



you care for them, we care for you

The experiences of unpaid carers during the Covid-19 pandemic

*March 2020
to March 2022*

Appendix 1: Carers' Voices



Support & services available to carers before the pandemic

Describing support before the pandemic

Carers say:

"The only support that we ever did have was from Occupational Health when my husband first left hospital."

"Before the pandemic, we just muddled through together, doing the cooking and the shopping, looking after each other."

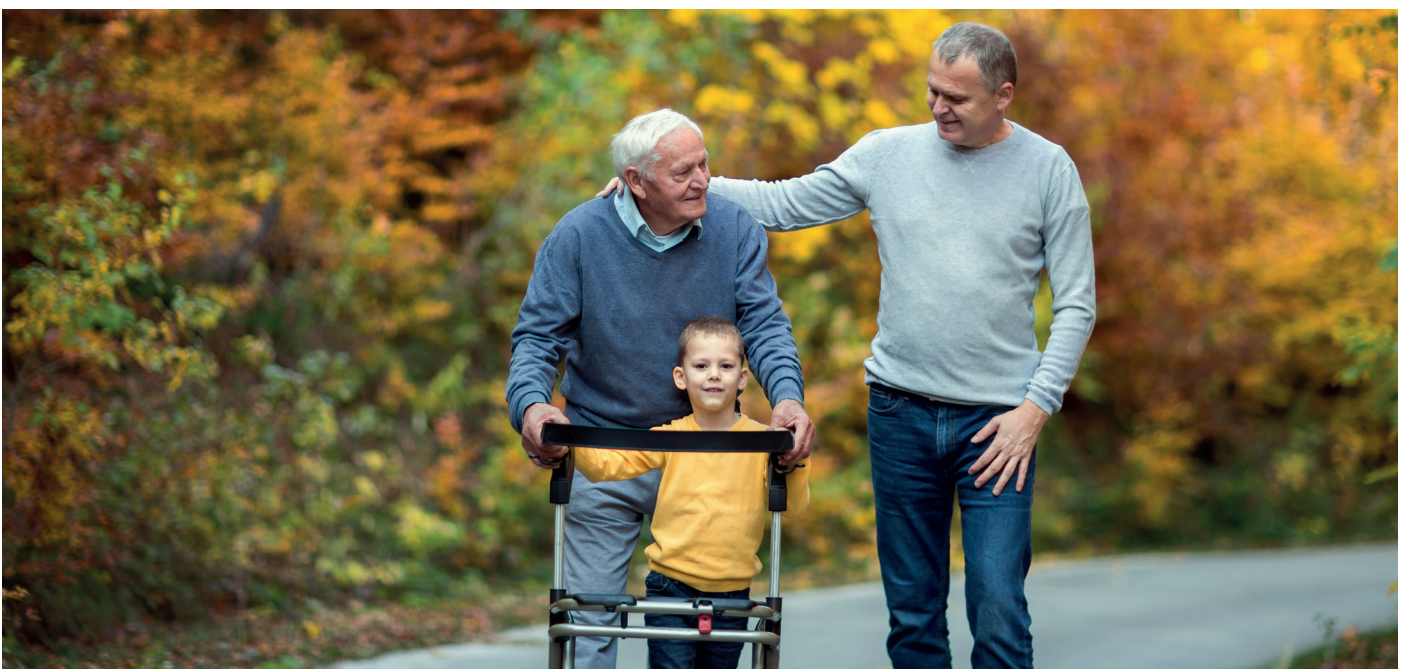
"Before the pandemic, family and friends did of course come to visit, or drop in for a coffee, but that was more about socialising or giving me moral support rather than day to day care."

"The support I get [to help with the cared for person] from my family, my adult son, is minimal."

"I did have a couple of meetings with someone about Carers' Resource and the kinds of things I could get help with, someone from the hospital discharge team that put us in touch with them. But there wasn't anything then that I particularly thought I really needed before, and then of course we couldn't join because of lockdown."

CR staff/volunteers say:

"While the services and support existed, even before the pandemic the actual level of service was patchy across different areas. In theory the support was there, but not easy to access."



Why don't unpaid carers access support? The barriers they face

Barrier: Identifying as an unpaid carer

Carers say:

"I really don't like the term. I give support, family support, to my brother who has a learning difficulty. I don't call myself his carer."

"I have been supporting my Mum and Dad for more than 10 years now, but I am not really their carer. They are just quite elderly, and both have a few things wrong with them. But the main reason I support them is with their appointments is because of a language barrier."

"I was a carer for eight years for my neighbour, and didn't really think of myself as an unpaid carer for a long time. It was something that gradually built up over time. At first, it was a few errands here and there. Eventually, it was taking him to appointments, and getting more involved."

"We went along to a local Stroke Group, but my husband wasn't particularly keen. My husband really wanted more of a sense of normalcy, we both did really, rather than being defined by the stroke, and by me as his carer. I'm his wife."

"For my dad, he only really wanted me to help out with the things he could no longer do. He would never have entertained a social worker or a care worker, even if that had been offered to him."

CR staff/volunteers say:

"Young carers in particular might not identify themselves as a carer. They just think 'this is my family situation', they don't know that they are a young carer. However, once they have been assessed, they usually are really happy to buy in to the support they are offered."

"[We] work with people whose children have autism or other conditions, but they would just say they are being a parent."

"Guilt is another barrier. The carer might feel that they shouldn't need support while they care for their individual, for example they might feel guilty at the idea of their cared for going in to a care home while they go on holiday for a break."

"Language and cultural differences could be barriers, people might think it is not appropriate to ask for help. People might think they ought to keep the care in the family."

"Cultural barriers certainly exist, some South Asian communities are less likely to recognise the term 'carer' in their family context."

Why don't unpaid carers access support? The barriers they face

Barrier: Supply and demand

Carers say:

"We were assessed as entitled to a care package of 5 eight-hour days and 5 ten-hour nights, plus 42 nights respite. In reality this could not be accessed, as no facility was able to meet my daughter's complex needs."

"There just doesn't seem to be the capacity in social care, in the care you can get in the community, or in district nursing. There just isn't enough."

"We have had a lot of local community health services shut down and move to regional hubs. People might have to travel to Middlesbrough rather than Ripon or Northallerton."

"If like me you can't drive, the timing of appointments can make it hard. The appointment might be for 8am, so I have to factor in getting up early enough to make sure [the cared for] is ready and sorted, and then have quite a long travel time to get to the appointment."

