Northamptonshire Carers

Carers' Voice Northamptonshire

healthwatch Northamptonshire

Experiences of caring during the coronavirus pandemic

Key findings, recommendations, and responses

Summer 2021

"I have been left providing the emotional support for three people struggling with Covid restrictions. There does not seem to be any support available."

"My father's health significantly deteriorated during the pandemic and has now become very frail. It has been hard to get any diagnosis due to no physical GP appointments where they would have been able to see the issues my father is now facing in his health …"

"As a former carer and now carer champion I can't believe how quickly Northamptonshire Carers responded to moving online and Zoom support."

"… It has been incredibly hard for me to have little to no time to myself. The impact, emotionally, has been enormous as my daughter needs a high level of care."

Contents

Summary

Feedback received by Healthwatch Northamptonshire in 2020, along with what Northamptonshire Carers and Carers' Voice Northamptonshire heard, suggested that changes to services during the coronavirus pandemic had affected those who provide informal (unpaid) care to family and friends and that there has been an increase in the number of unpaid carers. To find out more about the experiences and needs of carers we worked with Northamptonshire Carers and Carers' Voice on a survey, interviews and a consultation event.

We spoke to 144 people – 80 carers shared their experiences though a survey, 56 people (unpaid carers, young adult carers and professionals) at an online consultation event, and eight people were interviewed.

The findings of this work show that the impact of the pandemic on carers had been huge, with many working tirelessly and at breaking point, having to do more to meet the physical and emotional needs of those they care for without much support from others or respite. Whilst some have been able to access online support others have felt alone or isolated.

Carers have told us that their physical, mental and emotional wellbeing has suffered from the extra strain on them, and many are concerned about the worsening condition of those they care for, exasperated by the reduction in health and care services, the need to stay away from others or the anxiety caused by the pandemic.

These findings are very similar to those reported by Carers UK[1], showing that the impacts of the pandemic on carers in Northamptonshire are the same as those felt around the UK.

This report also highlights the support carers need, both during the pandemic and longer term and suggests ways that carers could be supported to recover from this time, and which changes to the way services have been delivered they would like to stay.

Many carers took the time to tell us in detail about the difficulties they have faced during the pandemic, and we are very grateful to them. Whilst we have tried to summarise all that they told us, we have also included many of their insightful quotes so that the voices of carers are heard. We hope we have given carers a voice through this report. As a carer commented:

> "I would like to thank you for doing this research. No-one has really asked me how I've coped this year caring for my parents. I have muddled along and it is only when I answer your questions that I realise how tough it has been."

We have shared the findings of our survey with the service providers and planners to inform their work and help them to continue to deliver good quality care and support carers at this time and beyond. You can read their responses to our report and recommendations on pages 22-25.

The survey data and findings from the consultation event were shared with Northamptonshire Carers and the unitary councils (North Northamptonshire and West Northamptonshire) prior to the publication of this report.

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[1] Caring behind closed doors: six months on - The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers - October 2020: www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on

You can read the key findings (with example comments), recommendations and responses to the recommendations below.

The full findings and methodology are available at www.healthwatchnorthamptonshire.co.uk/report/2021-06-29/caring-during-coronavirus

"It has been a pleasure to work with Healthwatch and Carers' Voice on this insightful report which has been thoroughly planned and compiled. It was great to hear the voices of carers at our engagement event in February and the survey compliments this well. As well as highlighting how carers and young carers have been disproportionally affected by coronavirus, it provides useful recommendations which we will seek to deliver ourselves and alongside partners."

Gywn Roberts – Chief Operating Officer, Northamptonshire Carers

"During the first wave of the pandemic we were all in react and respond mode, there was no time to really drill down and identify where there maybe additional or hidden needs, or where situations may be worsening for some.

It was during the early onset of the second wave where we were able to take a breath and identify sections of our communities that needed more support and where we needed to understand the additional needs they may have.

Working collaboratively and in partnership with other organisations like Northamptonshire Carers and Healthwatch Northamptonshire was invaluable from an engagement perspective as it enabled us to inform our forward planning for the COVID response, whilst taking account of the specific needs of different groups of people."

