



Care during Covid-19:

6 A carers perspective

Local health
and social care
shaped by you

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Background

Patients and service users are, quite rightly, the main focus in health and social care. The people who care for those patients and services users can be overlooked however, even though their contribution is vital.

We set out to understand the experiences of carers, both paid and unpaid, during the Covid-19 lockdown, and as we gradually emerged back into society.

This report provides an insight into the challenges that carers have faced and what has been most valuable to them. It will be shared widely with the health and social care system in Gloucestershire to offer a good understanding of carers and those they care for.

What we did

To understand the impact of coronavirus on carers, Healthwatch Gloucestershire held several focus groups. We invited paid and unpaid carers to share their experiences with us. Twenty two unpaid carers came forward, including four young carers, and we talked with them in five focus groups plus two interviews. One care provider came forward and we held a focus group with four paid carers who look after clients with complex care needs in their own homes.



We asked a series of questions and noted responses and discussions. The questions were designed to understand how well carers and cared-for people were coping, the challenges they face, what has been helpful and the outcomes they experienced.

Key themes

- A sense of community and mutual support are highly valued.
- The lack of health and care services has been challenging for unpaid carers.
- Life online, including virtual appointments, has helped some people.
- Digital exclusion was keenly felt in places.
- An over-reliance on the carer by loved ones and professionals, was a concern for some.
- An appreciation of friendship, nature, and a slower pace of life has come to the fore.

What paid carers told us

Only four paid carers came forward to feedback about their experiences of caring during Covid-19, but their comments are indicative of the challenges faced.

How have you and the staff you work with been coping?

Everybody told us they had coped badly or very badly.

- “I have been very anxious and feeling under a lot of pressure.”
- “The worry that you may have Covid and take it home is always present and a very real concern.”
- “I have just been getting on with it, but sometimes this has been hard.”
- “I have been both physically and mentally very stressed throughout this time.”

The spread of infection was a very real concern. Half the group had spent up to eight days and nights with a client to mitigate the risk.



What are the main challenges you have encountered?

- A lack of staff to cover all the shifts – although this was acknowledged as nobody’s fault as some staff members needed to shield themselves and were unable to work.
- Huge pressure on the remaining staff.
- The physical and mental challenges of very long shifts, sometimes over 24 hours.
- Delayed medication reviews for clients from the GP.
- “In the early days it was very difficult to get a Covid test, and the manager had to really push for this.”
- PPE – not always having the correct masks and not having enough gloves.
- Not being able to have fuller PPE unless a client was confirmed as having Covid, rather than suspected Covid, which was impossible as no one would test the client.

One carer spoke about a client who had an infection, dying during her shift. She explained that he had not received the level of input that he would normally have received prior to the pandemic. The ambulance team arrived in full PPE, in stark contrast to her own experience: “We all look after people with no such protection offered to us.”

Have there been any positive outcomes in your work?

None of the carers felt that working practices had improved, but some positives were highlighted:

- More online training through webinars which saved travelling time.
- Less traffic on the roads which made working journeys easier.
- The reduction in fuel prices as community carers spend a lot of money on petrol.
- The camaraderie between carers forged friendships and brought them closer.

Who or what has been most helpful?

The bond with each other and a sense of a shared experience was unanimously appreciated by the paid carers. They told us how they had laughed and cried together.

For some carers, family and pets helped them through.

Is there anything else that you'd like to tell us?

- The group felt strongly that they are frontline workers and their work should be recognised.
- The carers had latterly had fortnightly Covid tests, but have realised that they are being taxed on these.
- They expressed anxiety about being in public spaces such as shops because of the risk of infection which they could carry into the home of one of their clients.

"We are not recognised for the work that we do. I finished a 16-hour shift and went to a supermarket on my way home to shop using one of the key worker slots. I waited in the cold for 40 minutes for the shop to open and was turned away because I didn't have an NHS badge. I felt humiliated and cried when I got home."

"Sometimes I feel very ashamed to say that I am a carer."

