calls, four a day, two care workers, to reduce the amount of people entering Mum’s home. I have moved in with her, for the shielding period, and I’m providing the care she needs.
Prior to this outbreak, I could rely on other family members getting involved in taking my wife’s shopping, or out for coffee, etc, giving me a break and some free time to do activities just for myself. Coronavirus now means I have that responsibility for 100% of the time.

However, 9% of carers said they are providing less care for one or more reasons. 7% of carers are providing less care because they are following Government guidance and reducing their social contact. Those caring for a parent were most likely to have reduced the amount of care they are providing for this reason with 13% selecting this option. This is often a source of great worry and concern of families, but they are doing their best to adjust.

**Has the amount of care you are providing changed since the start of the coronavirus outbreak?**
(Extract of carers who said they are providing less care)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am providing less care than before because I am following Government advice and reducing face to face contact with the person I care for</td>
<td>7%</td>
</tr>
<tr>
<td>I am providing less care than before because I am no longer spending as much time with the person I care for</td>
<td>3%</td>
</tr>
<tr>
<td>I am providing less care for another reason</td>
<td>2%</td>
</tr>
</tbody>
</table>

I am trying to provide daily video contact instead of twice per week extended visits that I usually do. I am delivering shopping and then sitting in his garden to make phone calls for him and provide moral support just once per week for an hour as can’t go within three metres.

I suffer from asthma so I cannot share my father’s care with my sister. We have temporarily asked all our care workers to stay away from our father’s to restrict his care to one person. My sister has taken over all my father’s care travelling to his house four times a day.

Other reasons for providing less care included being unable to visit the person they care for in a care home and having to take a step back from caring for their own health reasons. For those telling their concerns about care homes, they were desperately worried about the long-term impact on their relatives’ health and wellbeing.

I can no longer get in to the nursing home to see my Mum to provide emotional support and she is unable to use technology to engage with me.

Around a fifth of carers (22%) are providing the same level of care.

Caring for someone with MND is the same in lockdown as normal. Nothing has changed apart from I am more conscious about distancing from people when out shopping to try and ensure I do not bring home the virus.

Prior to the coronavirus outbreak, Carers UK had already raised concerns about the high and sustainable levels of care being provided by families, as a result of an underfunded care system. This situation has clearly been exacerbated by this crisis, demonstrating the value and key role that care services play in supporting families and friends who are carers.
Changes in the type of care being provided

For many carers, the type of care they are providing has also changed due to a change in circumstances, services or the needs of the person they care for. Carers were asked if they were providing more of any of the following types of care and were able to select more than one option. Notably, 69% of all carers are providing more help with providing emotional support, motivation, or keeping an eye on someone either in person, phone or online. In each of the nations this figure was slightly higher, with 72% in Scotland, 73% in Wales, 70% in NI.

Are you providing more of the following types of care since the start of the coronavirus outbreak?

<table>
<thead>
<tr>
<th>Type of Care</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Providing emotional support, motivation or keeping an eye on/checking in on someone either in person, by phone or online</td>
<td>69%</td>
</tr>
<tr>
<td>Practical help in person (e.g. preparing meals, shopping, laundry, housework, household repairs, taking to doctor/hospital)</td>
<td>53%</td>
</tr>
<tr>
<td>Practical help at a distance (e.g. arranging for food and medicine deliveries)</td>
<td>40%</td>
</tr>
<tr>
<td>Taking them for exercise (e.g. short walk, run or cycle)</td>
<td>36%</td>
</tr>
<tr>
<td>Personal care (e.g. dressing, bathing, washing, shaving, cutting nails, help with eating, using the toilet)</td>
<td>34%</td>
</tr>
<tr>
<td>Arranging/coordinating care and support, medical appointments and other help</td>
<td>26%</td>
</tr>
<tr>
<td>Help with moving around (e.g. with walking, getting up and down stairs, getting into and out of bed)</td>
<td>25%</td>
</tr>
<tr>
<td>Helping with paperwork/financial matters (e.g. writing letters, filling in forms, dealing with bills, banking)</td>
<td>25%</td>
</tr>
<tr>
<td>Helping with medication (e.g. making sure he/she takes pills)</td>
<td>24%</td>
</tr>
<tr>
<td>Helping with medical care (e.g. giving injections, changing dressings)</td>
<td>11%</td>
</tr>
</tbody>
</table>

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.

The type of care I now give is more time consuming as I have to do a 20 mile round trip to care for my parents, doing their shopping, sorting out prescriptions and paperwork as well as trying to keep my daughter busy with activities inside the home.

Many carers spoke of the exhaustion of providing constant care, including mental wellbeing support for the person they cared for – whether to reduce anxiety, reduce challenging behaviour or calm hyperactivity. Comments from carers also show that the closure of key day services and specialist provision has been particularly hard for certain groups, such as those caring for some with a learning disability, autism, or dementia. Many spoke of increases in challenging behaviour because of the person not understanding circumstantial changes or the new rules that they must follow.
Financial pressures

Many carers already faced very difficult financial situations due to their caring responsibilities. Prior to the coronavirus crisis, 1.2 million carers were already in poverty. Previous research has found that caring can result in a sharp reduction in income, due to the extra costs of caring, this can be compounded if they have had to reduce their hours, and/or the person they are caring for has had to give up work due to their illness or disability. Carer’s Allowance, the main carers’ benefit is only £67.25 a week (2020/21 rates), the lowest benefit of its kind.

