

COVID-19 IN SCOTLAND: THE IMPACT ON UNPAID CARERS AND CARER SERVICE SUPPORT WORKERS

ACKNOWLEDGEMENTS

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About Carers Trust Scotland

Carers Trust Scotland is part of Carers Trust, a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

With locally based Network Partners we are able to support carers in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that unpaid carers count and can access the help they need to live their lives.

INTRODUCTION

In March 2020, the UK, along with many other countries, entered a national lockdown in response to the spread of the coronavirus. Since then, travel restrictions and local and national lockdowns have continued to impact the lives of unpaid carers, carer support workers and carer services across Scotland.

From November 2020 to May 2021, Carers Trust Scotland carried out research to understand the experiences and challenges that the pandemic led to in Scotland for unpaid carers, and consequently, carer support workers and carer services.

As the UK continues the vaccination programme and the gradual lifting of lockdown, unpaid carers and carer support workers look towards the future of support in the 'new normal.' This report makes recommendations and suggestions, built from the experiences of the research participants. These can support carer services to build back sustainable organisations and ensure continued quality support for unpaid carers in the future.

Terminology

An unpaid carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

A carer support worker is a paid member of staff who works for a carer service, supporting unpaid carers.

A paid carer is someone who is employed to provide care on a paid basis.

Although the terminology and legislation referred to in this document applies to Scotland the experiences, challenges and recommendations are applicable across the whole of the UK.

METHODOLOGY AND PARTICIPANTS

Beginning in November 2020, unpaid carers of all ages and carer support workers in Scotland were invited to take part in the research through completing surveys, focus groups and one-to-one interviews.

Surveys were widely shared with participants via professional networks and Carers Trust Scotland social media channels. The surveys were open to participants until 7 May 2021. Over this period, focus group invitations were sent to carer services, and participation throughout the project has come from across Scotland.

Participants	Survey	Interview and focus group	
Unpaid carers	461	17	
Carer support workers	131	90	

The data collected emphasises the individual voices and experiences of unpaid carers and carer support workers and is suggestive in its nature rather than representative of unpaid carers' experiences universally.

The snowball sampling technique does not focus on specific unpaid carer communities. The survey participants are predominantly white, female and in the 45-64 age range. In part, this is in line with Scotland's 2011 census data that found women more likely to be unpaid carers than men; and those in the 50-64 age bracket more likely than other ages to be unpaid carers (1).

However, this approach means that the unique experiences of specific unpaid carer communities may be missed. Future research on the impact of coronavirus may focus on specific carer communities, to capture and understand experiences unique to different unpaid carer groups.

Table 1: Carers' ethnicity

What is your ethnicity?				
Answer choices	Response per cent			
Gypsy/Traveller	0%			
Black/Black Scottish/Black British	1%			
White Scottish/White British	92%			
Indian/Indian Scottish/Indian British	1%			
Bangladeshi/Bangladeshi Scottish/Bangladeshi British	0%			
Chinese/Chinese Scottish/Chinese British	0%			
African/African Scottish/African British	0%			
Caribbean/Caribbean Scottish/Caribbean British	0%			
Pakistani/Pakistani Scottish/Pakistani British	4%			
Mixed or Multiple Ethnic Groups	1%			
Prefer not to say	1%			

(1) https://www.gov.scot/publications/scotlands-carers/

Table 2: Time spent caring

How long have you been caring for?				
Answer choices	Response per cent			
Less than a year	2%			
1–3 years	11%			
3–5 years	10%			
5–10 years	24%			
More than 10 years	52%			
I became a carer because of the coronavirus pandemic	1%			

Table 3: Carers' ages

What age are you?				
Answer choices	Response per cent			
Under 18	2%			
18-24	4%			
25-34	5%			
35-44	20%			
45-54	30%			
55-64	27%			
65+	11%			
Prefer not to say	1%			

SECTION 1: UNPAID CARERS

CHANGES TO CARING

Since the beginning of the pandemic, some unpaid carers have modified the type of support they are providing.

"Although my face to face caring role has decreased due to the risks of COVID19 I am providing additional telephone and emotional support."

"The caring is different as we can no longer meet. It is all done online."

"Because I'm also a full time student I fulfill a lot of my caring role over the phone, so though I do less physical caring or housework, I provide a lot more emotional support, which has also increased during the pandemic."

Table 4: Caring roles during the coronavirus pandemic

Thinking about your caring role during the coronavirus pandemic				
Answer choices	Response per cent			
I am spending more time caring	90%			
I am spending the same amount of time caring	8%			
I am spending less time caring	2%			
I am caring for more people than before the pandemic	0%			

Table 5: Why are carers spending more time caring?

I am spending more time caring because				
Answer choices	Response per cent			
Local authority services have stopped running	29%			
The person(s) I care for needs have intensified	46%			
I am caring for more people	5%			
The person(s) I care for does not want paid carers to come into their home	7%			
I do not want paid carers to go into the home of the person I care for	5%			
I am not spending more time caring	8%			

For many unpaid carers, the needs of the person(s) they care for have intensified during the pandemic. Some unpaid carers felt that the restrictions had contributed to a deterioration in the condition of the person(s) they care for which in turn had intensified their own caring role.