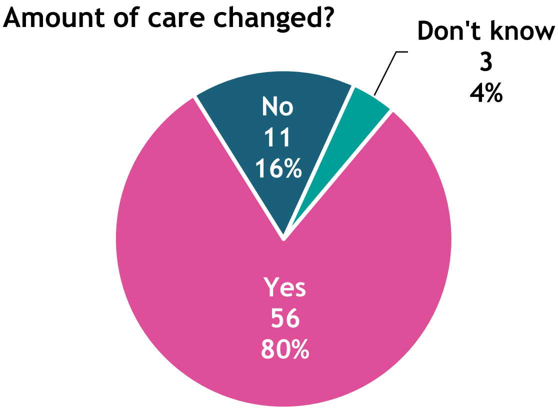
Nicki Eames-Barton - Communities Officer, Social Impacts Cell, Engagement Lead, for North Northamptonshire and West Northamptonshire Unitary councils (previously Northamptonshire County Council)

Key findings

Challenges of caring during the pandemic

Changes to care

- 80% of survey respondents told us that the amount of care they provided had changed because of the coronavirus pandemic, with most saying they were now providing more care – at least 73% of all survey respondents.
- The most common reasons for providing more care were the needs of the people being cared for becoming more complex (33% of all respondents), local services (such as day care or specialist schools) being closed (27%), and people that normally help carers to have a break not being able to help (25%).



- Eight people (11% of all respondents) commented that they were having to do more for relatives who were now isolated or who's independence had decreased due to not being able to see others and/or shielding. Concerningly, some of this loss of independence or increased frailty may be irreversible.

> "Since the start of the pandemic my older sister has been shielding, and become more frail, therefore my care for her has increased regarding shopping, accompanying her to health appointments, etc., and helping with jobs around her house. Although she did have a cleaner once a fortnight from Age UK, this is currently not happening."
>
> "The care for my [sibling] has increased as we've not had [their] support worker during COVID and I've also been studying at home to protect [parent] as [they have] leukaemia which means I've been around more and they've also needed me more both practically and in terms of emotional support." – *Young carer*

Reason for providing more care	Number of people	Percentage of survey respondents
The needs of the person/people I care for have become more complex	25	33%
Because local services have been reduced/closed (e.g. day care or specialist school)	20	27%
People that normally help me so I can have a break are not available or are unable to help	19	25%
I am providing more care for another reason	18	24%
I am worried about paid (by the NHS/council or privately) health and social care staff having contact with the person I care for	9	12%
My employment hours/status has changed so I have more time	8	11%
Paid health and social care staff have reduced personal care	7	9%
Local services have opened but I am worried about services being COVID-secure so am not using them	5	7%

Impact of changes

- 52 survey respondents (69%) told us more about how their caring had changed and the impact this had on them. Almost one-third (31%) commented on how they had less support from or access to health and care services. This caused problems for people that needed medical support, including tests and diagnosis, especially where a diagnosis was required to get support. People also had less help from other services and/or relatives and some felt unsupported in other ways, including when relatives were discharged from hospital.

> "My father was admitted into hospital with pneumonia in November, although care in the hospital was good, discharge was disgraceful… I was not told my father was discharged and awaiting collection by hospital staff, a family member rang him to find out he was sitting crying in the discharge ward waiting for me to collect him and not knowing where I was. My father had no additional support put in place for him at home on his discharge and was not well enough to look himself and took a lot of work from myself and my family to get him back to reasonable state of coping at home. All this has led to myself struggling to balance time between work, family and my father's care and my father's health deteriorating rapidly with no medical support."

- Carers at the consultation event and survey respondents also told us about the financial hardship they faced, which had increased for some during the pandemic when they were having to provide more care or activities at home or having to shop for others or purchase Personal Protective Equipment (PPE)
- 29% mentioned being under increased strain, including being exhausted, finding things stressful or other impacts on their wellbeing.

> "… I am exhausted mentally and physically and feel I have nobody to turn to. As a family we feel isolated and very depressed."
>
> "Given up all voluntary work and hobbies as no time or no longer permitted. No longer able to exercise effectively as no gym, no physio, no time. Cannot exercise alone so not much fresh air. So pain is much, much worse, sleep really bad and weight has ballooned. Very depressing."