The coronavirus outbreak is likely to have a lasting impact on many people’s finances, with many jobs and income levels affected alongside changes in lifestyle. Caring already carries increased costs, but there may be further costs from heating, equipment for adapting the home, technology, or the need to find specialist food. This research confirms finances are a concern for many carers, with 38% agreeing or strongly agreeing with the statement “I am worried about my financial situation”.

Rise in costs

Worryingly, the vast majority of carers have seen an increase in costs since the coronavirus outbreak. When asked if they had seen an increase in their household costs, 81% said they were spending more – the biggest reason for an increase was spending more on food.

Are you spending more money on any of the following things since the start of the coronavirus outbreak?

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Yes, I am spending more on food</td>
<td>72%</td>
</tr>
<tr>
<td>(e.g. because of getting food deliveries, because of having fewer choices about what to buy)</td>
<td></td>
</tr>
<tr>
<td>Yes, I am spending more on household bills</td>
<td>50%</td>
</tr>
<tr>
<td>Yes, I am spending more on technology to keep in touch with the person I care for</td>
<td>19%</td>
</tr>
<tr>
<td>Yes, I am spending more on equipment</td>
<td>11%</td>
</tr>
<tr>
<td>Yes, I am spending more on something else</td>
<td>11%</td>
</tr>
<tr>
<td>Yes, I am spending more on social care support</td>
<td>6%</td>
</tr>
<tr>
<td>No, I am not spending more on anything</td>
<td>19%</td>
</tr>
</tbody>
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6 In Scotland, carers in receipt of Carer’s Allowance, are paid an additional payment twice per year a Carer’s Allowance Supplement. This was part of a commitment to raise Carers Allowance to the level of Job Seeker’s Allowance
Carers highlighted that own-brand and cheaper products were often not available to purchase and their usual routine has changed, resulting in higher food bills.

Not been able to shop in cheaper shop, you have to get whatever you can, this takes a lot of my caring time up. Also still haven’t received food vouchers from school.

Food bills have increased, but primarily because of fear; as my Mother says on a daily basis, this week could be the last week, so she would like another piece of cake, she would like a sherry with her meal, so strict budgeting has gone.

The impact of more time at home is leading to increased costs on phone bills, entertainment and equipment for the people they were caring for.

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.

Spending so much more money on school supplies and also sensory toys for my nine year old as he has more severe autism. Also having issues getting specific food brands so having to buy what I can in bulk as he only eats a very select amount of things. We haven’t left the house in four weeks. Extra on heating, TV, internet, all to keep him amused.

Judging by our previous research,7 this will push families already at the edge of financial stress into debt, or further into debt, with lasting impacts in the long term on their health and wellbeing.

81% of unpaid carers are spending more money at the moment. (72% are spending more on food and 50% are spending more on household bills)

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Impact on working carers

Working carers were already struggling to juggle the pressures of working and caring, trying hard to balance providing practical and emotional support, managing appointments, and keeping an eye on the person they care – all alongside paid work. Research undertaken in 2019 has shown that over 600 people a day were giving up work to care for a loved one. Carers UK has also estimated that almost 5 million people were juggling work and unpaid care for an elderly, ill or disabled relative.

The coronavirus outbreak continues to have a significant impact on work with social distancing measures meaning many businesses and other organisations are struggling to continue to operate. This is likely to lead to an increased unemployment rate and changes to how we work across the UK.

Our survey shows that the crisis has already had a significant impact on working carers’ jobs. 1,230 respondents who indicated they were in paid work before the crisis were asked for details about their current working situation. Almost a fifth (17%) reported either having lost or given up their job or being unable to work because of the social distancing rules. All these options indicate that the individual is no longer being paid, meaning that they are likely to have seen a dramatic reduction in their income.

### What is your current employment situation in light of the coronavirus crisis?

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am working from home</td>
<td>41%</td>
</tr>
<tr>
<td>I am a key worker so I am still going to work as normal</td>
<td>16%</td>
</tr>
<tr>
<td>I have been furloughed</td>
<td>13%</td>
</tr>
<tr>
<td>I am unable to work because of the current social distancing rules and am not being paid</td>
<td>9%</td>
</tr>
<tr>
<td>None of the above</td>
<td>7%</td>
</tr>
<tr>
<td>I have given up work because of caring</td>
<td>6%</td>
</tr>
<tr>
<td>I have been unable to work because of illness</td>
<td>3%</td>
</tr>
<tr>
<td>It is not possible for me to work from home so I am still going to work as normal</td>
<td>2%</td>
</tr>
<tr>
<td>I have lost my job</td>
<td>2%</td>
</tr>
</tbody>
</table>

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8 Carers UK (2019) ‘Juggling work and unpaid care’
9 Ibid
Many of the self-employed or those on zero hours contracts were having a particularly challenging time seeing sharp reductions in incomes, and challenges accessing Government support.

My husband’s business folded due to the coronavirus so he has had to take on three nights at a supermarket to help pay the mortgage. This makes it even harder for us to keep our son safe from the infection.

Balancing caring responsibilities with work, remains a challenge with previous arrangements including school, day care and other family members providing support no longer an option for many with 6% having had to give up work since the coronavirus outbreak.