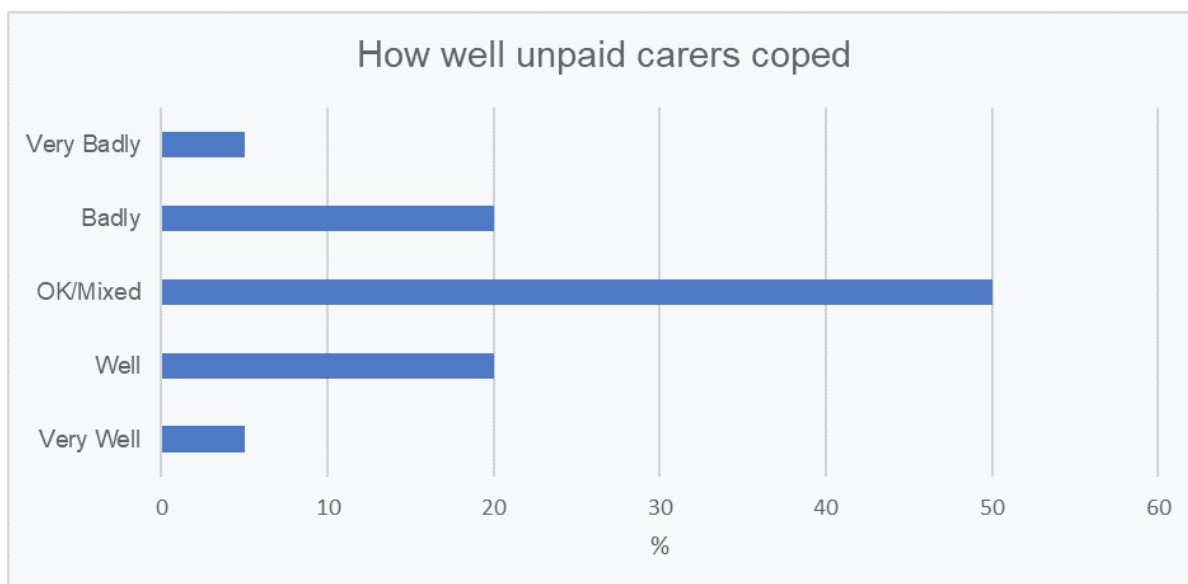
What unpaid carers told us

Unpaid carers expressed mixed experiences about caring during Covid-19 and the effects on them personally. We noted the themes and analysed how many times particular issues were mentioned - these are represented as percentages of total mentions.

There was an almost even split between people who were or were not shielding. Two people were shielding but had not received a letter about this for a month following lockdown.

How are you coping during this time?

There was a full range of experiences in coping.

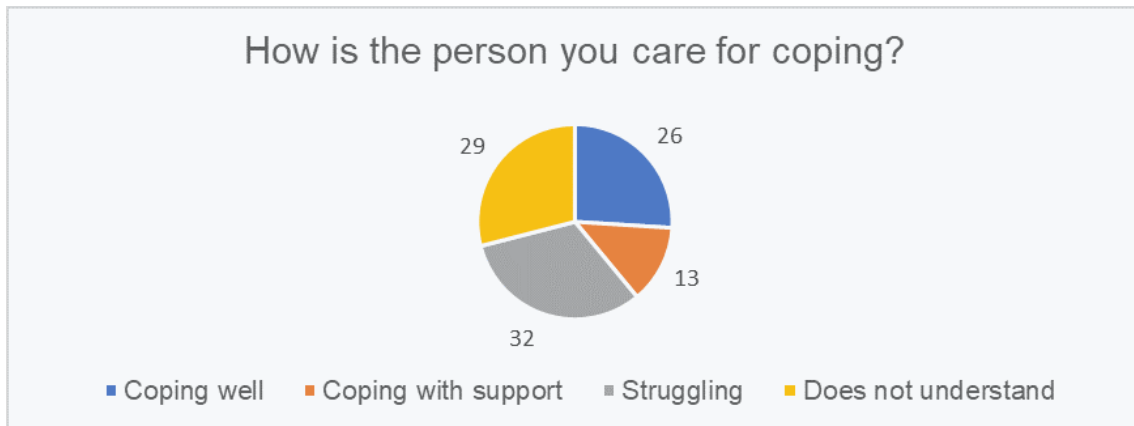


Comments included:

- “Very up and down and pretty intense.”
- “I was doing well but now I’m worried sick.”
- “I am stuck in the same routine day after day and walking on eggshells.”
- “After my initial concerns about how we were going to cope, I realise the time has flown by.”

How is the person you care for coping?

The majority of people were struggling or coping only with support, while others coped well or were unaware of coronavirus.