"There was an after-school group she could have gone to, but it was really hard to get my daughter there."

CR staff/volunteers say:

"The difference in people's circumstances is almost a barrier to getting the right support; what is on offer just can't meet all of the complex demands. I think this is more pronounced for young carers than older carers. One young carer might be helping in a busy household to care for a sibling with autism, a second might have a highly physical carer role that they need respite from, and a third might be caring for their single parent with terminal cancer. All very different family contexts."

"People's circumstances are really diverse: there's the middle-aged mum who helps her daughter care for her disabled granddaughter, while her own mum, who has severe arthritis, lives with her; there's the woman who is supporting her sister with a child with autism while her brother-in-law is treated with cancer. There is no single solution or support package – or even agency – that can cover all circumstances."

"Where young people live can be a barrier that prevents them from accessing support. They might not be able to get to a support group, for example, particularly the little ones who are under 11 years old."

"Some unpaid carers wouldn't attend groups, or therapy sessions, or any of the support they could have taken up, because they didn't have anyone that they knew and trusted to sit with the cared for."

Why don't unpaid carers access support? The barriers they face

Barrier: Information about support and services

Carers say:

"We have never really known what is out there, we just muddled through together, and weren't sure where to ask when things were getting a little bit harder for us."

"It never occurred to us to ask for help, it's not a massive amount that we need, we didn't even know where to start."

CR staff/volunteers say:

"Lack of information is definitely a problem when thinking about young carers. It's really helpful if there is information shared in schools, about the situations young people might find themselves faced with, and about the help or groups that might be able to give them some support."

"Often a carer will ask for help when they, or the person they care for, can't cope any more. You'll go to see them and they'll say 'my head is spinning, I have a stack of paper and leaflets, you are the sixth person I have seen and I have all of these forms to fill in. I don't understand where to start'."

Barrier: Cost

CR staff/volunteers say:

"Respite Care is hard to access anyway. The financial assessment is very onerous; there is a needs assessment for the cared for, and an assessment of the carer, and then the financial situation is assessed. Adult Health and Social Care in North Yorkshire don't give much funding for respite care, and there are not many facilities."

"The private sector has tried to increase the capacity, but it is at a cost that not everyone can afford. Any cost associated with care is still putting people off."

"The costs for home care have gone up massively. Paid for care has gone up to £28 per hour on average, but I have heard of companies charging £34 per hour."



Why don't unpaid carers access support? The barriers they face

Other barriers

Carers say:

"I suppose I knew a time would come when it starts to get too much, but you just hope that it is a long way off. You just keep going, trying to have a normal life."

"I think us older people are frightened that if we ask for help, their husband or wife will end up in a home. It is like admitting that we can't cope, and then social services are going to get involved."

CR staff/volunteers say:

"The cared for person may well be eligible for overnight respite care or for regular day care, but absolutely do not want to accept it."

"Carers have to be ready to accept help and support. Sometimes only a crisis situation forces this to happen."

"[Worry about social services involvement] can trickle in to how they think about other organisations working in this space. People can be unwilling to accept support because there is an assumption that we are all social services."



Covid-19 pandemic & unpaid carers' experiences

Carers' experiences differed widely

Carers say:

"Social services told me that me and my daughters were coping fine, so they were closing my case. No consultation. They just headed for the hills."

"The at-home care we received through social services was, and still is, so good."

"Our social worker really stepped up. Social services personally delivered PPE to us."

New carers were particularly badly affected

Carers say:

"We were already waiting for an appointment for an assessment before Covid. I think it might have depended on whether you were at the beginning of assessment, or if you were already in the system and had got to the right people. We just didn't see anyone for months and months."

CR staff/volunteers say:

"If you had a social worker before the pandemic, you probably still had some access, but if you were waiting to be allocated a social worker, the priority was for high risk cases and the criteria definitely changed. Paid for care was similar."

Some carers saw little or no change

Carers say:

"Nothing really changed for us, in terms of the care that me and my sister give to my parents, we split the duties between us. We have never thought about getting any support from anyone. We have just carried on in the family. During the pandemic, nothing really changed in that regard. We carried on going to see them."

"We weren't really getting any support before the pandemic, so nothing changed in that respect. And we are pretty isolated anyway, as we couldn't go out that much even before."

Covid-19 pandemic & unpaid carers' experiences

Lockdown closed much support

Carers say:

"We were supposed to get paid for support of four hours a day, for three days a week. But the support from paid carers was interrupted, throughout 2020, when either they had suspected coronavirus, or they thought my daughter did, and said this meant they could not support her."

"Respite unit closed and day care facilities closed for a long period of time so no support whatsoever during this time."

"A venue that held a support group and play session closed down for good due to Covid. Myself and my mum shielded due to being CEV and therefore my mum couldn't come over or take us out at weekends. And playgroups closed down which meant I had no-one to talk to for support."

"I had only just managed to persuade my Mum to have someone sit with her a couple of times a week, as well as her going to a group one full day a week, when the pandemic started and everything else stopped."

"Groups locked down. No social opportunities. Or face to face appointments. Huge issue with our paid carers."

"The sitting service that we had only just got settled in with stopped completely in March 2020. Our routines just went out the window, and of course we weren't supposed to have friends or family coming into the house. We took all of that really seriously."



Covid-19 pandemic & unpaid carers' experiences

Experiences during the second and third waves



Carers say:

"We continue now to receive support from the people we used before, but this has been received in different forms, mainly on-line or over the phone. My husband is a patient at the National Hospital for Neurology in London and we have not been for any in-person appointment since the pandemic."

"I wasn't accessing support during the lockdown. When things opened up, I considered it but changed my mind when I realised they were all virtual groups."

"All of the support that I used stopped completely initially. The support group eventually started using Zoom at the end of 2020, but the point for me was to get out of the house with my husband and mix with other people."

"The care provider asked if I would stop using them due to staff shortages."

"We have been left to provide all the care, something we haven't had to do for 17 years; this had a big impact on me. We were very cautious for two years and our contact with anyone was very limited. My support networks were affected, I couldn't access the activities that help me look after myself such as swimming and tai chi."

"There are ongoing challenges managing my daughter's care, dealing with social services and continuing health care, just trying to get the support that is needed. I feel like they are sending me into an early grave."