"Due to increasing frailty and illness of the person I care for, the caring element time has increased substantially."

"Physical and cognitive status of both parents who I look after has deteriorated due to covid pandemic, becoming more housebound and no day care."

"Lack of external support being available has been a major factor in care needs intensifying."

"Being indoors as much has made my daughter very needy she doesn't even like me going into other rooms."

As a result of lockdowns, travel restrictions and shielding requirements, unpaid carers have found that they are now with the person(s) they care for more often. Some unpaid carers live with the person(s) they care for, and others changed their living arrangements to be able to provide care during the pandemic.

"The care home visiting restrictions led me to decide to bring my mum back home so I have been caring for her at home ... It's been very difficult but at least I can finally have meaningful contact with my mum again."

"I care for my teenage daughter and am working from home most if not all of the time, so my caring role is fairly constant."

"It's everyday all day now. But before I was able to go out and got a break but since the pandemic, it's been a year since I have been out at all."

"Because of the pandemic I have mostly spent the last year with my cared for person due to shielding." The restrictions on travel and socialising have also made it more difficult for unpaid carers to receive support from family and friends. In some cases the person(s) who would have shared the caring role is vulnerable to the virus, resulting in more responsibilities for the primary carer.

"There is no provision for carers to assist with what's needed! And less family friends can help due to covid."

"Other family members have health vulnerabilities, meaning that I felt it was my duty to keep them safe."

"Before the pandemic my siblings shared more of the care, but this hasn't been possible. They've done what they can, shopping, doorstep visits etc. Recently mum has gone downhill, and even though we've taken the decision to responsibly allow family into the house I'm still stuck at home."

Many statutory services, local organisations and other services providing paid carers or day care services for the person(s) being cared for, paused their services. This increased the demands on unpaid carers who had to step in to fill the gap in provision.

"No care package was available for the person I am caring for due to the onset of Covid. I had to take on sole carers role/responsibility due to this."

"I would be happy to have Carers but they have stopped work due to the pandemic."

"I am spending more time caring because my parent can no longer go to groups in the community, I am spending more time with her because I want to give her lots of mental stimulation and to ensure she has daily exercise."

"Agencies funded by Local Authorities have stood down services."

In some cases, unpaid carers or the person(s) being cared for wanted to stop support from paid carers to limit the risk of the virus. These understandable precautionary measures placed additional responsibilities on unpaid carers.

"The person I care for doesn't want carers coming into their home so consequently I'm caring more."

"My son was advised that carers were needed else where by people living in supported accommodation - which we understood. We also did not want to increase his risk by having carers coming into the house."

"I need to shield my daughter as much as possible. I am also high risk so carers at home would not be an option."

THE IMPACT ON UNPAID CARERS

The impact of caring for longer hours, and having to meet more intense needs means many unpaid carers have struggled with both their physical and mental health during the pandemic.

Table 6: Carers physical and mental health

Thinking about your health as a carer throughout the pandemic, how is your physical and mental health?						
Much worse thanWorse thanThe same asBetter thanMuch betterthan before the pandemicbefore the pandemicBetter thanbetter before the pandemic						
Mental health	34%	50%	14%	1%	1%	
Physical health	23%	45%	28%	3%	1%	

"My own physical health has become significantly worse during the pandemic which is also impacting on mental and emotional health."

"Diet and exercise plus time away from care have all taken a back seat. It's just about getting through the day."

"I am more stressed, and no physical activity, so I feel lonely and low all the time."

Table 7: Impact on carers wellbeing

Thinking about your caring role since the beginning of the pandemic, have you felt ?						
	Much more than usual	More than usual	The same as usual	Much less than usual	Less than usual	Not at all
Stressed	52%	39%	7%	1%	1%	0%
Tired	55%	35%	8%	1%	1%	0%
Lonely or isolated	50%	29%	17%	1%	0%	3%
Anxious or worried	52%	36%	11%	1%	0%	0%

"I feel totally alone and the impact of caring has made my mental health decline rapidly."

"I am exhausted, feel very 'down' most of the time ... my physical ailments have gotten worse and I now need the strongest of pain relief every day as I have to be active to make the person that I care for safe and supervised. It seems endless, with only terrible alternative options."

"I have cried because I am so exhausted and tired, I cannot always function now because I'm tired."

"Mentally at times I've felt unable to cope during the pandemic. I was due to have a hip replacement before the pandemic. The physical side of caring has been unbearable at times."

A lack of respite opportunities helps explain some of the difficult feelings unpaid carers are facing. Both formal opportunities for respite such as an overnight stay; and informal respite such as work, school or hobbies, have been reduced or removed for many unpaid carers due to coronavirus restrictions.