I have no care during the day so I had to give up work. My daughter is completely reliant on care workers and usually she would be at school. My work is around her hours so never been an issue. Her grandparents usually sit for an hour when she gets home and I leave work but they are both in the vulnerable group.

Unable to work because of stress – no help from work to cope with the fact my son had nowhere else to be cared for but at home by me and they could only offer unpaid leave.

A further 13% of working carers have been furloughed from their job. For these working carers they are still receiving an income, but many are concerned about what it will mean for their jobs in the future.

I work full time always have so caring for my mum before and after work – at the moment non-essential retail stores have been closed so my business has put us on furlough for the foreseeable I am however worried about how long this will go on.

Some employers have been able to continue to operate, and offer changes to working arrangements. 41% of people are working from home. Managing caring and working from home can be challenging, with the emotional impact of not being able to take a break challenging for some carers to manage and the time spent trying to work whilst also juggling care.

Working from home has increased my stress levels because I am no longer able to use going to work as respite from my caring role.
Worries and fears

Caring for someone can be challenging and many previous research reports have evidenced the impact on carers physical and mental health\textsuperscript{10}. Alongside the usual stresses of ensuring that the person they care for is well looked after, the coronavirus outbreak has added additional pressure and feeling of being responsible for keeping the person they care for safe.

Many carers are extremely concerned about being able to continue caring safely and effectively, whilst maintaining their own health and wellbeing at this time.

\begin{quote}
I am terrified, to the point of suffering a panic attack, that either Mum or I will become infected and I’ll either have to battle to keep her isolated, or worse I might get ill and won’t be able to keep her safe because I’ll have to self-isolate.
\end{quote}

One in five (18\%) carers already feel unable to manage their caring role at the moment in part due to the increased hours in care and reduced local services, as highlighted in the previous section. The majority of carers (55\%) agreed or strongly agreed that “I feel overwhelmed and I am worried that I’m going to burnout in the coming weeks”.

\begin{quote}
I have no other family members except my parents who I live with and look after. That’s pretty damn stressful. If I burnout, who looks after them? Nobody. We have no external support. I am already faltering.
\end{quote}

\begin{quote}
I have a support network, but the main support I need is respite (which I usually get when he attends specialist provision) and no one can offer this at the moment. Even therapeutic support is tricky at the moment as son can’t cope with me being on the phone.
\end{quote}

Some carers were concerned about what the future would mean for care provision, and whether there would be a reduction in support for the person they were caring for.

\begin{quote}
I am worried that the council will strip away the care package, because due to the new law, they can. I am terrified that I am going to become too ill to care and my guys are going to be placed in unsuitable accommodation.
\end{quote}

\textsuperscript{10} For example Carers UK (2018) State of Caring 2018
Loneliness, isolation and taking time to look after their own wellbeing is a challenge for many carers, which has only been heightened by the coronavirus outbreak. One third of carers (33%) felt they were unable ‘to look after their own health and wellbeing’, and 44% stated that they were ‘lonely and cut off from people’.

Fed up, lonely, scared for my own mental and physical health, unsupported. We have just been forgotten. As I’m Mum’s carer we don’t qualify for any support from the council in terms of the food boxes or PPE or just even some moral support.

Some carers, who had been providing care for someone who lived at a distance, were struggling with not being able to visit the person they care for.

I didn’t expect to be far away and unable to be there. As he is vulnerable it’s best I don’t travel 136 miles to help, but it’s killing me emotionally.

Carers biggest concern was what would happen if they themselves become ill. The overwhelming majority (87%) of carers agreed or strongly agreed with the statement “I am worried about what will happen to the people I care for if I have to self-isolate or become ill”.

I’m so scared that either I or the care worker will get this virus and then what? No back up plan and no support.

And it stands my mother lives with me. If I fall ill due to picking up this virus in my job role – I have nowhere else I can go to isolate for two to three weeks away from her. Essentially, if I catch it and pass onto her; she’ll likely succumb to the infection. Feel I’m placed in a horrible situation.

Nevertheless, people were creating support networks with many carers finding help from the local community and friends and family highlighting that across the UK people that have wanted to provide support to vulnerable people and those caring for them. 57% of carers said they were able to keep in touch with family and friends.
Bereavement

A small number of carers shared that the person they care for had recently died, either as a result of the coronavirus outbreak or as a result of a pre-existing condition. For these carers the crisis had affected their ability to provide end of life care or the subsequent practical arrangements such as funerals. We would expect this to increase as the pandemic progresses and for this to have longer term mental health implications as people are unable to process grief in the usual way.

My mum died at the end of March. She tested positive for coronavirus. She had been not well and was taken to A&E where she was admitted and tested. She lasted four days and we could not see her or phone her.

My husband was rushed into hospital with pneumonia, treated and tested positive for flu. We were allowed to be with him for eight days in isolation and then he was taken to a local care home. No visiting allowed and five days later he passed away. We are now holding his funeral with only close family able to attend because of the lock down.
Practical issues faced by carers

The challenges posed by coronavirus mean that even more strain is being placed on the lives of carers who were already going above and beyond to provide care for family and friends. Respondents shared four common practical challenges that were causing significant concerns.