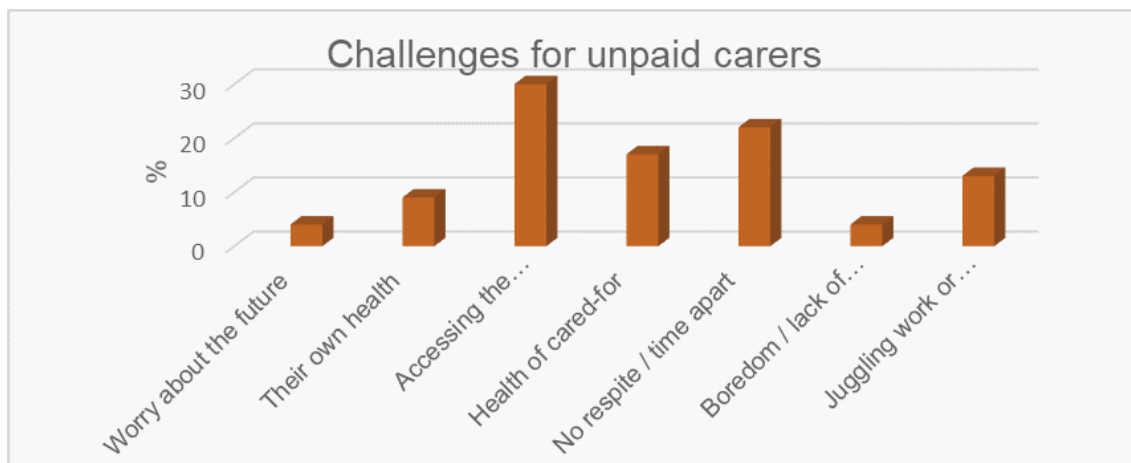


People said:

- “My husband has become fairly dependent on me.”
- “They don’t understand what is going on and have missed the routine and knowing what is happening each day.”
- “My daughter is doing surprisingly well.”
- “My husband had been coping, but now is not so good.”
- “My mother is not coping well and constantly tells me she wants to die.”

What are your main challenges?

Challenges varied according to personal circumstances, including location, work commitments and the nature of the needs for the person they care for. There was also some discussion about an initial lack of clarity and guidance.



The things that provoked most powerful personal challenges are reflected in these comments:

- “My mother had not been on the extremely vulnerable list, despite her age, and initially it was difficult to purchase enough food for her each week due to supermarket restrictions.”
- “Having no respite and having no idea when this will happen.”
- “The lack of clear guidelines around shielding and what you can and cannot do.”
- “Trying to balance being able to get my college work done, whilst waiting for lecturers to respond to my emails has been agonising and frustrating at times.”

What are the positive outcomes?

People spoke about the value of friendships. There were also new, local connections made and a sense of community.

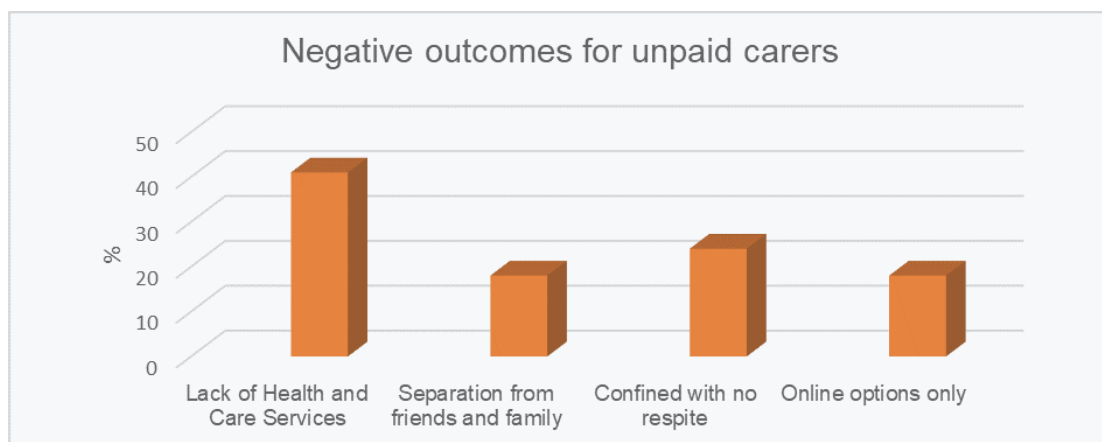


People said:

- “I have embraced Zoom and it has given me access to the outside world and a lifeline.”
- “We have visited our allotment almost every day and that has been good.”
- “We are contacting friends we haven’t seen for years.”
- “Not having to feel you are rushing around everywhere going to different appointments.”

What are the negative outcomes?

Four key themes were evident from the discussions.