Table 8: Respite

Since the lockdown began in March 2020, have you been able to access respite or breaks from caring?				
Answer choices Response per cent				
No	82%			
Yes	18%			

"I have no respite. I used to access support such as therapy, college, peer support, and the pandemic took absolutely everything away from me."

"I was a mess emotionally and had to fight to get some sort of respite restored but this only happened in January. And I have been reminded constantly that I can only access respite as an emergency so almost made to feel guilty for asking for respite."

"Mum used to attend [day care] centre twice a week and that time that she was out at the centre gave me the time to do things for myself; get out for a walk or go see a friend or even get the cleaning done in the house. But now that mum is home all the time there is no time for any of that."

"I asked for support from social services when I was in crisis due to one of the people I care for having Covid and all I was offered was access to PPE - which I was grateful for but there was no break or respite from the additional workload." However, some unpaid carers did note that they did not feel traditional respite options in the form of a stay away, was safe due to the risks of coronavirus. In general, many unpaid carers are very worried about passing coronavirus to the person(s) they care for.

"I'm worried about the person I care for catching the virus, worried I might catch it and pass it to her, worried I might catch it and be too ill to help her."

"The stress of trying to avoid catching Covid and passing it onto my two disabled sons, who live in different cities has been overwhelming."

"[Respite] is not something that we have actively sought nor indeed would want given the risk of increased exposure to the virus."

Table 9: Where have carers accessed support?

Where have you accessed carer support services (you can select more than one)?				
Answer choices Response per cent				
Local carers centre	36%			
Local authority services eg social work	12%			
Local charity/voluntary organisation	12%			
National charity eg Samaritans	1%			
GP surgery	9%			
Pharmacy	5%			
I haven't accessed any support services	42%			
Other (please specify)	16%			

Table 10: How have carers accessed support?

How have you accessed carer support services throughout the pandemic? (You can select more than one)			
Answer choices	Response percent		
1-to-1 video calls	9%		
1-to-1 phone calls	31%		
Video call group support sessions	14%		
Video call activities	8%		
Socially distanced meetings/walks	45%		
Meetings in the community eg cafes	1%		
Socially distanced meetings/support groups	2%		

Some unpaid carers have struggled to access support during the pandemic, due to the pausing and closure of services.

"There is nothing available for me. I used to have NHS therapy but new rules in the [local authority] psychology department mean they are removing all longterm psychological support and limiting it to 20 weeks maximum. I require ongoing support and this has been removed."

"The only support my family got was through [young carers project] who have supported my daughter throughout the pandemic and thankfully her worker was able to give me some information to assist me with a few things."

"Our 12 month support for aftercare after dementia diagnosis, was cut short due to Covid, plus our CPN was changed around the start of Covid which was unfortunate. I had amazing support from [staff at Carers Centre] to complete my Carers anticipatory care plan, done over the phone and very worthwhile."

"Local Authority has been of little help. The little that's been done required fighting for that input which nearly broke me as a human. If it wasn't for a particular person at [carers centre] I really can't imagine where I'd be." As support has moved online, many carer services secured funding for technology for unpaid carers, allowing them to connect digitally. While unpaid carers hugely appreciate the support they receive, the response to the online support has been mixed. For some unpaid carers, online support has been easier to access than in person support, particularly in rural and remote areas.

"The Caring through Covid grant to help me be able to afford an iPad for me time and connect to the outside world."



"[The carer] probably wouldn't commit to going to a club or a group in person, because it would be too risky ... if there was a problem it was in the next room rather than two buses away." **Carer support worker**

"I think for a geographical area like ours virtual support has been useful and something we will continue to use going forward." **Carer support worker**

However, some unpaid carers do not find the option of online support attractive. Carer support workers shared the difficulties that these unpaid carers could encounter in accessing online support:

"Carers who have IT barriers or disabilities that stop them from using online platforms, who need practical support with physical form filling etc or those who need the human touch were negatively impacted [by moving online]." **Carer support worker**

"Carers are keen to use face to face services that they have been accustomed to for years and years. Digital inclusion and remote working causes a lot of less digitally inclined people to fall through the cracks." **Carer support worker**

Some unpaid carers feel that online group support is inappropriate and cannot replicate faceto-face support.

"Video calls are ok for work and short calls with friends but not for dealing with serious emotional issues. Too impersonal."

"I prefer to meet people face to face for a chat. Technology is no substitute to seeing or speaking to someone face to face."

"Many of our carers prefer and get so much from actually having contact with someone, seeing a friendly face and getting that much needed hug and reassurance. Our carers love the door step visits, although hugs are out of the question at the moment. Being able to come in to the centre for a chat with a support worker or other carers really benefits carers, it is also giving them a break and reducing their isolation."

Carer support worker

Other unpaid carers struggle to find a private space where they will not be overheard, to talk about their caring responsibilities.



"We've found that it's a particular group of people that the zoom doesn't work too well with, because they are living in a house, possibly with someone with advanced dementia and they can't get that space to take part in a zoom meeting." **Carer support worker**

"I don't want to join a video group to discuss such private issues with people I've never met."