Contingency planning

Government guidance for carers advises that they develop contingency plans in case they are unable to provide their usual care, due to becoming ill or having to self-isolate. Contingency planning is something that Carers UK has always recommended that carers do with the support of family, friends, local services, local government, and health services, where appropriate. We have also asked local authorities, health and social care trusts and health bodies to be pro-active.

Many carers responding to the survey reported feeling unable to put contingency plans in place, as they do not have family members or friends who can take on their caring responsibilities. For some, it is the complexity of care which is the barrier, whilst for others, they simply do not have family close by, or who are able to provide support.

Only one in five respondents (21%) agreed or strongly agreed with the statement “I am confident that I have a contingency plan in place in case of emergency”. This was lower in Wales where only 16% agreed/strongly agreed, but higher in NI (21%) and Scotland (26%).

Comments indicate that even those who have a contingency plan in place before the crisis are fearful that stretched social services/work would be able to fill in any gaps in care their illness or self-isolation would cause.

I’m so scared that either I or the person I care for will get this virus and then what? No back up plan and no support.

There is only me that can look after my family member. I don’t have a contingency.

I have a contingency plan in normal circumstances but I worry that there won’t be the right level of support if I were to become ill now. I have just read that my local social services need to prioritise and will leave my Dad at risk.

Personal Protective Equipment (PPE)

A key theme emerging is the significant concern among carers about care workers coming into the house without adequate PPE and spreading infection. This has led some carers to reduce the support they receive from care workers, placing yet more strain on themselves. In some cases, carers have reported that services have been withdrawn because of care workers not having adequate PPE. Carers are also concerned about their own inability to access PPE for themselves and the impact catching coronavirus would have on their ability to care.

The PPE provided to the care workers is a flimsy plastic apron and gloves. It is protecting neither the care workers nor my wife. It is probably one of the biggest worries I have. I feel like we are sitting ducks.

My Mum’s care workers did not have the correct PPE to attend my Mum with a raised temperature so they withdrew care.
Accessing food and other supplies

Whilst many supermarkets and suppliers have introduced measures to help NHS staff, social care staff and vulnerable people with their shopping, many carers reported that they are facing challenges accessing the food, medication or other supplies that they need.

It is particularly concerning that 64% of carers are having some or significant problems accessing the basic necessity of food. It is also concerning that 60% of carers were having some or significant problems accessing cleaning or hygiene products, given that good hygiene practices are essential in reducing the spread of coronavirus.

I’ve got a child who only eats specific items (and that is part of their disability) he can’t swallow tablets and gets them disguised in the only yoghurt he will eat... yet I can only get three of any one item.

Sometimes I haven’t been able to get sanitary pads, soap, hand gel and antibacterial spray that I needed for the person I care for.

Are you able to access the supplies and support you need for you and the person/people you care for?

<table>
<thead>
<tr>
<th></th>
<th>I am able to access this without any problems</th>
<th>I am having some problems accessing this</th>
<th>I am having significant problems accessing this</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food</td>
<td>35%</td>
<td>46%</td>
<td>18%</td>
</tr>
<tr>
<td>Medication</td>
<td>56%</td>
<td>33%</td>
<td>5%</td>
</tr>
<tr>
<td>Money from your bank account</td>
<td>67%</td>
<td>16%</td>
<td>6%</td>
</tr>
<tr>
<td>Cleaning/hygiene products</td>
<td>36%</td>
<td>44%</td>
<td>16%</td>
</tr>
<tr>
<td>Items for personal care of the person I care for (e.g. incontinence products/skin care products)</td>
<td>37%</td>
<td>27%</td>
<td>9%</td>
</tr>
<tr>
<td>Technology to keep in touch with the person I care for</td>
<td>53%</td>
<td>9%</td>
<td>4%</td>
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Survey responses indicate that there is widespread confusion among carers about Government guidance on shielding and social distancing, and how it applies to them and the people they care for. Even for those who do understand the guidance, there is a significant challenge in following it.

How am I expected to work from home and provide care for my disabled son and mum who lives down the road? I work for the NHS there have been no help or support provided by my employer to help me manage...I have now been informed that I will be redeployed to the frontline and risk infecting my at risk son who has serious underlying health care needs. I’m at breaking point.

The advice being given regarding self-isolating / shielding is confusing. Government are claiming things are happening to support more vulnerable people when clearly they are not happening. I’m very reluctant to turn to GPs as they are being overwhelmed with queries. So many people are being let down.

It is hard to distance as care workers and health professionals come in and out of the home. I have had to go out more since lock down than I normally would to queue for food, get medication and help own family isolating.
The support carers need

With many carers under a significant amount of pressure and worried about the future, the restoration and reinstatement of care and support services at the earliest opportunity must be a priority.

In addition to this, carers were asked what support would help them through the coronavirus outbreak. Carers were given a number of different options and were able to add their own suggestions. The following were the top five:

1. More frequent testing of people with coronavirus symptoms or who have immunity
2. More help with contingency planning in case they aren’t able to provide care
3. Clear and specific guidance from the Government for unpaid carers
4. Better personal protective equipment (PPE) for unpaid carers and/or the social care workforce
5. A rise in Carer’s Allowance

61% of carers said that more frequent testing would help them. Comments indicated that carers were concerned about the lack of testing, or access to testing equipment, as they were worried about passing infection on to the person they care for themselves, or that paid care workers would do so themselves during visits. This was also a particular concern for people who identified as ‘key workers’, and who were still going into work as normal.