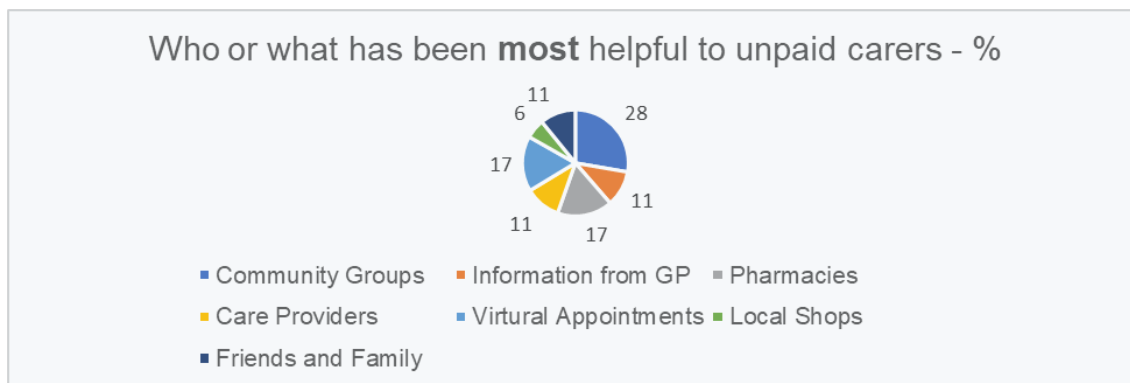
Comments included:

- “My own health investigations being put on hold and who knows for how long?”
- “Realising that everything is catered to be accessed online and that does not suit everyone and there do not seem to be any alternatives.”

- “Not being able to see my friends and go out - I have found this really hard.”
- “My caring role has been 24/7.”

Who or what has been the most helpful?

Apart from the good weather, which was mentioned by almost everyone, carers felt most helped by their community and local groups. Virtual appointments made a positive difference to some and local pharmacies were also appreciated.

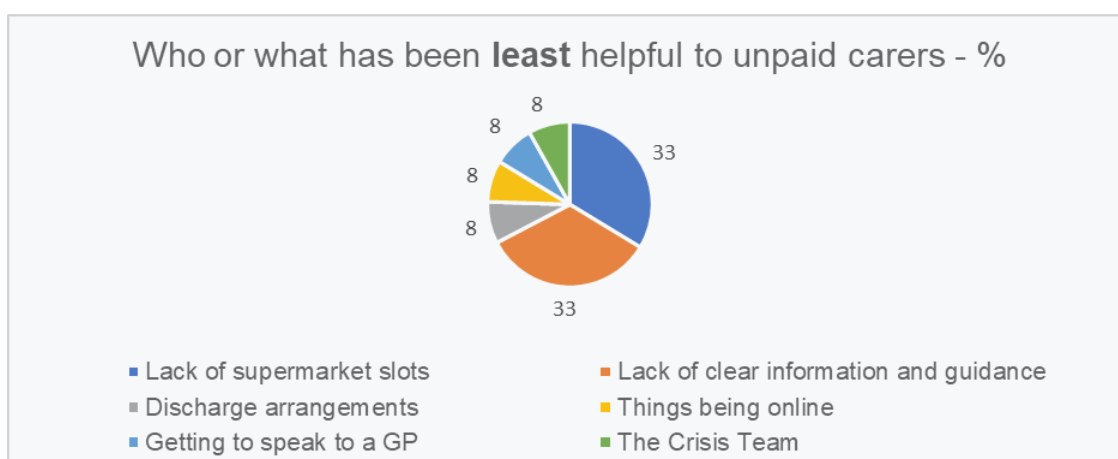


Positive comments included:

- “The community spirit within the village and those who stepped up to volunteer.”
- “My husband being able to have virtual appointments with his psychologist.”
- “The local pharmacy delivers our medication.”
- “My neighbours have been brilliant and helped me a lot - I do not like asking for help, but sometimes it is nice when someone does something for you.”

Who or what has been least helpful?

Two main issues emerged - the lack of supermarket slots and the lack of clear information and guidance.



People said:

- “I was trying to get a supermarket slot - nightmare!”
- “There is so much conflicting information.”
- “Information is only accessed online.”

What did you miss during lockdown?

The sense of isolation came through strongly. People said:

- “Definitely my friends and spending quality time with them.”
- “I miss my family because they live far away, and I cannot see them as I used to.”
- “Being able to go out if I want to.”

What is the emotional impact on you?

The majority of unpaid carers found elements of enjoyment. This was outweighed by a combination of negative emotional experiences. People said:

- “Sometimes I feel a little guilty at how well we are doing and how much we are enjoying the lockdown.”
- “I cannot believe where the time has gone, which must mean I’m doing ok!”
- “I am not sleeping and have no motivation to do anything.”
- “My mood has reduced since the lockdown and I wonder how I will fill another day.”
- “It is exhausting - my husband and I just exist together; we are no longer a couple.”

Acknowledgement

Healthwatch Gloucestershire thanks all those who shared their experiences, thoughts, and insights. A special thanks goes to the manager and staff from a care provider as well as the Carers Hub and Young Carers for their help with this project.

Disclaimer

This report is a snapshot based on the experiences of those we spoke to and is not designed to be a representative portrayal of the experiences of all paid and unpaid carers. It is an account of the experiences of those willing to contribute confidentially at the time.



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