

Carers' experiences of remote care and support models: learning from the pandemic

August 2022

Background and context

Over the past two years, we have seen a rapid shift to digital healthcare and a shift within the voluntary sector to using digital support models.

We have been reflecting on how this has impacted upon carers and think that it is timely to take stock of how carers have experienced the widespread move of both health services and community support to remote or online models.

In this work, we will apply a wide definition of carers, looking at family based support models to understand the experience of 'the person who supports a patient', rather than only that of formally recognised (or self identified) carers.

Methodology

To inform this work, we have:

1. Re-analysed the data we collated for our work on [Unlocking the digital front door - keys to inclusive healthcare](#) (May 2021), [Our Covid Voices](#) (Oct, 2020) [Online Peer Support](#) (Dec, 2020), with a specific focus on the needs, experiences and hopes of carers.
2. Met with a key group of our members and people with lived experience to discuss, review and input into the findings, recommendations and examples of good practice.
3. Collated this learning pack.

In our wider work around digital and remote care, we have found:

1. People understand the reason for and potential benefits of remote care.
2. Many people have struggled to access services during Covid.
3. People might be digitally excluded for a range of reasons.
4. People present with a range of support needs; one size does not fit all.
5. Poorly executed remote care negatively impacts on experience and quality of care.

Section 1: Carers' experiences of remote and digital health and care

What we heard – challenges around privacy

- There are specific challenges around privacy between carers and the people they care for, in relation to digital care.
- For many carers, their caring responsibilities are their greatest source of stress. Speaking to a health professional about how this is affecting their health or to a peer support group about how they are coping can be helpful, but it might be very difficult to find a private spot to have these conversations.
- For the person they care for, there may be challenges around privacy and disclosing things about their health and wellbeing that may feel uncomfortable.

What we heard – challenges around privacy

“From day one with our surgery we said we want to allow the other person to access our medical records and talk about each other because we didn’t want a situation where a doctor would say ‘we can’t give you that it’s confidential’, so we made that agreement but there might be people who don’t want that and have got children around and don’t want to discuss their mental health or medical condition or what have you and that could be a real problem and it could put people off and they won’t bother. I can think of people who it certainly would affect.”

What we heard – needing support with using digital

- People experiencing digital exclusion may be more reliant on family members and carers for support.

“It might be a bit more difficult for my Dad who has long-term health conditions to access digital health care by himself but luckily, we are able to help him. My Mum’s also able to help him so if he did have to have any virtual visits or anything like that it should be okay because he has people to support him.”

What we heard – importance of feeling independent

- Barriers relating to digital exclusion can add to a feeling of loss of independence – both for carers and the people they care for.

“With the sight issues, we are still trying to be fiercely independent. I battle a lot to try and keep my independence because if I was to give up on things I do now, even though I can only just about do them, it will start affecting my mental health...”

What we heard – access to and experience of health and care services

- Like the wider population, many carers have faced challenges with getting through to health or care services, however, this can be particularly burdensome for carers who have to navigate the health and care system for two or more people.

“It is frustrating that you have to wait a long time to get answered on the phone and then you’ve got to make arrangements with the doctor if they have to make a decision whether they need to see you or not... It is frustrating not being able to access the doctor as normal but we’re fortunate in respect that we’ve not had too badly.”

What we heard – access to and experience of health and care services

- Some carers feel that they have lost trust or hope in getting a response from health and care services.

“The fact that you don’t contact the surgery as much as you might have done before simply because you think oh no that’s alright, that’ll go away sort of attitude. Which is not comfortable but I don’t think it’s going to change, I think that’s going to be the routine for it in the future, you’ve got to phone up and you might get a response, you might not. It’s all the potential worries in the future.”

What we heard – access to and experience of health and care services

- Like the wider population, some carers feel lost in the system, having to repeat their story time and time again, however, this can be particularly burdensome for carers who have to navigate the health and care system for two or more people.