56% of respondents said that clearer and specific guidance from Government for carers would help them. Carers are anxious about how to ensure they are providing care as safely as possible currently, and also what will happen in the future.

I would like clear and precise information about disabled person I care for having to get medical treatment for CV 19 and carer/patient not being allowed to stay with them. Autistic and severe learning disabled will be incredibly anxious and unable to cope.

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.

51% of carers said that better PPE for unpaid carers or the social care workforce would help support them at this time.

I think as unpaid carers we should be given some level of support in the provision of PPE – although I appreciate that there is currently a shortage – what would happen if, as an unpaid carer, I was taken ill?

59% of carers wanted more help with contingency planning in case they were unable to provide care.

Better information as to how I would deal with situation if I was taken ill – would I have to move out of the house? Where would I live? Who would look after my husband? ...I feel I am racing down a river with no paddles!
43% of carers said that a rise in the level/rate of Carer’s Allowance would help to support them at this time.

‘I think it’s unfair that I am not offered an increased Carer’s Allowance yet paid employees, self employed and businesses are helped. My life is harder now but I get no extra help.’

‘I already felt under appreciated as an unpaid carer and even more so now. The amount of Carer’s Allowance is just not good enough, I think we deserve so much more. I care 24/7 and have no plan to stop yet us carers are being forgotten yet again.’

Other areas that carers said would help them included:

- Increased financial support
- More support from Local Authorities (Health and Social Care Trusts in Northern Ireland) and local services
- More support from their GP and community pharmacies
- Someone to talk to
- More support in the community e.g. from local volunteers
- More advice and information around benefits entitlements
- Paid leave or flexibility from their employer to support the person they care for
- Identification in order to be able to prove that they are a carer.

‘[I have had] no meaningful support from social care. Son considered highly complex but only one vague phone call from someone I don’t know who gave me a phone number to ring if needed. No checking in to see how we are. I’m pretty stoical but feel abandoned by them and alarmed that they haven’t made an effort to check he’s okay.’

‘I would like more support and understanding from my employer. One of their communications accepted that those with children at home could work reduced hours at times to suit them – basically do the best they could. No such flexibility for carers – not even a mention.’

‘Employed carers and NHS staff have ID cards but we as non-paid carers don’t have any ID. I think this should be addressed as if I am stopped by police for being out I have no proof I am a carer on my way to or home... and I am not allowed to use the special hours for shopping. All I have is my Carer’s Allowance letter and national insurance card.’
Carers supporting each other and their local communities

Despite facing huge pressures and increased levels of care, some respondents shared stories of how they are supporting other carers and their local communities during the crisis. However, many also responded that they were completely overwhelmed and were unable to even consider doing this due to the need to concentrate on their own caring role.

I have set up WhatsApp group for local parent carers and another WhatsApp group for carers juggling care and work commitments. The groups provide vital peer support and an opportunity to check in on people who are likely to be feeling vulnerable right now.

I have been picking extra bits of shopping for shielding neighbours and cut their small front lawns to cheer them up. I’ve been making an extra effort to be friendly and chatty from a distance as I know the difference a small conversation can have to someone who’s lonely.

My family are 1st line contacts for approx. 30 households in our village and we are helping one self-isolating household with their food and medication needs on a twice weekly basis. We are also baking and delivering home made cakes and biscuits once a week within our village. All monies are going to local food bank to help them feed those in most need.

I’m part of a local volunteer team, fetch others prescriptions when I go, shop for two other vulnerable households and wash the paid carers’ cars while they visit to say thank you.
Conclusion and recommendations

Caring can be challenging at times, and impact on all aspects of life from health and wellbeing, to finances. Carers are now under even more pressure as a result of the coronavirus outbreak, providing more care than they were beforehand, as well as managing concerns about how to keep themselves, and the people they care for, safe and as well as possible.

Carers UK’s response to the crisis: Providing advice to carers, raising carers’ concerns, working with Government, local government and the NHS.

Since the outbreak, Carers UK has placed a high value on information and advice to carers, providing carers with clear information about the changes, new rules and how to manage.

Carers UK, Carers Wales, Carers Scotland and Carers Northern Ireland quickly raised issues with our Governments on behalf of carers, highlighting the concerns carers have been raising with us through our help line, online forum and our communication channels. We are continuing to work hard to ensure that carers voices are heard by the nation Governments, and that they provide support, advice and guidance for carers. We are pleased that all four nation Governments have developed some mechanisms to support carers, and have worked with them on this.

We will be using this research to campaign for more support for carers from both national and local Government and the NHS, including in the devolved nations.

Summary of short term recommendations

The UK and Nation Governments, key public bodies and others must, as a matter of urgent priority:

- Increase awareness and recognition of the role of unpaid carers.
- Ensure that the impact of reduced services on carers and their families are closely monitored in terms of carers’ health and well-being, ability to care, in order to avoid burn-out. Support must be reinstated and restored as soon as possible.
- Raise the level of Carer’s Allowance.
- Ensure testing is increased and delivered quickly, including testing for unpaid carers.
- Ensure that local authorities have sufficient resources to carry out contingency planning with carers. Local government and local partners need to find a way to support carers in delivering this. This must also go hand in hand with effective risk mapping.
- Continue to place a high priority on guidance, information and advice for carers, that adapts to their needs.
- Increase the delivery of PPE to social care and ensure unpaid carers are also included where they are caring for those who are most vulnerable.
- Ensure systems are in place for carers to provide access to food and reduce the challenges carers face in getting food.
- Ensure that if this crisis continues, those unable to work because of caring are continued to be supported to retain their jobs for as long as possible, as well as ongoing flexibility for carers to continue to juggle work and care.
- Increase investment in mental health and wellbeing support for carers.
- Continue to ensure that there are creative ways of supporting carers, through technology, through local communities and with the continuation of key support.
- Ensure that all national guidance aimed at service delivery that suggests carers take on more responsibilities also consider the risks to carers.
- Ensure that there is sufficient investment in end of life care, death and bereavement services.