Covid-19 pandemic & unpaid carers' experiences

The pandemic disproportionately impacted unpaid carers

Carers say:

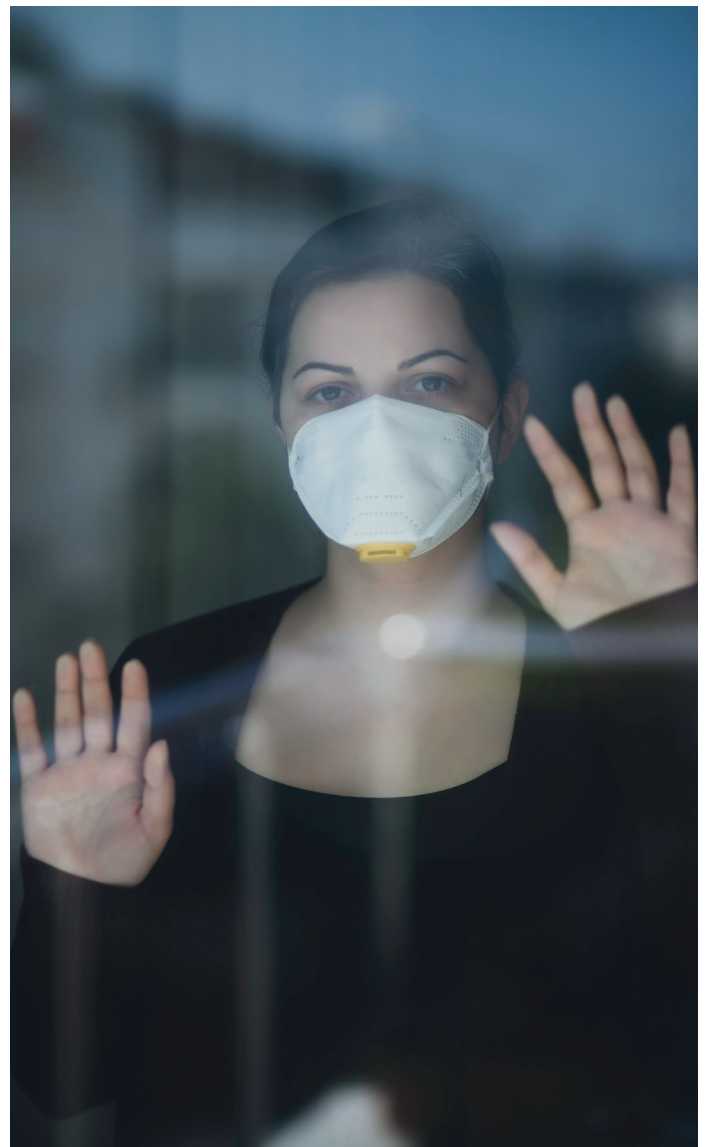
"Unpaid carers were forgotten before the pandemic, and while the last two years have been hard, the previous 21 years have been hard. As a carer we can't slow down, there is no time to stop regardless of the pandemic."

"Can you remember how difficult supermarket shopping was? The one person rule in supermarkets. What was I supposed to do with [the cared for person] if I couldn't take them into the store? I couldn't leave them at home safely, wasn't allowed to get anyone to sit with them. Should I lock them in the car and race around, grabbing what I could?"

CR staff/volunteers say:

"Carers who look after people with autism or mental health issues have really been overlooked. For people with autism or mental health conditions, routine is often a vital part of helping them to function and to feel safe. A lot of carers felt very exposed and often vulnerable themselves."

"We all have heard how people were horribly affected. One example sums the whole horror: the parent carer of a child whose mum was diagnosed with terminal cancer at the beginning of the first lockdown. The family could not go and see mum in hospital, the rules were very strict at the hospice, and at that time there were direct-to-crematorium funerals in Bradford district. The family could not see mum in the final months, couldn't say goodbye at the end, and it devastated them. But for this woman, her mum had been a great support to her as a parent carer, so she has lost her mum and the only respite support that she has ever had."



Covid-19 pandemic & unpaid carers' experiences

Caring responsibilities made it hard to stick to Covid-19 restrictions

Carers say:

"Shielding and self-isolating was impossible when reliant on care staff coming into the house."

"I care for my husband, and for my father who still lives in his own home but is elderly. In the tier restrictions, I would get my husband up, showered and dressed, breakfast together and then go over to my Dad's for the morning. I carried on doing that, even when we were in lockdown because who else is going to do it?"

"Our son is autistic, and he really needs to spend a lot of time outdoors, he needs to be able to run, that's how he copes. It's how we cope. In the first lockdown, we were so worried about fines. It was just another layer of stress for us all."

Lack of information and advice for carers

Carers say:

"The shielding information was diabolical for those using a tracheostomy tube, and there still is not a lot of information. I had a lot of PPE supplied, but most of it was not at all what we needed. I was sent numerous sets of goggles despite asking not to have any more sent."

"The only advice I got was from Carers' Resource about how to minimise Covid infection for myself and the person I care for. I also got assistance from them to get a food parcel delivered from the Council and someone to go shopping each week of the first lockdown as we were both shielding. We also had regular wellbeing calls also received from Carers' Resource."

"The council sent a letter, and it did list their services that you could get if you needed support. But it was just for the general public, I mean not specifically for people who are caring for someone."

CR staff/volunteers say:

"It was confusing for parent carers with a child with autism or similar conditions, as there was a real lack of clarity about which children could access school and education."

"I know it was a very difficult and shifting environment, but some of the guidance was confusing and not particularly well explained for people in caring roles. Carers would be asking whether they could go out with the person they cared for; or they wouldn't know whether they could visit the person they cared for."

Covid-19 pandemic & unpaid carers' experiences

The stakes felt higher for many carers

Carers say:

"I received minimal support before Covid, as the person I care for won't accept help from anyone but me. My few coping resources/outlets have gone and that's what causes the pressure as the intensity caused by Covid has increased the stress."

"We have been very cautious the whole time; we are very worried about Covid. I would say in the early months, I had real anxiety about Covid. My husband's stroke has changed our mentality, somehow, we feel very vulnerable and we have not wanted to take any chances."

"Everybody has been affected so differently. I think it depended on their circumstances, and their personality, too. If you have had Covid, if you have known someone who has been very ill, or who died from it, the restrictions are likely to have made more sense to you. If you did not have that experience, it has probably been more frustrating, the restrictions probably seemed too harsh and were therefore harder to follow. If you knew the person you care-for was already quite ill, then the threat of Covid really did feel like a major hazard."