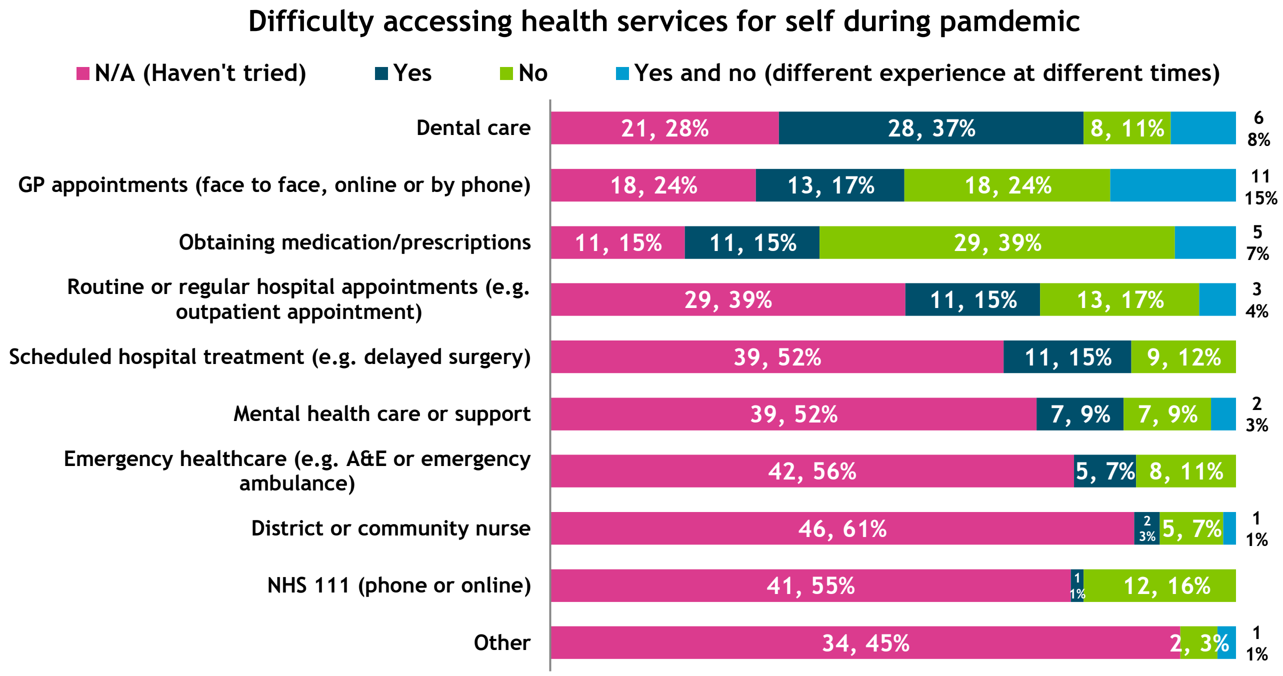
- One-fifth (21%) also told us about the impact of lockdown on the person they cared for and their needs, including those that had become more isolated or lost independence, and some carers were also having to cope with increased anxiety and mental health issues of those they care for as an effect of the pandemic. Some also were anxious about themselves of those they care for catching coronavirus.