THOUGHTS ON THE FUTURE

Table 11: Accessing support in the future

The pandemic has meant that many carer support services have been delivered online. In the future, how likely would you be to access the following ...

	Extremely likely	Very likely	Neither likely or unlikely	Quite unlikely	Very unlikely
1-to-1 video calls	11%	24%	25%	17%	23%
1-to-1 phone calls	20%	33%	25%	11%	11%
Video call group support sessions	10%	18%	20%	23%	29%
Video call activities	11%	19%	22%	21%	27%

Some unpaid carers have found benefits to the new ways of accessing support, primarily through remote or online means. However, for others, traditional methods of support, and the ability to meet face to face remain important.

"For normal young carers stuff like going into the hall, that would be good because I miss that. I treat young carers as time to relax and talk to friends and have a nice time."

"I prefer in person a lot more. It's just easier to get to support, and it's like my own little time."

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However, unpaid carers are also worried about the legacy of the pandemic, and the impact on both themselves and the person(s) they care for. Many are worried about how a 'new normal' will accommodate the person(s) they care for; as well as being worried whether they can continue to give the level and intensity of care they have been providing.

"I am normally calm and aware of my own health but the long term consequences for my daughter's future was grim before the pandemic and now it is even worse."

"I have struggled and getting too used to being indoors now not sure if when over I will get back to being my bubbly sociable self."

"Thankfully, all three have got through this last year but it has had a lasting effect on my health both mentally and physically leading to me wondering if I really can continue to be the major support to all three going forward."

"Worried about how long I can sustain the level of care into the future."

"My personal health and that of my loved one has significantly declined ... I expect that the delays to access the healthcare we both need will have long-term effects on both our outcomes."

Home schooling alongside caring responsibilities has interrupted the learning of some young and young adult carers, and many are concerned about the impact the pandemic has had on their learning and educational attainment.

"I went through my first year test and I know I really struggled on that because all the stuff we were meant to learn in P7, we didn't."

"A lot of teachers told me that I should have been able to do [school work] more because I was at home ... but because of other distractions I found it hard."

"Sometimes I wanted help with my work but my mum was always downstairs with brother ... it was a bit annoying."

"I missed out some gaps ... we're all struggling a bit with that because we all missed such a large gap."

Overall, the pandemic has presented unique and challenging difficulties, with long-term consequences for many unpaid carers.

Table 12: Positive impacts

Has the pandemic had any positive impacts on your life?				
Answer choices	Response per cent			
I have had more time for myself	5%			
I have been able to spend more time with the people I live with	29%			
Working from home has provided me with flexibility	17%			
I have had more time to relax	4%			
There have been no positives	55%			

While some unpaid carers have embraced flexible support options; been better able to manage time working from home; and have enjoyed being able to spend more time with the people they live with; for many carers, the pandemic has been a challenging time.

"I find it hard knowing that every day is the same as the one before namely, making meals, doing washings, filling dishwasher and in between caring duties which range from feeding him, assisting him to the toilet. Assisting him everywhere."

"Being able to cope in itself has been positive."

"Isolation/lockdown has had a huge negative effect on my life. Mentally and physically. I can't go anywhere or see anyone other than the person I am caring for."

"I feel a bit abandoned and forgotten."

SECTION 2: CARER SUPPORT WORKERS

CHANGES TO SUPPORTING UNPAID CARERS

There have been key challenges for carer support workers throughout the pandemic. The challenges faced by unpaid carers impact the work of those supporting them.

Table 13: Challenges in supporting unpaid carers

Have you found any of the following to be challenges in supporting unpaid carers during the pandemic? (You can select more than one)				
Answer choices	Response per cent			
Unpaid carers not having access to IT	87%			
Unpaid carers needs have become complex	74%			
Statutory services closing or being unavailable	82%			
Less services have been open or available to signpost unpaid carers to	81%			
Some unpaid carers do not want to access support remotely	79%			
Processing new clients	27%			
Building rapport and relationships remotely	47%			
Lack of respite options for unpaid carers	89%			
None of these options listed	1%			
There have been no challenges	1%			

Table 14: Changes to the role

Do you feel your role has changed since the beginning of the pandemic?				
Answer choices Response per cent				
Yes	65%			
No	35%			

Some carer support workers feel their role has changed, as they are providing different support; others feel that support is the same, but the delivery is different.

"We've also had to go and identify funding to get people digitally connected, and laptops."

"The teams work is now far more focused on managing online peer support groups, distributing PPE, and processing short breaks applications for unpaid carers applying for funds to do self care at home."

"My job description does not reflect what I am actually doing now."

"I spend a lot more time on the phone listening to peoples' worries."

"Everyday posed a completely new conundrum, in a completely new context that you then had to figure out for the individual you're talking to."