“So, many things happening so many times, I had to open the video call and keep repeating my situation, each time. I went through a difficult period. In the end, the doctor said I have got blood pressure that is causing me all these symptoms.”

What we heard – being with loved ones at important moments

- We heard from carers that it was difficult not being able to be with the people they care for at important moments – for example, not being able to go with them to hospital during the pandemic or not being able to be with a loved one in their last moments.

Wider issues we heard about from carers during Covid

- [Research from Carers UK](#) found that 81% of carers were providing more care since the start of the pandemic.
- Some carers are reaching crisis point because of loss of respite care.
- The shortage of and pressures on carer support workers has caused additional pressures for some carers.
- Many people don't understand what Covid means for disabled people and their carers – some carers feel forgotten about.

Section 2: Online peer support models

What is peer support?

While there are many definitions of peer support, they all have similarities and speak to common core values.

Generally, in peer support people draw on shared personal experiences, characteristics or circumstances to support each other to improve their health and wellbeing.

Peer support is a mutual approach in which people both give and receive support.

Our previous work on peer support

In our previous work on peer support at National Voices, we brought together various groups and people engaged in peer support, and asked them to share their learning around the pandemic, and we published two guides:

- [Peer Support - Opportunities and Challenges](#) (Mar, 2021)
- [Online Peer Support learning pack](#) (Jan, 2021)

Key themes from our previous work on online peer support

- Enabling online peer support requires specific skills – facilitating and moderating is hard work and requires training and support.
- Moderators and facilitators face particular strain managing online peer support, particularly at a time of increased need.
- Online peer support is not a cheap option – there are costs to platforms, and issues such as safeguarding and accessibility are not manageable without investment.

Key themes from our previous work on online peer support

- Peers need to be involved in “contracting” the terms of engagement for their group – agreeing the rules around moderation, facilitation. There are new issues to consider online – e.g. whether cameras should be on / off, around names and anonymity, muting etc.
- Many groups want to continue offering peer support online, but alongside face to face alternatives.

What we heard – benefits of online peer support groups for carers

- Online provision of peer support is a lifeline for many carers – during the pandemic online provision filled a gap for many people who had previously been accessing face to face support, but for many others it provided a new route to social support that had not existed at all before.
- Some voluntary sector organisations felt that they could reach more people using digital and remote models of peer support, whilst others found that they could offer online peer support in languages other than English for the first time.

What we heard – benefits of online peer support groups for carers

- Sometimes the circumstances of an illness, condition or disability a person cares for can be very rare. Online platforms can create opportunities for connection to other people with common experiences when that otherwise wouldn't be possible.
- Online peer support groups can be more convenient for people with mobility issues.

What we heard – concerns about online peer support groups for carers

- Carers can face challenges around privacy – carers' biggest stressors are often their caring responsibilities – online peer support could provide relief from this but it may not be possible for carers to find space away from the person they care for.
- On a related point, “in person” carer groups often (but not always) provide respite care or parallel support groups for people being cared for but this isn't part of many online offers – this is likely to be a real loss for some people.

What we heard – concerns about online peer support groups for carers

- It can be daunting for people to put themselves out there on screen with strangers who they might never meet in the real world.
- Some people feel that they have been forced online for peer support, even though in-person is more useful to them and provided respite.

Spotlight on good practice: Care for a Cuppa, [as featured by Nesta](#) (1 / 5)

When the COVID-19 pandemic hit, Carers UK knew many of their members would be struggling as local respite and day services shut down and health services became more difficult to access. Building on an initial pilot the organisation developed plans for online support sessions for carers - Care for a Cuppa was born.

Both staff and members were a little apprehensive at first. Staff were concerned about managing a regular “live” online space, particularly as their text-based online forum has sometimes become quite complex to manage.

Spotlight on good practice: Care for a Cuppa (2/5)

Many carers, like Della, were nervous about using Zoom. However, staff sent guidance and were on hand to talk:

"If I was stumbling with an obstacle of trying to do it, I just emailed and they'd talk me through it. [..] I was dead nervous at the beginning, because I'd never done a Zoom."