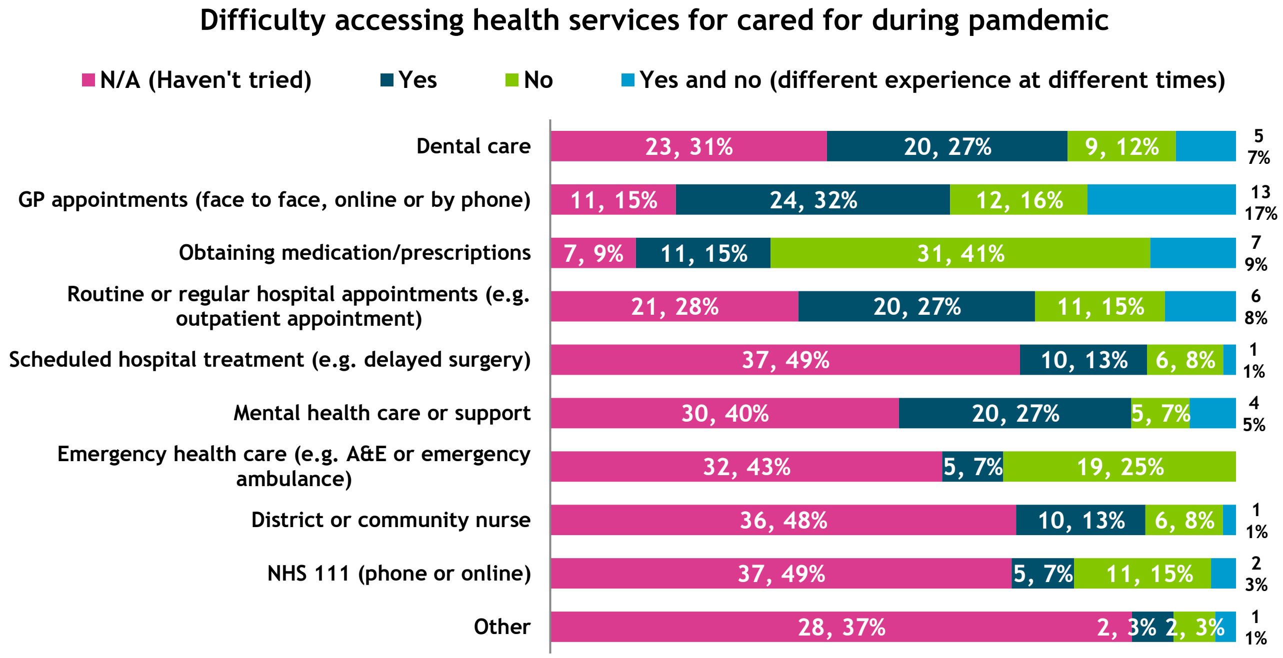
> "I have had to care more for my disabled homebound mother since this pandemic begun. Her mental health has deteriorated as has her physical health …"
>
> "I have been afraid to send my daughter to her day centre after a few staff members showed Covid symptoms. The home carers have not been in during various lockdowns because of the same reason …"

Changes and impacts on carers	Number of people	Percentage of respondents
Less support	23	31%
Extra strain on carer	23	29%
Impact of lockdown on cared-for person and needs	16	21%
Anxiety about catching/transmitting virus	12	16%
Having to do things differently	6	8%
Lack of information	5	7%

Experiences of accessing services

- Carers had mixed experiences of accessing health services, such as GP and mental health services, for themselves and those they care for. Accessing mental health services for those cared for was the biggest difficulty highlighted – an issue for two-thirds (69%) of survey respondents that needed this support.





- 42 survey respondents gave us additional comments about their experiences, 64% of which were negative. Difficulties described included being unable to get treatment or care or a diagnosis, either because of delays, a lack of follow-up, not being able to get an appointment or a service being unavailable. A few people had delayed appointments themselves to avoid the risk of exposure to COVID-19.

Services with a negative experience	Number of people	Percentage of comments
GP practice	10	24%
Hospital	7	17%
Mental health	6	14%
Dentist	4	10%
Social Care	2	5%
Memory Clinic	1	2%
Learning Disability	1	2%
ASD/ADHD team	1	2%
Adult Social Care Mental Health team	1	2%
Self-care	1	2%

Negative overarching themes	Number of people	Percentage of comments
Lack of treatment/care	19	45%
Communication	13	31%
Lack of support	11	26%
Direct impact of COVID-19	4	10%
Other	5	12%

- Some carers felt that health services were not supporting them, especially mental health services. Others told us about communication difficulties, including struggling to get through to services on the phone, and cases where communication was poor. Phone calls to the Northamptonshire Carers support line have also revealed that some social care self-funders felt unsupported, dismissed and isolated.

"Everything has been put on hold. But we are still here struggling and it's so hard with no support from anyone."