"I don't feel I can go out and risk getting Covid and bringing it back to my husband. I'm afraid it could finish him off. He's already weak and ill."

The effect of the pandemic on cared-for people was significant

Carers say:

"My husband used to go to a day centre for a full day and another for the morning and lunch. He really liked going, he liked getting out of the house, he liked having time away from me, and he enjoyed the company of the other men who also went, they were more like friends. He could not understand why they stopped in March 2020, and used to get incredibly frustrated and cross. Now, I don't think he remembers that he used to go. He has certainly deteriorated because of the lack of stimulation, despite my best efforts."

"My husband has suffered from dementia for the last five years. But during the pandemic, he's had no stimulation and he has got progressively worse. And this has been exaggerated by two stays in hospital in 2021. The first was supposed to be a brief stay, but one of the other patients tested positive for Covid so my husband's stay was extended. Then he fell and broke a rib, so was back in hospital again, and we weren't allowed to visit much. That time he came out like a zombie."

Covid-19 pandemic & unpaid carers' experiences

Carers say:

"My daughter's autism has spiralled out of control due to the changes in the pandemic, which has led to a change in her behaviour. She benefits from socialisation but her access to this has reduced dramatically. She sometimes hits me, which has caused physical harm. My relationship with my daughter has changed and I became carer, teacher, secretary, admin, but not mummy."

"My Mum's depression has really increased. We had to try to stop her putting the news on the Asian channel, it was too much exposure. Sometimes she exhibits OCD like behaviour. She is asking questions constantly. In the weeks and months when I couldn't use support to get us a break from each other, it really affected my moods, and my ability to sleep."

"We took all that isolating and shielding very, very seriously. After nearly two years of not going out, my husband is housebound by his own anxiety, really. He is still afraid of going out, and is worried for me if I pop out to the shop. It is very limited now."

"The main change is that my husband's fitness level has deteriorated over the pandemic. We used to be able to go to the local small supermarket; he could manage to walk around that. At least he got a little exercise. But we have not gone into a store since the pandemic. Now, the scope for what we can do has reduced because his stamina is not what it was. We have tried to walk outside each day in the nice weather, but we cannot go very far."

"My son put on weight, he was eating more for comfort and out of boredom, I think. Even though he could go back to college and pick up at the gym there, he just doesn't want to. And the meltdown we all have if I try to push him to do more just isn't worth it at the moment. Not after the couple of years we've had."

"My husband is more frail. He can't walk so far, is just that little bit less independent in the home. He can't carry a tray anymore; he is just such a fall risk now, I have to do so much more for him."

"My daughter doesn't try to do as much for herself now. I don't know if it is her confidence, or her condition has got worse, or if she's just got used to me doing it all for her."

Covid-19 pandemic & unpaid carers' experiences

Unpaid carers had to do more - often affecting their own health

Carers say:

"My work load has increased since the pandemic started, because my husband has lost a lot of strength and stamina, and my parents have both become more frail, because they only sat at home for two years."

"My Dad is still living by himself, but his needs have increased and he was needing more help from me. I am exhausted now, after these two long years, and so we do have carers going in to do the personal hygiene care for him."

"My daughter started a new college in September 2020, but I had to drive her [because drivers/escorts were not available]. Often this would be after a waking night to meet the needs of my daughter if overnight care staff were sick or isolating. My physical health has been greatly affected, to the point that I am no longer able to drive or be an escort, and so my daughter is not currently attending college. This is causing a great deal of stress, as my daughter has complex needs."

"Both of our lives shrank so much. We both got depressed, and both of us are less fit and less healthy than we were two years ago. Much, much less fit."

"My Mum couldn't quite understand why she wasn't going to her group, why she couldn't go to see her friends, why her routine changed. It made her even more anxious, and quite bad tempered. My Mum was demanding more of my time, she didn't understand that I had to work at home. Working at home, dealing with my Mum's bad temper, it has left me depressed and having to take time off work."



Covid-19 pandemic & unpaid carers' experiences



CR staff/volunteers say:

"We've seen carers having to do the heavy lifting to help to toilet people, whereas that would have been done by carer workers who know about manual handling, or there might be two workers, or they'd use a hoist. Unpaid carers made do and managed, but may have hurt themselves in the process."

"The changes in support certainly had a large negative impact on the physical wellbeing and fitness of a lot of carers, as they were unable to get out to exercise and many were not getting respite care, so that also takes a physical toll."

"Caring for someone with mental health issues during the pandemic has frankly left the carer with mental health issues. People with autism too have been particularly hard hit by the withdrawal of support and the lack of structure and routine the cared for person typically requires."

"The simple fact of being a young carer can really have detrimental effect on their mental and emotional health. They tend not to be able to switch off their role as easily as older carers with more life experience might, they carry with them feelings of isolation, of anxiety, of never finishing the job. School is respite for them. A break from home life. The biggest impact for young carers is on their own mental health, they've lost their sense of the world as a safe space. Now they are much more anxious, self-harming, and even refusing to go to school."

Covid-19 pandemic & unpaid carers' experiences

Household finances were often affected

Carers say:

"There has been a huge financial impact. We are at home more, so the heating has had to be on more, especially if carers are doing a waking night and need the heating on overnight. The additional cost of running nebulisers and other household appliances because my daughter was not at school also mounted up. And with my daughter not being at school and cared for there, we have had to drive more, increasing fuel costs."

CR staff/volunteers say:

"We also need to remember that the cared for might not be able to work, but they may not be getting the benefit that they are entitled to. Low family finances and not accessing the right benefits is often an issue that impacts on the development of young carers."

Some carers found there were positive effects

Carers say:

"You felt that you could always access services on the phone during the pandemic. I found that the lockdown was very positive for my personal situation."

"I'm fortunate that my son moved in with me in October 2021 and this has helped me manage my stress levels."

CR staff/volunteers say:

"For some carers, being at home all the time was helpful in some ways. For example, a young carer might be caring for someone who has depression, and would be worrying about them the whole time they were at school."

"People did remarkable things during the pandemic. I know one woman who moved her mother 200 miles to move in with her so that they might save some money by running just one household."

"I work with older carers, who are retired, and so the experiences they have shared with me or that I have observed will not be the same for all unpaid carers: for example, the household finances of my carers was largely unaffected as they are pensioners, or it might have improved as they weren't having to pay for fuel or transport."

