

Research highlights challenges faced by carers during COVID-19 lockdown

16 April 2020

New research, conducted by Mobilise and the Universities of Liverpool and Sheffield, highlights the challenges carers are facing during the COVID-19 lockdown and what they are doing to combat them.

There are millions of unpaid, informal carers in the UK currently looking after somebody vulnerable, keeping them well and out of hospital. However, the COVID-19 lockdown has severely disrupted carers' [sense of control](#) and autonomy. As a result, a growing number of carers are going online for support.

Mobilise, a UK organisation that helps people access the support they need to look after their loved ones, has been supporting carers with a daily 'Virtual Cuppa' since the UK Government enforced a national lockdown on 23rd March 2020. Facilitated by a professional Carers Coach, the Cuppa offers a relaxed and supportive online setting for carers to check in with other carers around the country and discuss the challenges they are facing.

In collaboration with Mobilise, researchers from the Universities of Liverpool and Sheffield have been examining these Cuppa conversations closely in order to answer the following questions: What are the common challenges that carers are facing during COVID-19, and what are they doing to combat these challenges?

Here are the key findings of the research over the first two weeks of the lockdown – 23rd March to the 1st April.

Managing restrictions and uncertainty

In the early stages of the national lockdown, carers were experiencing a loss of control, routine and community, which naturally left many carers feeling overwhelmed. One carer stated how restricted and isolated they felt by the lockdown: "It's like a

prison. The walls are closing in."

Carers were also extremely worried about the impact of the lockdown on their loved ones' functioning. For example: "My biggest fear, because she has mixed dementia, is that by the time it is all lifted, my Mum will have forgotten me."

Some carers were frustrated that members of their local community were not following social distancing rules, which they believed was putting their loved ones at risk: "Makes me angry because they're putting my husband in jeopardy. They're just being selfish, absolutely selfish."

Words such as 'social distancing', 'lockdown' and 'PPE' have become common parlance in recent months. During the Cuppas, carers were critical of the media's coverage which had a significant impact on their mood: "I get very depressed when I watch the news. I feel so sad for these people dying" and "I keep looking for some good news, some promising news, something that's going to give us a bit of hope. And every day I get disappointed."

From challenge to acceptance

The researchers found that the early stages of the lockdown were characterised by isolation and restriction which was making carers feel worried and frustrated. As the days passed, carers gradually began to accept the lockdown and view their situation more positively. Two carers stated: "Although this is a very real situation. There is some hope and it's not all doom and gloom" and "What keeps you going is the 'light at the end of the tunnel'."

Carers also began to take a more critical view of information relating to COVID-19, for example: "It's definitely worth checking with experts rather than... news because what they're trying to do is get you to click on the link, because there's a lot of scare-

mongering going on and it is frightening" and "You can't just avoid it. You have to make an active choice to say, no, I'm not gonna look at that. I know enough already today"

From passive to active

The second week of lockdown saw a shift from passive distraction and avoidance techniques to more active methods of dealing with the lockdown. Carers began to overcome the sense of frustration and started to make small changes to look after themselves as well as their loved one. Carers stated: "As you're only allowed out once a day, I just go in the garden or listen to music", "Being able to come out or work in my shed in the garden and have something useful to do because I can't get out" and "I'm just taking that few minutes out whenever needed. Just taking that second out to breathe because it's so intense trying to plan for every eventuality."

Another carer stated that they were making use of free online training courses to keep them not just stimulated, but educated.

The importance of community

Social connection has never been more crucial. A sense of community is by far the most consistent theme to emerge from the Cuppas during the early stages of COVID-19 lockdown. In addition to their primary caregiving roles, carers received and provided support to others.

The lockdown made face-to-face support between carers impossible but that did not stop the carers from helping each other out online. This sense of community, including support from carers organisations, had a profound effect on carers' wellbeing and spurred them on to continue looking after their loved ones.

Dr Warren Donnellan, University of Liverpool, said: "What is remarkable from our findings is just how quickly carers have adapted to the challenge of COVID-19. Despite feeling isolated and restricted, carers have established routines and found ways of managing the uncertainty. Whether out of necessity or otherwise, carers have summoned the strength

to receive and provide support to those in need; not just their loved ones but also members of their community.

Here are seven 'hints and tips' the researchers have compiled for carers following their analysis of the conversations:

1. Don't feel guilty for feeling frustrated or anxious
2. Control the controllable
3. Accept that COVID-19 is uncertain, unpredictable and, to a large extent, uncontrollable
4. Establish a routine within the parameters of [lockdown](#)
5. Limit news intake to what is important; be critical and seek information from reliable sources
6. Self-care is as important as the care you offer to others
7. Engage with your community and share support with fellow carers and carers organisations

Sharing experiences

Dr Donnellan adds: "Unpaid, informal carers have been described as the 'backbone' of long-term care. So far, COVID-19 has shown us that online tools are helping carers sustain their important role through challenging times."

If you are caring for somebody and would like to share your experience to help others, please sign up to this study here

<https://james816492.typeform.com/to/NZSI88>

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Provided by University of Liverpool

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