"Delays from mental health team meant we have still not had an official diagnosis, repeated postponement, which has impacted on services/benefits, etc. that we could otherwise access. Admiral Nurse was a great help to support the family as carers. Difficulty getting doctors surgery follow ups. The subject was a former NHS nurse but there is no support/charity for retired staff."

"Getting a GP appointment is nigh on impossible. Even getting through by telephone is almost impossible. No other form of contact is possible at the moment."

- We also received some positive comments about where remote appointments had worked well for people and from those who's treatment had gone smoothly.

"Epilepsy nurse really accessible can call her any time."

"On a positive, GPs have been brilliant at [our] practice. When a new GP took over the practice, they created a new phone line that does everything. More people are also manning phones to accommodate circumstance. Prescription reviews with [our child] are booked in by the practice, whereas previously the parents have had to make initial contact. You can easily pre book follow up appointments further in advance and always send you a reminder by text which they never did before. Monthly carers newsletters are now received by email from the GP."

Services with a positive experience	Number of people	Percentage of comments
Hospital	3	7%
GP	2	5%
Pharmacy	1	2%
Physiotherapy	1	2%
Age UK	1	2%
Epilepsy nurse	1	2%
Child mental health	1	2%

Positive overarching themes	Number of people	Percentage of comments
Phone and video appointments worked well	6	14%
Good and efficient treatment	5	12%
Good support	2	5%
No delays	2	5%

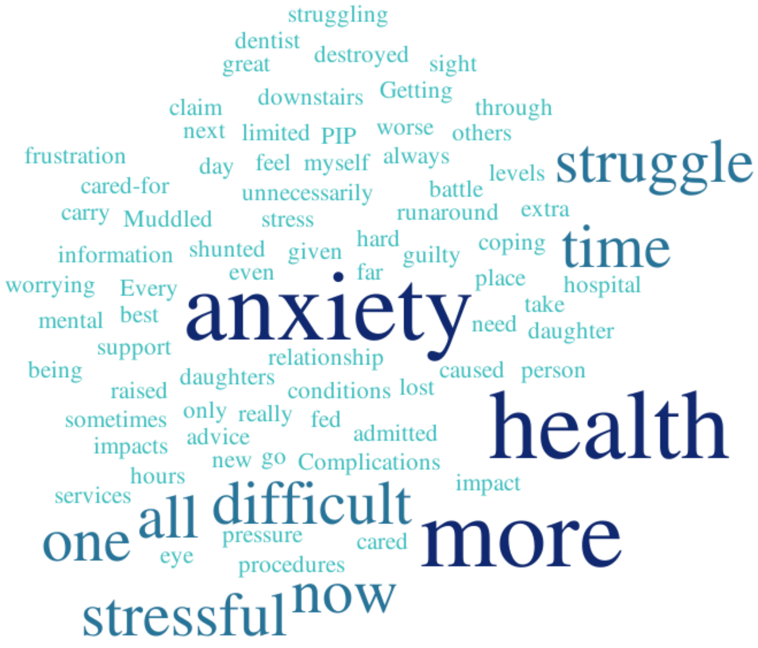
Impact of difficulties

- The comments highlighted the impact on the health of the people being cared for as well as the increased worry and stressed caused to the carers.

Negative impacts overarching themes	Number of people	Percentage of 31 comments including impact
Impact on health or care of cared for	20	65%
Emotional impact on carers	18	58%
Other	4	13%

> “It has been a double whammy, being a carer is hard enough, this has made it ten times more difficult; lose support, family support not able to be around, professional support, physical support too.”

A word cloud on comments about impact:



Support services

- Carers were asked which other support services they used and whether they were available to them. Most services had not reopened or resumed, especially before or after school provision and day services. Some said that a service had reopened/resumed but that they were not using it, particularly specialist schools, sitting services, activities or support provided by local charities, and residential care.