Covid-19 pandemic & unpaid carers' experiences

The pandemic often reduced carers' capacity to care

Carers say:

"I have to be 100% vigilant all of the time now; my husband is much more confused and disorientated, he wanders and doesn't really settle to any things that used to hold his attention before. I am on call 24 hours a day. I am utterly, utterly exhausted. I also know that I am less tolerant and less patient with my husband than I used to be. I hate that. I try my best, but always feel like I am at the end of my tether."

I think that there are lots of layers of effects, piling on top of each other. Some were issues before and the pandemic has concentrated them. Other issues are directly due to the way we have had to deal with the pandemic."

"I feel that it is very easy as a carer under stress experiencing frustration with services to be labelled as a 'mad woman' when I just needed help."



CR staff/volunteers say:

"The change in support and services definitely had a severe impact on many carers' ability to provide that care. It has been harrowing and isolating and incredibly lonely for a lot of people. Carers would often find themselves doing things to help their loved one that other people, such as care staff, would have routinely done. It has changed their relationships."

"There were some real safeguarding concerns for some young carers. The online or phone contact made you increasingly aware of what was going on in the home, or you might find that the carer couldn't speak freely."

"If they did not already have domiciliary care in place, it was difficult for people to access it and so that changed the nature of the care the carers provided."

Carers didn't get respite, so got no rest and were on alert all of the time. They didn't get enough exercise, so couldn't manage their stress. Stress induced some really vivid dreams, disturbing their sleep. That has got to have a lasting impact that we probably are not aware of yet."

Experiences of primary and secondary health care

Experiences varied widely

Carers say:

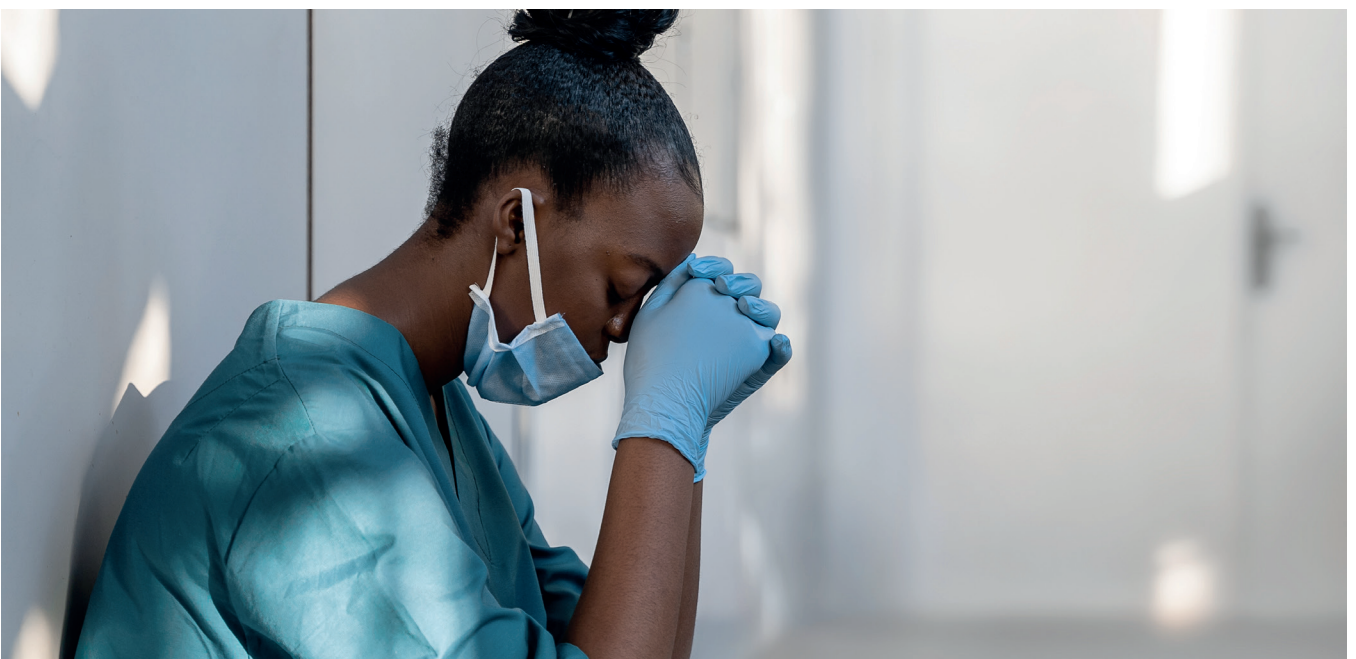
“The NHS response to Covid was excellent. From treating people in the early days when we didn’t have a clue what was really going on with the virus, to the vaccine roll-out.”

“We have had hospital appointments, and appointments at the GP face to face when it was necessary, and they’ve all been very smooth, the staff have been excellent. My wife had an appointment, I pushed her wheelchair from the car to the hospital doors, and someone then took her in for her appointment, they were very helpful.”

“Dealing with Covid, which my Mum did get while in her care home, I think the NHS generally have been fantastic.”

“My Granddaughter needed back surgery, as she had a herniated disc diagnosed in March 2021. It took a lot of effort to battle through the GP, to get past the consultant’s secretary, we had to be very, very assertive to get her operation. Not everyone has the ability, resilience or confidence to keep pushing for what they have been told they need.”

“The services in both primary and secondary care relating to Covid were absolutely excellent. I received excellent care from A&E, was seen very promptly and referred to the cardiology unit. The primary care wellbeing service that I have received support from has been excellent. And the GP has been really thorough; they were really compassionate and although they were really busy, they made me feel like a human being.”



Experiences of primary and secondary health care

GP services were badly affected



Carers say:

"We had difficulty from the very start of the pandemic getting through to my own and [the cared-for person's] GP practices for support. We eventually got support from nurses on the Goldline service, and they helped smooth the multiple admissions to hospital and the hospice."

"I couldn't see a doctor and the telephone consultation was a bit of a waste of time. It led to a three hour wait in A&E to get checked out - this was for me to be seen but of course I had to take my husband with me because we weren't supposed to be going into each other's homes."

*"GPs ran for the hills, closed their doors, didn't want to see patients."
"During the worst of the pandemic, some surgeries just seemed to go to ground. One practice had a note up, telling people to just go straight to A&E."*

"I understand that the priorities had to be around the pandemic, and people with Covid. But even more recently it has been so hard to get to see the GP."