Longer term at the end of this crisis the UK and Nation Governments must:

- Further increase recognition of the role of unpaid carers and support, including financial support.
- Improve carers’ rights to take time off to juggle work and care.
- Make social care a priority for funding to ensure that it delivers vital support to people who need it and that the NHS systematically identifies and supports carers.
- Ensure that the needs of carers and the people they care for are fully considered in any recovery plans that follow.
Short term recommendations

The UK and Nation Governments, key public bodies and others must, as a matter of urgent priority:

Increase awareness and recognition of the role of unpaid carers during the coronavirus outbreak.

Carers have been and continue to provide vital and essential care supporting older, disabled and chronically ill people, protecting some of the most vulnerable people in our society during the coronavirus outbreak. Despite this, carers do not feel they have had the recognition and awareness of what they do and how their lives have been affected during this crisis. The UK and nation Governments should promote awareness of the important role of unpaid carers, more regularly highlighting their role in key communications and briefings.

Ensure that the impact of reduced services on carers and their families are closely monitored in terms of carers’ health and wellbeing and ability to care to avoid burn-out. Support must be reinstated and restored as soon as possible.

Carers are taking on more hours of care as a result of the reduction in local care and support services. This has come at a time when many support services and social care packages had already been reduced. This has left many carers concerned they will burnout and an anxiety that services will not be restored. All Governments across the UK need to monitor the overall impact of social care needs and social care legislation closely, regardless of whether any legislative easements are applied. Services need to be reinstated and restored for carers and their families as soon as possible. Should those bodies not have sufficient resources to do so, Governments must provide this funding.

Raise the level of Carer’s Allowance11.

The vast majority of carers have seen an increase in the amount they are spending, from the availability of low cost food options, having to pay for equipment or technology to support the person they are caring for, or the increased cost of being at home for longer. While there have been above inflation increases in other benefits to recognise financial challenges, there has not been a rise in the main benefit for those caring 35 hours a week or more, Carer’s Allowance. This is still the lowest benefit of its kind at just £67.25 a week (2020/21 rates).

We welcome the change all Governments have made to the eligibility criteria for Carer’s Allowance, increasing the length of breaks in care if the person being cared for is impacted by coronavirus so that Carer’s Allowance can continue to be claimed. We also welcomed the emphasis from the UK Government (and governments in Scotland and Northern Ireland) that emotional support can be included in the 35 hours of care provided a week. The UK Government (and nation Governments in Scotland and Northern Ireland) should recognise not only the additional costs that carers are facing but also the additional care they are providing and raise the level of Carer’s Allowance. The UK Government should raise the level of associated carer premia.12

“Each government in the UK should consider establishing other financial supports which could be provided to deliver additional support to carers who are facing the greatest hardship through local and national support funds.”

Ensure testing is increased and delivered quickly, including unpaid carers.

Carers’ most popular request was for increased testing reflecting their concern that either paid care staff could pass coronavirus on to themselves or the person they are caring for, or carers themselves could pass on the virus. Announcements from Governments across the UK to increase testing for paid care staff coming into the home and for staff working in care homes are welcome to reduce risk, reduce anxiety for families and to help them return to work to provide the vital support that so many people rely on. It is also important that all paid care workers and staff in care homes are regularly tested even if they are asymptomatic or self-isolating to ensure they do not pass the coronavirus on to the people they are caring for. Carers also want to be considered a priority for testing when it is rolled out more widely, to ensure they are not putting the person they are caring for at risk.

11 In Scotland, carers in receipt of Carer’s Allowance are paid an additional payment twice per year of a Carer’s Allowance Supplement. This was part of a commitment to raise Carer’s Allowance to the level of Jobseeker’s Allowance
12 The UK Government has powers over carers benefits in England and Wales but devolved administrations in Scotland and Northern Ireland are responsible for decisions over Carer’s Allowance in their respective nations. The UK Government retains powers over income replacement benefits and carer premia in Income Support, Universal Credit and Pension Credit across the UK.
Ensure that local authorities have sufficient resources to carry out contingency planning with carers. Local government and local partners need to find a way to support carers in delivering this. This must also go hand in hand with effective risk mapping.

Carers are worried about what will happen if they are no longer able to care, or they fall ill. Many older carers were particularly worried about their disabled adult sons’ and daughters’ short-term needs should this happen. The majority of carers wanted more support to help them create contingency plans. Nation Governments need to ensure that local government (Health and Social Care Trusts in NI and Health and Social Care Partnerships in Scotland) have enough funding to deliver this. Local government and local organisations need to provide carers with advice and information, and support carers to have a contingency plan that meets their needs and they feel they can rely on. All Governments in the UK need to ensure that there is sufficient funding to put in any additional care needed. Locally, local authorities and health bodies need to ensure that carers’ high level of input is clear and evidenced in risk mapping.