	I started using this during the pandemic	This continued throughout the pandemic	This has reopened/ resumed but I am getting a lower level of support than before	This has reopened/ resumed and I am getting the same level of support as before	This has reopened /resumed but I am not using it	This has not reopened /resumed	Total (100%)
Day services	0	1 (9%)	1 (9%)	0	2 (18%)	7 (64%)	11
Care home	2 (40%)	1 (20%)	0	0	1 (20%)	1 (20%)	5
Residential care	1 (25%)	0	0	0	2 (50%)	1 (25%)	4
Specialist schools	0	0	0	0	2 (100%)	0	2
Before and/or after school provision for my disabled child	0	0	0	0	1 (33%)	2 (67%)	3
Activities provided by Northamptonshire Carers	1 (9%)	6 (55%)	0	1 (9%)	1 (9%)	2 (18%)	11
Activities/support provided by a local charity (e.g. meals on wheels)	1 (20%)	0	1 (20%)	0	2 (40%)	1 (20%)	5
Visits from NHS or council-funded care workers	2 (20%)	1 (10%)	2 (20%)	0	1 (10%)	4 (40%)	10
Visits from self-funded care workers	2 (20%)	1 (10%)	2 (20%)	1 (10%)	2 (20%)	2 (20%)	10
Sitting service	1 (25%)	0	1 (25%)	0	2 (50%)	0	4
Other breaks services	0	0	0	0	1 (50%)	1 (50%)	2
Support from local community or NHS volunteers with shopping, prescriptions, etc.	5 (63%)	0	0	0	1 (13%)	2 (25%)	8
Total	**15 (20%)**	**10 (13%)**	**7 (9%)**	**2 (3%)**	**18 (24%)**	**23 (31%)**	**75**

- The impacts of support services being closed or changed included carers having no or less support or help and having to do more. Two people found it hard not being able to visit their loved ones in care homes and two told us that virtual support was not as good – although this support was still valuable.

> “Services appear stretched/non-existent; difficult to find more care/support; family tend to try to cover more and more care which is difficult when they have their own family/needs.”
>
> “My sons day care has re-opened and has been offering Zoom sessions which he has taken part in but it’s not the same, he cannot attend as he would need a letter from his GP to do so which has been declined as he is classed as highly vulnerable.”

> "We have both lost access to key workers and talking therapies. This has made life unnecessarily difficult for both of us. Some of the people I know in similar circumstances have found themselves discharged without proper process - care plans, risk assessments etc. I can phone the duty manager and not get a call back and it has been the same with PALS. Come second lockdown it was easier to just not bother with trying anymore."

Impact of change in services	Number of comments
Support/services	**10**
No support/help	*6*
Couldn't access support	*2*
Services stopped and started	*1*
Difficult to access support/help	*1*
Less help/hard for carer	**5**
Having to do more	*3*
Other support stopped	*1*
Exhausted - need break	*1*
Care homes	**2**
Can't visit care home so delaying care	*1*
Deterioration of older person - can't visit care home	*1*
Shielding	**2**
Not going to college as shielding	*1*
Can't have help because shielding	*1*
Virtual not as good	**2**
Other	**3**
Cared for reluctant	*1*
Lack of information	*1*
Isolation for older people	*1*

- Four people told us about some good support they had received, including from Northamptonshire Carers, and some of those interviewed discovered additional support services they could access online to support their own health and wellbeing.