Table 15: Working patterns

Thinking about your working pattern during the pandemic, do you agree or disagree with the following statements? Answer choices Neither Strongly Agree Disagree Strongly disagree agree agree nor disagree My workload has 45% 31% 17% 7% 0% increased I am working a 16% 41% 14% 22% 7% different pattern of hours 21% I am working 30% 16% 27% 6% beyond my contracted hours

"Caring roles have been increased obviously, we are so so busy at the moment. I have taken on young carers and parent carers ... we are so busy with parent carers phoning and just needing that support."

"A lot of our work now is the whole family, it's not just the young person ... And it's all areas. It's benefit checks ... Have you got enough food in your cupboard."

"My role has seen more crisis and mental health support compared to previously. Sessions also tend to be longer due to the complexity."

"One to One work with carers is much more intense due to length of time restrictions have been in place and changes to cared for many carers now in crisis and deep distress."

"Increased calls about vaccine and PPE and COVID-related funding for carers ... Pressure of increased referrals is high."

EMOTIONAL DEMANDS

Particularly in the early stages of the pandemic, it was challenging for some carer support workers to adapt, and this impacted on their confidence in their positions.

"I felt completely hopeless for a while ... how can I support carers, how can I do any of the work I did before."

"It's changed a lot ... there's times where I've felt totally useless."



"My confidence in my ability has reduced ... my confidence and my perception of myself has reduced."

"I thought, I've been in a job eighteen years, and that job doesn't exist anymore. I just found that really quite difficult."

Being unable to give unpaid carers certainty feels difficult for carer support workers, who are accustomed to providing reassurance and being confident in the information they provide.

"Every time you think you've got it and you're telling the carer, it changes again."

"It's hard to keep giving people hope sometimes."

"You don't feel as adequate during your working life, you certainly don't feel as adequate during your day to day life either."

"That feeling of not having the answers for them, that wasn't always easy."

Carer support workers have noted unpaid carers requiring greater mental health and emotional support. However, unlike in the office, carer support workers have not had their colleagues around to debrief from these distressing calls.

> "Some cases now in the last few weeks ... of anonymous callers expressing suicidal tendencies. Not happening a lot – thank goodness – but it does and it has happened."

"Due to resources and services in the community being limited my role has seen more crisis and mental health support compared to previously."



"So where you would normally put the phone down in an office situation and go and speak to a colleague, or go into the kitchen and make a cup of tea and have a cry ... you've got no buffering there for the staff."

"We are supporting carers' mental health in a lot more depth that we are used to or trained for."

"Virtual team support is good but it's no replacement for popping the kettle on and chatting through challenging cases with colleagues. This has had a negative impact on my mental health." Alongside the emotional demands of work, carer support workers are dealing with their own professional and personal challenges brought by the pandemic.

"There are things that go on in everybody's lives but [carers] are just unaware of it ... because you do put forward such a professional front and they know that they can rely on you."



"At the end of the day, although you're a worker you're human and we've been affected by Covid as well."

"Not only has this pandemic impacted my working life, it's obviously impacted my health, my mental health, my family life. I'm a single parent working at home with two children, and that's the reality for a lot of people"

HOMEWORKING

Homeworking has both costs and benefits, and works differently for each individual carer support worker.

Table 16: Taking breaks

Thinking about your working pattern during the pandemic, do you agree or disagree with the following statements?					
Answer choices	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I find it harder to take breaks, than in the office environment	38%	34%	13%	11%	4%

"Personally I feel working at home is taking its toll on my mental health and cannot wait to get back in to the office. Yes I get more work completed at home, however this is because I do not take regular breaks and will work later."

"I've said all the way along to both teams ... you need to take regular breaks ... I was just back to back Teams meetings all day ... when I did get back to [staff member], she was like 'I don't think you're following what you've been telling us!"

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Table 17: Home working

Thinking about home working, do you agree or disagree with the following statements?						
Answer choices	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I have the equipment I need to work effectively from home	44%	41%	5%	5%	2%	3%
I have a private space to work from	37%	27%	7%	18%	8%	3%
l find it difficult to keep my work and home life separate	19%	29%	19%	21%	8%	4%

Not all carer support workers have the necessarily privacy or dedicated workspace at home.

"At home, my workspace is on the dining table and I don't feel I 'escape' from the computer and paperwork that sits there waiting for me to start work again. My home is not my haven anymore."

"As I don't have anywhere other than my bedroom to work, I do find it hard at times to separate work and home life. I miss chatting to my colleagues in the office and I miss the walk to and from work."

"We are very short on space and I have to work at the kitchen table ... I am constantly interrupted which is not ideal when I am in the middle of a confidential phone call to a carer ... As time goes on I am finding it harder."

Some carer support workers miss giving face-to-face support, especially as some unpaid carers prefer this method of support.

"Although offering support remotely allows for my day to be spent more efficiently I don't think that it is what the majority of carers find most helpful."

"We're not wanting to become a call centre. That's not what we are here for."

"In general carers tend to prefer face to face as they find it more supportive to actually be with someone and I miss the non-verbal communication, body language, facial expressions and so on." However, some carer support workers find value in the flexibility and time saved on travel. Others have said home working was the only possible way they could balance their work, caring and childcare responsibilities. Many would appreciate a blended approach to work moving forward.