Increase the delivery of PPE to social care workers and ensure unpaid carers are also included where they are caring for those who are most vulnerable.

Carers joint fourth concern is lack of PPE for themselves, and many of their comments relate to the lack of PPE for social care workers coming into their own home. They are concerned that the lack of PPE for paid care staff has the potential to spread coronavirus amongst high risk people. Announcements which have promised an increase in PPE are welcome, but only if this is adequate and delivered quickly. Carers looking after multiple people, caring at a distance, who have to leave the home and those caring for someone who is shielded or otherwise at very high risk also need to be prioritised for receiving PPE. There must be local mechanisms in place to deliver this.

Ensure systems are in place for carers to provide access to food and reduce the challenges that carers face in getting food.

A significant number of carers are having serious problems accessing food, notably including difficulties with online delivery slots, access to volunteer support, lack of time to queue and shop, and not being able to shop with the person they care for. All Governments across the UK should work with supermarkets and voluntary and community organisations, such as Carers UK, to help identify those most at risk of not being able to access food and prioritise them for home deliveries and support.

Each Government needs to provide clear information about alternative sources of support for people in vulnerable circumstances that cannot access supermarkets or home delivery because of demand. Local authorities and other partnerships are putting in place local support systems and working with community groups to help. Carers need more information about how to access this support and each nation, where it has not done so already, should ensure that national information and helplines enable carers to find out about this assistance.

Carers have also raised the issue of identification to prove that they are able to make essential journeys or access priority shopping times, skipping queues if necessary.

Carers’ ID must be a priority for all local areas, clearly encouraged by each nation’s Government, to ensure that this is provided for carers.

13 Please note the provision, funding and delivery of carer support is delivered by different institutions in the devolved nations
Ensure that if this crisis continues, those unable to work because of caring are continued to be supported to retain their jobs for as long as possible, as well as on-going flexibility for carers to continue to juggle work and care.

The coronavirus outbreak has the potential to have long running ramifications for many people, including working carers, who will have to balance local services returning and caring for a vulnerable person. Governments across the UK should ensure that any easement of the restrictions on work and social distancing do not negatively impact on working carers. If any of these measures are continued, they are more likely to affect carers. The UK Government must include measures to support employers to continue flexibility for carers with mechanisms to ensure that carers’ ability to retain their jobs and work is not affected.

Increase investment in mental health and wellbeing support for carers.

Caring for someone can be challenging and isolating, with a reduction in local care and support services and with many carers taking on more care during the coronavirus outbreak. It has also added additional pressure and feelings of being responsible for keeping the person they care for safe. Increased funding for mental health and wellbeing services should explicitly include carers who are more likely to experience anxiety and mental health conditions – which is needed from Governments and local commissioning bodies. All governments should also ensure carers continue to get support from national programmes such as NHS Volunteers in England and other local and national volunteer programmes, including ‘listening ear’ emotional support services, so they can stay connected to their communities.

Continue to ensure that there are creative ways of supporting carers, through technology, through local communities and with the continuation of key support.

Services have tried to continue support for disabled and older people and carers in creative ways. Carers UK has introduced online wellbeing chats with carers, people have been given technology to communicate, care home residents have used online communication for the first time, fitness sessions are being run by local carers organisations, carers services have increased befriending support and telephone contact, new online activities have been developed for people with learning disabilities, etc. Whilst there are services that cannot be delivered through technology, many services have found new ways of delivering support. The continuation of this creative approach should be encouraged and supported financially whilst also investing in longstanding and valued support services.

Increase investment in end of life care, death and bereavement services.

Coping with the end of a family member or friend’s life is challenging at all times. When services are stretched, family and close friends caring for someone at the end of life at home need extra support, as well as key guidance and information on what to expect. The coronavirus outbreak means many family members are unable to spend the last hours and days with their loved one in hospital, supported living or a care home, adding extra pressure and strain at a difficult time. We welcomed the UK Government’s commitment to ensure people have a right to say goodbye to their loved ones and every nation Government should commit to the same principle. As long as this crisis continues, Governments and NHS bodies have a particular role to play to ensure that there is sufficient investment, care, guidance and support for carers.
Caring behind closed doors in Scotland

Carers UK’s survey into the experiences of over 890 Scottish current and former carers has found that the coronavirus crisis is having a profound impact on carers’ lives. Not only are many carers in Scotland providing more care than before, they are suffering financially and are worried about the future.

Before the crisis, carers were already providing substantial hours of care. This has increased further, with 78% of carers providing more care due to the coronavirus outbreak. This has resulted in carers on average providing 10 additional hours of care a week. Shockingly, nearly 4 in 10 (39%) of carers are providing more care as a result of local services reducing or closing.

For many carers, the type of care they are providing has also changed due to a change in circumstances, services, or the needs of the person they care for. 72% of all carers are providing more help with emotional support, motivation or keeping an eye/checking in on the person they care for.

Many carers already faced very difficult financial situations due to their caring responsibilities. The coronavirus outbreak is likely to have a significant impact on finances, 38% of carers agreed or strongly agreed with the statement “I am worried about my financial situation”. Carers are also seeing an increase in costs, with 79% of carers spending more money at the moment. 70% are spending more on food, and 53% are spending more on household bills.