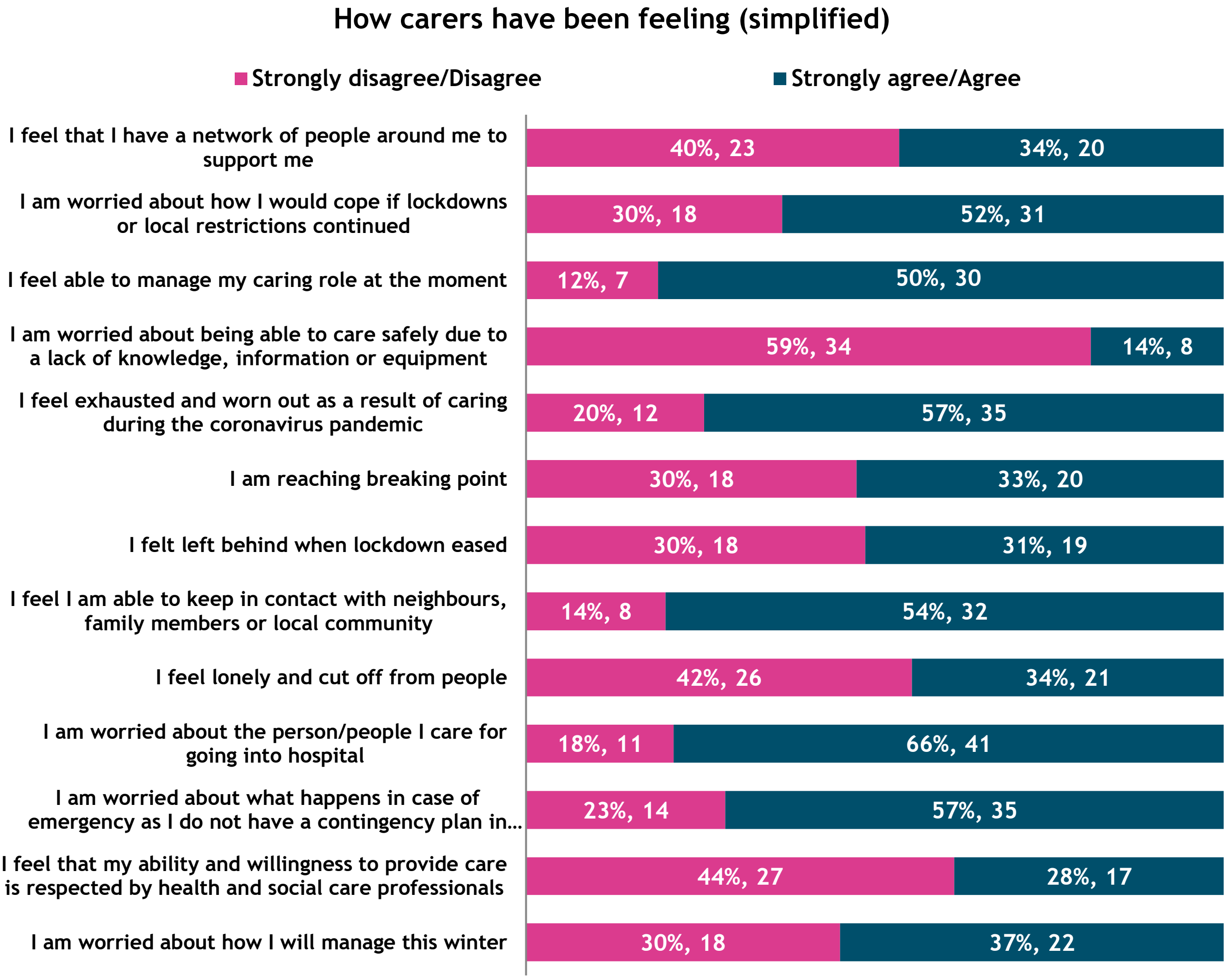
> "Stroke outpatients team were amazing. Visited dad three times a week for three months of rehab… Had two days of respite care for mum from a carers charity when I was at breaking point. Will be forever grateful for their support in a time of great need."
>
> "I had a series of phone calls from Northamptonshire Carers last year, which were helpful, and I know I can contact them should I need to."

Other impacts of the pandemic on carers

Concerns of carers

- 57% of survey respondents agreed that they felt exhausted and worn out as a result of caring during the coronavirus pandemic and 52% were worried about how they would cope if lockdowns or local restrictions continued. Two-thirds of carers were worried about the person or people they care for going into hospital, and 57% were worried about what would happen in the case of emergency as they did not have a contingency plan in place. Almost half (47%) felt that their ability and willingness to provide care was not respected by health and social care professionals.

- Most people thought they had the knowledge, information or equipment to care safely – although 14% did not, and half (50%) felt able to manage their caring role at the time (compared to 12% who did not).
- 54% felt they were able to keep in contact with neighbours, family members or the local community, but concerningly, 40% did not feel they had a network of people around them to support them, 34% felt lonely and cut off from people, 33% felt they were reaching breaking point, and 31% felt left behind when lockdown eased.



"I am [over 70], and two members of my family rely on me heavily for care and support, both have different needs, my sister is becoming more frail, so her needs are more physical and my son will always need support to cope with everyday life which can baffle him at times. Some days I just want to run away and hide and feel that mentally and physically I cannot cope anymore, but they are only "some" days. They don't have any other support currently, so I just get on and do."