Spotlight on good practice: Care for a Cuppa (3/5)

Care for a Cuppa has proved very popular and effective. Staff facilitate the sessions, moving into breakout room if numbers rise beyond 12. While facilitators sometimes suggest a theme for discussions, the best sessions flow after an initial round of introductions.

"When you become a carer, it's like a totally new world... And carers, we all understand one another. You have to be a carer to understand how it feels... I'd say to a new carer, 'Do it.' It's the best thing you could possibly ever do and it'll be your lifeline and you won't look back, and I'd encourage anybody."

Spotlight on good practice: Care for a Cuppa (4/5)

Many carers have become “regulars” since April, but new people continue to join. Sessions are promoted through social media, member communications and other channels.

Alongside Care for a Cuppa, Carers UK also run Share and Learn sessions - themed Zoom sessions on everything from welfare rights and benefits, to Latin Dance. There are also sessions for specific groups, including carers from ethnic minority groups and male carers.

Spotlight on good practice: Care for a Cuppa (5/5)

Carers UK's experience during the pandemic has demonstrated the significant need for, and power of, peer support among carers. Many carers feel isolated and anxious when they join the groups, but connecting with others lifts the burdens of navigating complex systems, and dealing with the emotional strains of caring, as Della attests:

"It lifts that weight because you're holding it in all the time, and you've not had anybody to talk to, and it's just nice. It's nice to have problems shared and to talk to people who get you and who have got empathy for each other."

Read Care for a Cuppa here: <https://www.nesta.org.uk/case-study/carers-uk/>

Recommendations and next steps

Key takeaways – government and health system leaders

- Ensure that carers and the people they care for have a choice about if and when they access health and care services through remote and digital models.
- One size doesn't fit all – continue to invest in a mixture of in-person, online only and hybrid peer support groups.
- Invest in respite care and grants to enable carers to participate in peer support – whether online, hybrid or in person.

Key takeaways – government and health system leaders

- In some instances, online peer support may be cheaper, but it can't be free (and often you need more staff input online than in person).
- Invest in targeted digital inclusion training and provision of digital devices for carers.
- Work with carers to understand where digital tools could be most meaningfully used, for example, if they are unable to be with their loved one at a key moment in life.

Key takeaways – advice on setting up online peer support groups for carers

- One size doesn't fit all. The key concern for the future was the need for a mix of provision to suit different needs – so there is concern that an “online only” future will be preferred because it is cheaper, but at the same time concern that online provision will be withdrawn. Clearly a mixed economy is the answer.
- Given that we know carers are busy and that most carers are were providing more care since the start of the pandemic, consider how you can develop online peer support which is flexible, for example, by using an online forum where people can post at times that are convenient to them.

Key takeaways – advice on setting up online peer support groups for carers

- Consider how carers might be able to access respite care in order to take part in your group.
- Online peer support groups can feel more formal. It may feel harder for people to communicate as openly as before or to read the room or body language. Make online groups smaller so that peers can feel more relaxed and engaged.

Key takeaways – advice on setting up online peer support groups for carers

- On a related point, while ultimately people find connection and mutual support online, it helps to create a focus for conversation – whether it's an activity, sharing knowledge or discussing a particular theme. This helps people feel motivated to get online and confident to attend. Think outside the box when identifying activities people might like to do e.g. yoga, scrabble.
- Be prepared to offer grants to people so that they can take part in online activities.

Key takeaways – advice on setting up online peer support groups for carers

- Don't assume that everyone will feel confident using online platforms. Find ways to show and inform people on how to use your online platform.

Acknowledgements

We would like to thank our members and lived experience partners for your advice and input in the development of this learning pack.

The funding for this work was provided courtesy of the Commitment to Carers Programme, Experience of Care Team, NHS England and NHS Improvement. We would like to thank you for your support.

Get in touch

 info@nationalvoices.org.uk

 020 3176 0738

 www.nationalvoices.org.uk

 @NVtweeting