"GP surgeries seem to be sticking with phone consultations, and I really don't understand why. A lot of people can have a satisfactory appointment, and some conditions can be dealt with over the phone, but it doesn't work for everyone."

"It takes an age to get hold of anyone, you've got to fight your way past the receptionist to ask for an actual face to face appointment. I know they have to keep the staff safe, I know they want to keep the patients safe, so I don't know what the answer is but it is hard work going for regular appointments and check-ups."

Experiences of primary and secondary health care

Hospital care experiences were more positive – but still problematic

Carers say:

“Hospitals seem to have returned more readily. Of course, there are restrictions in place, there is social distancing and masks and so on. But they seem to be better able to see patients.”

“I had to go to A&E and that was a nightmare because I had to leave my husband at home, and I didn’t think that was safe.”

“Mum needed a blood test for her liver function, but the hospital would only allow Mum in, without anyone to support her. She really was unhappy and quite scared about that.”

“My Dad needed some follow-up support, for a cancerous growth. He was supposed to have a check-up every three months, and they did not happen. Ongoing clinical support just wasn’t happening.”

“We had such an awful time when one or the other of us had to be in hospital. It was scary for the person in hospital, you didn’t feel like you were able to have as much care, and it was a nightmare for the person at home, trying to find out what was going on. You can’t blame them [NHS staff], they were lovely. But really busy, stressed themselves.”

“The actual hospital care was good in difficult stretched circumstances but it was difficult to find out what was going on, about discharge etc. as I could not visit or get to speak to someone on the ward by telephone sometimes.”

CR staff/volunteers say:

“You hear of examples of patients being discharged too early from hospital, either going home too early and putting an even bigger burden on their carers, or being discharged to care homes which meant that their carer and family could not visit them.”

“The pandemic highlighted that there is a lot of confusion about the role of unpaid carer, especially amongst medical staff. If you are not a paid carer, the role is not necessarily acknowledged. There was confusion whether the carer could be with their cared-for while they were being treated, even if they had intellectual disabilities.”

“There is still a lack of understanding about the unpaid carer role. We heard of hospital nurses asking carers to prove they were ‘registered carers’. It highlighted the informal status of being an unpaid carer.”

Experiences of primary and secondary health care

Covid-19 vaccine roll-out experiences

Carers say:

“The paid care staff got their vaccines before I did as my child’s unpaid carer. I was finally able to take a letter to my GP explaining I was a carer, but it felt that each local authority was providing different information.”

“It was frustrating to have to go twice for the first two - my husband’s appointment came through first, then mine, but of course we both have to go out for each appointment, as I can’t leave him at home safely.”

“We had six separate visits to get jabbed. I don’t think people realise how much organising is needed when you are a full-time carer and have no other support. It should have been possible to get my vaccine done during the same visit that my husband’s was done.”



Innovation, new access routes and technology

New or innovative support and services used by carers

Carers say:

“One change that really helped was being able to upload pictures to the GP to get a faster response. It was really helpful in a bit of a panicky situation. Uploading photos was a good way to get accurate information to the GP.”

“We used technology during the pandemic when my husband or my dad were hospitalised, or when I couldn’t visit my mum in the care home. The staff helped us use the technology to keep in touch, like WhatsApp messages, Skype calls, and Zoom. It helped but it wasn’t the same as being able to see people.”

CR staff/volunteers say:

“One innovation is the Treacle.me app, started by social prescribers in our area. It includes all sorts of services, support, groups, information - so when we are doing our carers’ wellbeing review or generally thinking about the needs of a carer, we can find it all on that one App. It’s amazing, and I have suggested Carers’ Resource services should be listed on there.”

“Frontline staff helped children and young people to access the KOOTH App, or signposted them to online counselling services tailored to the child.”

“We did a lot of activities where we delivered kits – like craft kits, or Mind and Draw – and then did the crafting and making together online. Or we delivered a pizza making kit, and did a Zoom chat while they ate their pizza. We did an Escape Room that they had to work online together to solve.”



Innovation, new access routes and technology

Digital exclusion remains an issue

Carers say:

"I used to go to a group that Carers' Resource told me about. When it stopped because of the pandemic, I think there was some online way of continuing but I wasn't really interested by that."

"Somehow, having to go online for everything seemed to make me more aware of the situation and how isolated we were, reminding me that we could not see people in person."

"A lot of this relies on people having good WiFi. Us out in the North Yorkshire villages have rubbish broadband. Some people don't even have a computer, because there's not been much point. We might even have old style phones, because the WiFi is always so patchy."

"One new development that I do not think was helpful was the NHS Track & Trace App - having that pinging people all of the time really raised the anxiety levels of a lot of people; there were instances of people being told to isolate when they hadn't been anywhere to mix with anyone."

"I had a funny moment when I wanted to talk to the GP about something on my neck that looked like it had gone a bit funny. She wanted me to take a photo with my phone. I said yes, but she'd have to make an appointment for me to hand over the phone. It isn't a Smart phone. She laughed and made me an appointment to go and see her."

"My husband had a chest infection, and we had three weeks of doing obs every day, and then phoning through and talking about the results. That was fine, it was reassuring. I'm happy using some technology. It can really save time. But if it is badly designed, or wants too much information, I get fed up of it. I won't use it."

"The telephone consultations and the online services are really no more convenient than going to the surgery or clinic. I still have to be there with my parents in order to translate for them."

"My Dad has Parkinson's and we found that he really struggles to use the phone, especially when there is a menu of numbers to press. With his Parkinson's tremor, he finds it really hard to select the right number before the message changes or moves on. He is a little better on a laptop, but not much."

"My experiences have left me really mindful of where I make the online calls, I want privacy and to maintain confidentiality; and I just don't always want professionals looking into my house through the screen."

Innovation, new access routes and technology

CR staff/volunteers say:

“Worth Connecting [a project by Carers’ Resource] was making sure people can access digital media or learn how to use it better. Getting people to a point that they could video call, and see that smiley face of someone they knew. There is still some resistance to using IT and tech. But people are realising that it is good to see friends, and if they have mobility issues, they can still be sociable.”

“There was a lot of redistribution of digital media and IT within the community locally. There were local groups that sprang up around the district to help.”

“Some children and young people don’t have access to computers or they might have to share one device with siblings and parents. I know some schools tried to fill the gaps where they could.”