Caring for someone can be challenging and many previous research reports have evidenced the impact on carers physical and mental health. Alongside the usual stresses, the coronavirus outbreak, has added additional pressure and feeling of being responsible for keeping the person they care for safe. The majority (53%) of carers agreed/strongly agreed with the statement “I feel overwhelmed and I am worried that I’m going to burnout in the coming weeks”.

Carers biggest concern was what would happen if they themselves become ill. The overwhelming majority, 87%, of carers agreed/strongly agreed with the statement “I am worried about what will happen to the people I care for if I have to self-isolate or become ill”.

In addition to the UK wide recommendations, Carers Scotland further recommends that the Scottish Government:

- Provides a Carer Wellbeing Fund equivalent to the Student Fund of £5M directly to carers centres and young carers services to enable those centres to help carers facing financial hardship as a consequence of COVID-19.

14 For example, Carers UK (2018) State of Caring 2018
Caring behind closed doors in Wales

Carers UK’s survey into the experiences of over 270 Welsh current and former carers has found that the coronavirus crisis is having a profound impact on carers’ lives. Not only are many carers in Wales providing more care than before, they are suffering financially and are worried about the future.

Before the crisis, carers were already providing substantial hours of care. This has increased further, with 79% of carers now providing more care due to the coronavirus outbreak. This has resulted in carers on average providing 11 additional hours of care a week. Shockingly, over a third (36%) of carers are providing more care as a result of local services reducing or closing.

For many carers, the type of care they are providing has also changed due to a change in circumstances, services, or the needs of the person they care for. 73% of all carers are providing more help with emotional support, motivation, or keeping an eye/checking in on the person they care for.

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Caring for someone can be challenging and many previous research reports have evidenced the impact on carers physical and mental health15. Alongside the usual stresses, the coronavirus outbreak, has added additional pressure and feeling of being responsible for keeping the person they care for safe. The majority (57%) of carers agreed/strongly agreed with the statement “I feel overwhelmed and I am worried that I’m going to burnout in the coming weeks”.

Carers biggest concern was what would happen if they themselves become ill. The overwhelming majority, 85%, of carers agreed/strongly agreed with the statement “I am worried about what will happen to the people I care for if I have to self-isolate or become ill”.

In addition to the UK wide recommendations, Carers Wales further recommends that the Welsh Government:

- Publishes guidance to local authorities outlining timescales and process by which they should revert to ‘business as usual’ regarding the carers rights laid out in the Social Services and Wellbeing Act.
- Makes assurances that the rights of carers in Wales are strengthened, and not weakened, after the resolution of the changes made under the emergency laws enacted under COVID-19 legislation.

15 For example, Carers UK (2018) State of Caring 2018
Caring behind closed doors in Northern Ireland

Carers UK’s survey into the experiences of over 420 carers in Northern Ireland has found that the coronavirus crisis is having a profound impact on carers’ lives. Not only are many carers in Northern Ireland providing more care than before, they are suffering financially and are worried about the future.

Before the crisis, carers were already providing substantial hours of care. This has increased further, with 78% of carers providing more care due to the coronavirus outbreak. This has resulted in carers on average providing 10 additional hours of care a week. Shockingly, Nearly half (45%) of carers are providing more care as a result of local services reducing or closing.

For many carers, the type of care they are providing has also changed due to a change in circumstances, services or the needs of the person they care for. 70% of all carers are providing more help with emotional support, motivation or keeping an eye/checking in on the person they care for.

Many carers already faced very difficult financial situations due to their caring responsibilities. The coronavirus outbreak is likely to have a significant impact on finances, 33% of carers agreed or strongly agreed with the statement “I am worried about my financial situation”. Carers are also seeing an increase in costs, with 77% of carers spending more money at the moment. 71% are spending more on food and 51% are spending more on household bills.

Caring for someone can be challenging and many previous research reports have evidenced the impact on carers physical and mental health. Alongside the usual stresses, the coronavirus outbreak, has added additional pressure and feeling of being responsible for keeping the person they care for safe. The majority (64%) of carers agreed/strongly agreed with the statement – “I feel overwhelmed and I am worried that I’m going to burnout in the coming weeks”.

Carers biggest concern was what would happen if they themselves become ill. The overwhelming majority, 87%, of carers agreed/strongly agreed with the statement “I am worried about what will happen to the people I care for if I have to self-isolate or become ill”.

In addition to the UK wide recommendations, Carers Northern Ireland further recommends that the Northern Ireland Executive:

- Commit to longer-term investment in social care and carer support
- Bring forward stronger legislation to support carers across Northern Ireland acknowledging the vital role they play in our health and social care system
- Work across government departments to ensure carers are supported in all aspects of their lives

16 For example Carers UK (2018) State of Caring 2018
Caring behind closed doors

Forgotten families in the coronavirus outbreak

April 2020

If you are a carer looking for information and guidance, please visit the help and advice section of our website carersuk.org/help-and-advice or get in touch with our advice team by emailing advice@carersuk.org or phoning our Helpline on 0808 808 7777 Monday – Friday, 9am – 6pm.

Across the UK today 6.5 million people are carers – supporting a loved one who is older, disabled or seriously ill.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person's health, finances and relationships.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

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