Table 18: Home working positives

Thinking about home working, do you agree or disagree with the following statements?						
Answer choic- es	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
Working from home provides me with greater flexibility	27%	46%	17%	4%	3%	3%
l prefer working from home	21%	19%	26%	21%	11%	2%

"I am also a carer for my adult son who is now home fulltime due to COVID, I would have not been able to continue working without being able to transfer working from my home."

"There are less distractions at home which allows me to focus more on my work."

"I think blended working is the best way forward. I am an adult carer so working from home allows me to be closer to the person I care for but I also find that I have to stop myself from logging on during the weekend and checking emails during the night."

"The lack of balance available because of lockdown restrictions means it can be very isolating. In the longer term I would like to have a mix of home, community and office based work."

REMOTE AND ONLINE SUPPORT

Remote support cuts travel time, and has allowed some carer support workers to support more unpaid carers. However, for others it is important to note that quality of support is as important as quantity of support.

"Remote support is useful when the only alternative is NO support."

"Though remote working has cut travel time, calls to carers are now far longer ... Not being physically present is a big challenge when dealing with grief and anxiety."

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"It has been easier and less time consuming as there was no need to travel ... I could reach out to much more carers on any given day ... Having said that, carers who have IT barriers or disabilities that stop them from using online platforms, who need practical support with physical form filling etc or those who need the human touch were negatively impacted."

"Yes I can support more carers remotely but the level of the support is not the same as actually meeting someone." Carer support workers have found some unpaid carers to be very receptive to online support, and as such have been better able to reach and support those who faced barriers to attending groups in person.

"We have a dementia group ... and for that group particularly, carers fed back that they actually prefer the online group because it's not so awkward for them to have to try to get ready, and get out and travel quite a lot of distance."



"Online activities suit some carers. There is no need to find replacement care or travel. This makes it much easier for them to participate in activities and groups."

"I seem to attract more men to the groups as opposed to the face to face groups. Also those living in rural areas can access groups more easily, so keeping the groups going via zoom is an excellent way forward along with face to face groups."

However, not all unpaid carers engage with support remotely, making it difficult for carer support workers to offer services during times of restrictions.

"We've lost that personal touch ... and I know everyone tries really hard on the phone but it's just not the same ... it's not the same for carers."

"Remote communication has been difficult at best - many young people don't enjoy using digital methods to engage in this way."

"The young carers have not engaged well with the online groups, only the outdoor groups when they were allowed e.g walking group, allotment."

"Many of our carers prefer and get so much from actually having contact with someone, seeing a friendly face and getting that much needed hug and reassurance."

Workers shared that it is not always possible to get a full picture of an unpaid carer's situation over the phone, and informal opportunities to check in on unpaid carers are lost in a fully online world.

"You'd see some of the kids that didn't come to the centre, you'd catch them at the school."

"People will tell you they're fine on the phone. But you can't see their body language, you can't see their eyes. You can't see what they're really feeling."

"Working remotely has meant we can speak to more unpaid carers on a daily basis ... but it also means you are not getting the whole picture for some of the more vulnerable unpaid carers, whom you would have made a home visit."

"You know they're not even telling you the half of what's going on ... they are not sharing what they would otherwise share."

"Many find it difficult to talk openly, may not be a safe space, unknown who else is in the room, replies can be 'fine' 'ok'."

LOCAL AND STATUTORY SERVICES AND PARTNERSHIP WORKING

Carer support workers and wider carer services highlighted the ability of third sector organisations to respond rapidly and with agility to the restrictions set by the pandemic. Many staff and services have adapted and worked flexibility throughout to be available for unpaid carers.

"We are like the fourth emergency service."

"But I think we all deserve a bit of a round of applause getting our staff sorted out, and the IT sorting out ... finding out what they are entitled to for remote working ... it's all of those things to try and make sure people have got what they need at home."

"We were very lucky because our respitality worker ... has worked with other charities around mental health ... so what we started to do was implement wellbeing calls that were separate to the [carer support worker] calls."

"We've all done a really amazing job to be as adaptive, and as responsive ... rather than just going right okay 'we are just going to stop our service completely, and because we can't do it, we're just not going to do it' – to really be as agile as we've been in the environment, is amazing."

As many organisations and statutory services withdrew or paused support for unpaid carers due to COVID-19 restrictions, carer services remained open. For many unpaid carers, carer services provided continuity in a turbulent landscape.

"As we adjusted/responded to the pandemic fairly quickly, I feel we ended up carrying out a lot of additional work as we were the only people available. For example, it was impossible to get hold of Citizens Advice so we had to learn new skills and info to support our case loads."

"Where CAMHS and places like that, it was okay for them to send someone a letter and say well we'll be in touch when we get back up and running. Well, we were having to do video calls ... to maintain people's mental health ... I couldn't quite understand why these services stopped."