Local groups stepped up to provide support

Carers say:

“A local group called SOP, or Supporting Older People, were new, or new to us anyway. SOP really came to the fore during the pandemic. They sorted our food shopping and did help with other things.”

“During the worst of the pandemic, the local pub was delivering vegetables and fruit. People really rallied around their neighbourhood. The local support group was picking up our prescriptions, they were really excellent. After restrictions lifted a bit, I felt like there were people much worse off than us who needed the support group more, so I stopped using them. But they were so helpful when we needed them.”

“When my husband returned from a hospital stay, we had a girl come and visit us for 6 weeks afterwards [Carers’ Resource - Home from Hospital]. My husband really enjoyed those visits and really got on with her, they had a good relationship, and it did him good. It’s a shame these things have to come to an end.”

“I have really valued the support from Carers’ Resource, you knew there was help and that they were always there. I’ve been caring for 30 years since my husband had a stroke and it’s been really tough. I can’t explain how great Carers’ Resource have been.”

CR staff/volunteers say:

“A lot of people and organisations locally stepped up. The local chippy gave the over 60s a free meal. The greengrocer who would deliver to people isolating for free. The voluntary organisations running the local food banks, or food parcel delivery. The community food store with a pay-as-you-feel cafe. New things did spring up to try to support people.”

Innovation, new access routes and technology

Carer's ID card proved valuable

CR staff/volunteers say:

"Can you imagine how the "one person only" rule in supermarkets was for carers? That's one of the reasons we came up with the Carer's ID Card. At least people could show the store staff that this person is vulnerable and cannot be left alone, they need to be with me."

"The Carers' ID Card has been a great innovation. You might have a woman caring for her husband who has dementia, but he won't admit it or acknowledge it. She can discreetly show the card at the Doctor's surgery or clinic, so that they know she does need to accompany her cared for person."



Life in spring 2022

The legacy of Covid remains

Carers say:

“My mum died in a care home at the beginning of 2021. My dad died after a short stay in hospital and then a hospice in Spring 2021. So I have had two Covid funerals. I couldn’t get to see my mum but I did have Skype calls, and there was once where I thought she smiled, that she recognised my voice. We couldn’t go to see my dad in hospital at all, and only got called into the hospice when they told us there was nothing more they could do. It was horrible. There were screens everywhere, and the masks, and aprons. Only one person was allowed in. They tried their best, the doctor did come and talk to me, but it was really horrible.”

“The other thing I think we forget about, are the Covid funerals. We had three. No one could be at the first one with our family member, the second two, a few of us were able to gather outside the church. Those Covid funerals were tough.”

“I was home schooling my daughter, working at home for eight hours a day, caring for my Mum. My Mum couldn’t understand why she wasn’t going to her group, why she couldn’t go round to see her friends, why her routine changed. It made her even more anxious, and quite bad tempered. My Mum’s depression has really increased.

Sometimes she exhibits OCD like behaviour. She is asking questions constantly. My Mum was demanding more of my time, she didn’t understand that I had to work at home. Working at home, dealing with my Mum’s bad temper, when I couldn’t use support to get us a break from each other, it really affected my moods, and my ability to sleep. I was in a panic all of the time; I couldn’t make straightforward decisions. I was in a pandemic panic state, just not thinking right. In the end, I used a Befriending Line that was literally a lifeline. And I got four virtual support sessions that really helped me understand my state of mind.”

“This is so difficult, I feel awful, as I am so full of admiration for what they [the NHS] have done. But my experiences of hospital during the pandemic has been awful, it was awful when my mum got Covid in her care home, when my dad went into BRI, and my husband into Airedale. It is not the people, they did their best, but there must be a better way to care for people and keep everyone safe. It was difficult to find out any information, you couldn’t get hold of the ward, you were sitting outside in the car or at home, absolutely going out of your mind with worry.”

“We’ve all heard in the news about how hard it is with care at home. My Mum’s carers are supposed to be in four times a day. But there is really high staff turnover, people are off, it is hard for paid carers to give support, when they are racing round in their cars to work to really tight time slots. They’re just doing basic stuff, no time for proper care.”

“Even recently, it was very difficult to access respite following a stay in hospital, I had to push for it for my husband with support from the local Parkinson’s group.”

“Why can’t we just see a GP now? I would much rather be there face to face. The language barrier is even more obvious over the phone. There is lots of repeating and talking over each other. And you can’t show the doctor what’s wrong.”

Life in spring 2022

CR staff/volunteers say:

“Dementia Forward has only reopened in last four months, and those care homes that ran groups even more recently. It has been difficult for carers to find some day care service so that they can catch up with things at home, or see friends, or just have a bit of a break.”

“Even in March 2022, the perception is that GPs services are offering decreased appointments still. For some practices, it can take repeat dialling over days to get through; we have had to challenge GP practices in order to get clients an appointment.”

“The system feels a little broken now, because social workers are hybrid working.”

“I feel that more people are on the brink of the situation breaking down and need support but the support and services are not enough. On some occasions carers are having to fight for their entitlements or feel the social workers are not able to support properly.”

“There is a care crisis, in that demand has gone up during the last six or so months, staff have left because they’re exhausted, or there are shortages because of Covid cases, and the providers are completely swamped.”

The effect on young carers is ongoing

CR staff/volunteers say:

“Young carers have had two years of backseat education. Those going into exams now, some are ready and some feel like they are two years behind. We will be seeing some emotional and behavioural results down the line, the children who are making the important transitions from year 6, and from year 10, they haven’t had the same life experiences that previous cohorts have had.”

“During the lockdowns, young carers had no connection without their screen, they’ve found comfort in connection online. Young people might be more comfortable accessing CAMHS online rather than face to face in future. Some now don’t want to speak to anyone, they’d rather type online. We need to think differently about how we design and deliver services for young people now. But I do wonder what impact all the screen time, and no face-to-face time, will have in years to come.”

Life in spring 2022

Fears and anxiety over the lifting of restrictions

Carers say:

"I started going back into my dad's house to the laundry and things once we were allowed to do that bubble thing. He has definitely gotten old during the last couple of years, he is very frail now. But he still won't have anyone else come to the house. It is partly an Asian view, that family should do the caring, but it is also because he is still wary of people bringing Covid into his home."

CR staff/volunteers say:

"There are people who are in fact more worried since the Government said we don't need to follow any restrictions, as Covid case numbers are going up, and some are as scared now as they were in the early phase of the pandemic."

"There is a big shift mentally for people who have spent so long isolating. There is a sense that, as the rest of society opens up, carers and cared for people are remaining behind closed doors."

Continuing impact on all aspects of life

CR staff/volunteers say:

"Carers I support have talked about having ongoing grief, really heavy grief, two years down the line."

"People experienced trauma. They were - are - traumatised. There was a sense that 'you're on your own, with your cared for person, get on with it'. There have been a lot of missed diagnoses and misdiagnoses. Some of the carers I work with now have a terminal illness, because they did not receive a timely diagnosis."

"The number of young carers appears to have increased tenfold and the need for support is high, post pandemic restrictions. Their stress has increased, and the needs of each young carer has gone up too."

"Covid is still affecting staff who work in the community. The Airedale Collaborative Care Team, who refer carers of people who are unwell to Carers' Resource, have staff ill or isolating, and so there are waiting lists for assessment. Covid is still out there."

"Some people were already on the edge. For example, a single mother with a disabled child who also has her incontinent mother live with her, and during the pandemic they might have had a much-reduced income. Their financial cushion has eroded. If the washer breaks down, what do they do now?"

Life in spring 2022

Growing number of carers with more complex needs

CR staff/volunteers say:

“The carers I speak to are still struggling to access any statutory support. Whilst some services have reopened and there is more support available than last year, I am receiving more complex and desperate cases and the support is not adequate to meet their needs.”

“Since the easing of restrictions, there has clearly been a ‘rebooting’ of some services, but many of those services are changed or transformed in some way. Many organisations are trying to get back to face to face provision, but I think there’s been a bit of a paradigm shift that might be driven as much by economics and notions of ‘efficiency’ as much as public health. I think the fact is that the world and our sector in it is changed, but we’re not fully sure how it will pan out yet.”

“Autism, and other special educational needs, are likely to be masked by the fact that all children will be playing catch up after the impact on their education.”



Inside an organisation that supports unpaid carers

CR staff/volunteers say:

"We always have some pretty harrowing cases to deal with, but during the first year of the pandemic, nearly every client needed high levels of emotional and psychological support."

"We had questions or situations that we had never needed to address before. You'd be thinking, well what do I have in my toolbox to help with this? You would be wondering if your information was correct and up to date, wondering, am I doing the right thing?"

"When we were physically together, we could support each other as a team. It could be to make sure you were helping a client in the most appropriate way, finding services or support. It could just be a casual check in about your own wellbeing, or it could be a more structured meeting to offer support and advice or share experience. We lost all of that, sitting in our little boxes in front of a screen at home."

Demand is still increasing

CR staff/volunteers say:

"We are now seeing carers who would not have previously reached out. They're being recommended to us by carers who have already had assistance from us. In particular, we're getting self-referrals from parent carers of young adults, out of school age, who have been unable to re-join social activities, where the level of need has become acute."

"During the pandemic, I was able to stay in contact by phone with more clients, and more often, than when I was doing only home-visits. While that was great, during the crisis, I'm finding that they still want that level and frequency of access, but want it face to face again."

"We have increased the level of service offered online, but that does mean balancing online with what we can do with in-person support. Those aged 16-19 might now prefer to access the support online or on their phone. They want to be accessing the same level of support they had during the restrictions."

"We could reach more young carers because we were not having to factor in travel and logistics. Now we're doing a mixed of digital and travelling to face to face assessments, we are working a longer work day, just to fit in the work and the travel. Our capacity has also been reduced because of staff turnover or illness. We need to recognise that this is an increase of the demands on our time and service, and think about our delivery model going forward."

Inside an organisation that supports unpaid carers

Referral pathways and networks need to be rebuilt

CR staff/volunteers say:

“A lot of people who would have been helped before were left alone and isolated.”

“Referrals stopped if someone in the local Discharge Team or in community care were isolating, or ill with Covid, or just changed jobs. Their knowledge about other organisations and support, their networking, is lost.”

“Something surprising that impacted, and still is, on the levels of support available to carers: how much knowledge, advice and information is reliant on a human “network”. Our ability to signpost to other services, and the referral pathways to us, were quite fractured - we used to be able to check in with colleagues about where might have a respite bed, for example, or whether there might be crisis appointments. Working from home, hybrid working now, has meant some of that crucial, up to date information, has been lost.”

The impact on employee wellbeing

CR staff/volunteers say:

“We have heard or seen the worst of it. And we have had to deal with our own isolation, professionally.”

“Personally, I can’t believe how much it has affected me, trying to help with all the horrible stuff that has been happening to carers and their families for a whole year, and it just has caused me to have anxiety all the time.”

“There have been a few cases that really have had a long-lasting effect on me personally. It is a privilege and a pleasure to support people to give the care that they do, I love my job. But it has been so hard to provide support down the phone, and hear the harrowing experiences of carers, in call after call, throughout the pandemic.”

“Work have been great, there has been good support and counselling. My manager is wonderful. People have done their best to look after each other.”

“The Wellbeing Service scheme is only open to health and social care workers. It normally supports mental health and ME, but they pivoted the service in Bradford to help those with long Covid. It has been invaluable in sharing techniques to help deal with the fatigue and the cognitive impairment. It also meant that I had support from peers who were experiencing similar problems, so you know you are not going mad or imagining the effects of long Covid.”

Inside an organisation that supports unpaid carers

Positive lessons for future developments

CR staff/volunteers say:

“We were able to use online access to support young people who might not have had their needs met. For example, we have four young girls in different parts of the area we cover, who have similar needs. They came together virtually during the first lockdown. We have carried on with this model since: they meet up three times on line over a period of time; and then come together in-person on the fourth occasion.”

“We offered a lot more support and activities online, to avoid travel, so our services were much more accessible during the pandemic than before. It forced us to think creatively.”

“A challenge to us, and to others like GPs, might be assuming that older people just can’t use video calls. My mum is 93 and definitely could manage a virtual call. You see the visual cues and body language that you miss on the phone.”

“We forged very close connections with our local foodbank. During the worst of the pandemic, we were offered a special delivery service for our carers and a superfast response when we referred. We used this when carers had to isolate at home suddenly and needed supplies arranging. We have continued the relationship with foodbank staff, and we will work together in future.”

“We need to learn from our experiences during the pandemic, and adopt healthier working practices. We need to have proper breaks every day, we need to get out in the sunshine, we need time to be together but not talking about work.”





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