"It made me quite angry actually that people were discharged ... what was wrong with a phone-call now and again? But to discharge people that had mental health issues, it was almost cruel... and then you know where do they come? To us."

The disruption to referral pathways and closure or pausing of additional services has made it very difficult for carer support workers to make the necessary referrals for unpaid carers to receive the support they need. Communication with some statutory services is further complicated by online security measures, which makes communication across platforms more difficult.

"The number of organisations that we can signpost unpaid carers to for specialist support disappeared overnight and many times we have people tell us that there is no one else who picks up the phone and that is why they call the Carers Centre."



"I think people would be really shocked if they knew that NHS weren't allowed to reply to an email from us."

"There has been more and more work piled onto us by local and national governments, sometimes with unrealistic timelines and this has made a difficult time even more stressful." Carer support workers are concerned about the impact that the pandemic will have on partnership working with key organisations in the community, and the impact this may have on unpaid carer referrals and signposting.



"Because we've not been there for 12/18 months or whatever, are they going to remember to refer to us, or are they just going to refer to the counsellor because they are in house?"

Carer support workers do not feel their work, or the contribution of unpaid carers is adequately valued across society.

Table 19: Unpaid carers contribution

Do you feel the contribution of unpaid carers during the pandemic has been valued by local and national governments and the wider community?				
Answer choicesResponse per cent				
Extremely valued	4%			
Very valued	8%			
Somewhat valued	44%			
A little valued	31%			
Not at all valued	13%			

Table 20: Carer service staffs' contribution

Do you feel your role, and the role of your service during the pandemic has been valued by local and national governments, and the wider community?				
Answer choices Response per cent				
Extremely valued	7%			
Very valued	23%			
Somewhat valued	42%			
A little valued	15%			
Not at all valued	13%			

"Carers don't feel equal partners in care with statutory services, carers organisations feel the same."

"I think statutory bodies have done a good job of paying lip service to the value of unpaid care in communities, however I think there has been an absolute failure to back this up by concrete support for carers who are in absolutely desperate situations."

"Our work needs more acknowledgement. It's always NHS workers and council workers... we don't get recognised at all."

"I'm quite incensed that unpaid carers were not even spoken about and they were the ones that picked up the pieces. And the follow on was our workers were picking up the pieces because of the effect it had had on carers."

However, carer support workers also shared that unpaid carers are incredibly grateful for their input and value the carer service.

"I know that carers and people with disabilities that we support on the whole appreciate our work to support them."

"Carers are so grateful at the minute for any support, but the sad thing is they seem to think I do this out the goodness of my heart and I am a special person, but in reality it is all what they are entitled to."

"Carers consistently emphasise the importance of a phone call to give them space to talk and be heard."

MOVING FORWARD

Table 21: Work in the future

Is there anything about the way you are working just now that you think should be a permanent feature of your work in the future?

Answer choices	Response per cent	
Yes	89%	
No	11%	

There have been positives to engaging online for both unpaid carers and carer support workers.

"The option for carers to access us through technology should continue due to lots of carers finding this option more convenient due to their caring role."

"Some of the carers that won't engage through Zoom, that can't engage through Zoom because they're frightened of it or whatever, they've been on the WhatsApp. And they are very supportive of one another."

"I think it would be wrong for us to go back and not do the online stuff, because of the wide area we cover and the sheer numbers that we have."

Table 22: Remote support in the future

Although the course of the pandemic is uncertain, when there is an opportunity to run services similar to how they were before the pandemic, how likely would you be to use the following methods?						
	Extremely likely	Very likely	Neither likely or unlikely	Quite unlikely	Very unlikely	
1-to-1 video calls	70%	22%	5%	2%	1%	
1-to-1 phone calls	50%	28%	14%	7%	1%	
Video call group support sessions	46%	25%	11%	13%	5%	
Video call activities	44%	25%	12%	16%	3%	

Carer support workers noted that moving to a blended approach of working does not lessen demands on staff, time, resource or funding as there are unpaid carers who only engage in face-to-face support, and others who only engage online. Both preferences would need to be catered for in a blended model.

"We have lost some engagement as some of our service users do not wish to use technology and don't want support on the phone. However, we have engagement from service users who prefer to engage in this way and would not typically have come to groups."

"Online and remote support works for some but by no means all of the carers I support. The majority of older carers I support (especially those 80+) prefer face-to-face interactions."

"We've had feedback to say that the young carers who join our zoom groups enjoy them but the majority of our young carers aren't joining our zoom calls."

"A lot of the sort of interventions and things we've put in place to see people through the whole of the last year have been things that have actually been quite time consuming for us."

"We introduced regular welfare calls to all carers whilst working at home and were able to reach more than we would normally as we did not have to deal with the face to face in office. These calls have been lifelines for carers. We want to implement this in to our everyday service once we remobilise, however that will present capacity issues as we will be resuming services we had prior to COVID." Importantly, carer support workers expressed the need for individual organisations and managers to support them as well as to support one another as colleagues.



"I think we need to recognise that we're all human."

CONCERNS FOR THE FUTURE

The following themes emerged from the research with carer support workers:

How will technology and remote working be used?

"There is slight worry that tech won't be used to enhance, but to reduce."

How will services transition to providing post crisis phase support?

"We can't sustain this ... I'm out delivering PPE at a weekend! We must be really careful that we transition to a normal expectation."

How has the pandemic impacted on unpaid carers' confidence?

"The needs of these families are not only complex under 'normal circumstances' but all too often I hear from parents that their young person is now too terrified to go outside, even to the garden. Too many families have become prisoners in their own homes and I can't begin to think of how we start building confidence back into hundreds if not thousands of people who have 'given up the idea of going to school, work etc.'"

"People are just too scared, they are too scared to have anyone in – whether they could or they couldn't."

How has the pandemic impacted mental health and what are the long term consequences?

"It's like when this is over, we're going to have a new pandemic on its own of like, increased mental health because the support has just disappeared ... I think there's going to be so many more issues that are going to come up because we are facing them daily."

"Something I feel apprehensive about what are we going to be hit with when we can see people again ... we are going to be left to pick up the pieces of stuff they've not told us for a year ... what state are some of these young people going to be in when we actually do get to see them again?"

How will support packages look in the future?

"In many ways I fear for the future of carers whose cared for have care packages in place which were stopped during the pandemic. Many deemed to have coped because they did not access or receive support may find the local authority cuts care package post covid. the perceived coping may be used as a means to cut packages."

SUGGESTIONS AND RECOMMENDATIONS

The needs of carer services may change and evolve as they move forward in the post crisis phase of the pandemic. These recommendations and suggestions have been built with this in mind and informed by the experiences of unpaid carers and carer support workers throughout the pandemic.

1. Remobilisation plan

Carers Trust Scotland is one of the seven National Carer Organisations (NCOs) in **Scotland**. The NCOs and Scottish Government should work collaboratively, with carer services, to create a national remobilisation plan. The plan should support carer services to move positively to a post crisis phase of service delivery, and support carer services to build back sustainably. Statutory bodies should support carer services to meet any needs identified in the remobilisation plan.

Health and social care partnerships and individual carer services should consider undertaking their own evaluation, considering their needs moving out of the crisis phase of the pandemic. NCOs should facilitate an opportunity for carer services to exchange and share this learning across the country.

2. Reaffirm organisational purpose

After an acute period of reactive work in response to crisis, carer services need to reaffirm their organisational purpose. This will facilitate the development of service delivery models that allow services to achieve their purpose in a sustainable manner.

To assist in reaffirming organisational purpose and devising activity accordingly, carer services should consider the legal duties and purposes of other organisations, and what their role is in supporting unpaid carers. NCOs should provide additional support for this piece of strategic work.

As staff have absorbed crisis response into their work, carer service management are encouraged to revisit staff job roles and responsibilities, ensuring they are appropriate for a post crisis service.

3. Communication with commissioning bodies

In terms of carer service activity and implementation of the Carers (Scotland) Act locally, commissioning bodies should ensure their expectations and asks of carer services are realistic and in line with the available capacity of carer services. Commissioning bodies should recognise that the pandemic artificially increased carer services' output and throughput, not necessarily sustainable in a post crisis phase. A mutual conversation between carer services and commissioning bodies is encouraged to ensure expectations and asks are realistic.

To ensure management of expectations, carer services should clearly communicate changes to activity and/or delivery style to unpaid carers and key stakeholders.

4. Carers (Scotland) Act 2016 funding

Local authorities should be transparent on the Carers (Scotland) Act funding received and how it is allocated to deliver on priorities for unpaid carers. As carer services are commissioned to deliver outcomes for unpaid carers, it would be good practice to include them in conversations about how funding is spent. The expertise of carer services on carers' priorities and experiences should be recognised and included in Carers (Scotland) Act funding allocation decisions and conversations.

5. Supporting staff at work

Recognising the difficulties and demands the pandemic has placed on carer services and staff, the health and wellbeing of staff should be prioritised moving forward. Positive health and wellbeing practises should be embedded into support and supervision processes, and the wider work culture.

Scottish Government should support NCOs to continue to provide workforce development opportunities for carer services and carer support staff. Local and national governments should invest further in carer services and staff to ensure there is additional resource for training and wellbeing.

The pandemic has allowed for flexibility in working styles and support for unpaid carers. Agile working policies and procedures should be evaluated and considered. Carer services and managers should consider working preferences and the ability for flexibility moving forward.

6. Recognition

The contribution of carer services, as well as unpaid carers, to the care of those in the community should be recognised by local and national governments, statutory services, funders and NCOs.

Carer services should be recognised at a local and national level as an integral part of the health and social care landscape in Scotland. Carer services and their staff, and unpaid carers should be more involved in the formal decision making relevant to unpaid carers within integrated joint boards, health and social care partnership strategic planning and other relevant decision-making bodies. NCOs should work with statutory partners to ensure that this materialises in meaningful ways.



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