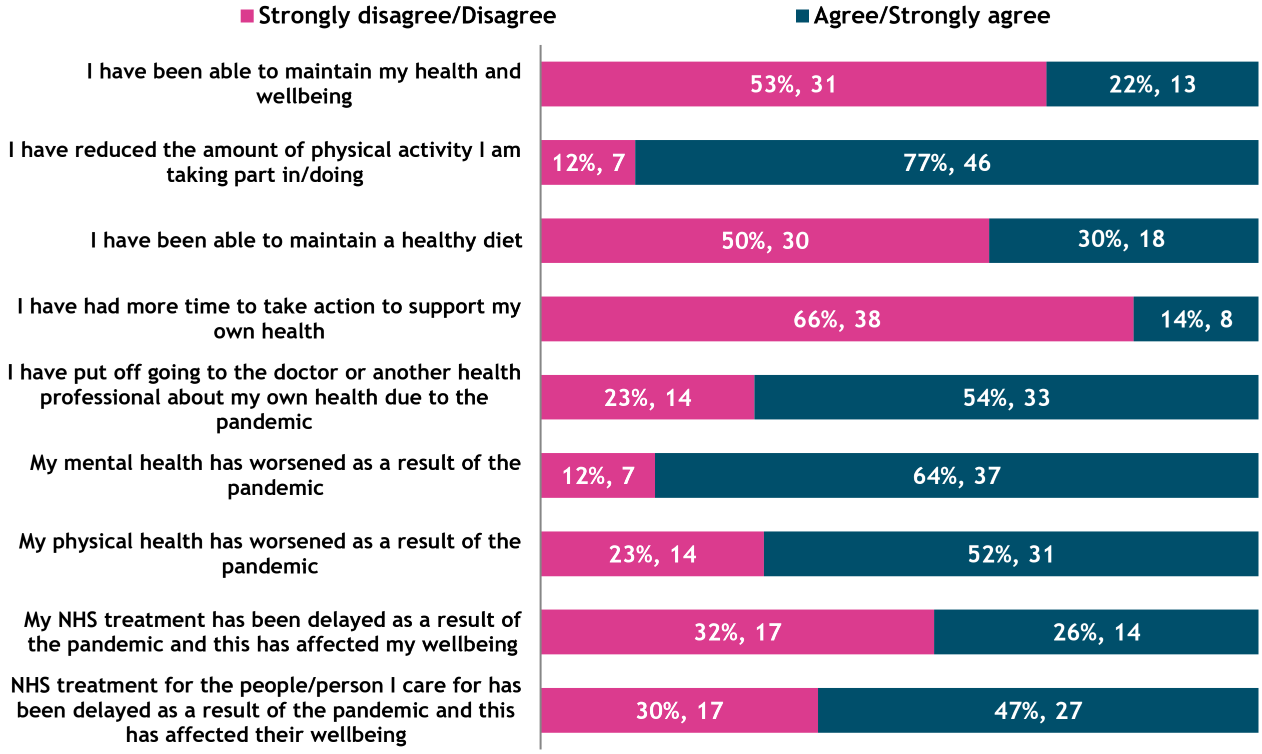
"I worry about everything regarding the virus, I am exhausted. I have had no extra support from anywhere. We have to live on next to no money - something else that there has been no help."

"If anything happens to me then my cared-for would be unsupported. I'm not sure I can keep myself well enough over the next few months to continue."

Impact on wellbeing

- Carers have felt many impacts of caring throughout the pandemic on their health and wellbeing. Only 22% of survey respondents felt they had been able to maintain their health and wellbeing. Nearly two-thirds (64%) felt their mental health had worsened as a result of the pandemic and half (52%) said the same about their physical health. 77% were doing less physical activity and only 30% were to maintain a healthy diet.
- 54% had put off going to the doctor or another health professional about their own health and 26% had had NHS treatment had been delayed as a result of the pandemic, which had affected their wellbeing (with delayed treatment also affecting the wellbeing of 47% of the people cared for).

Effects of pandemic on carer health and wellbeing (simplified)

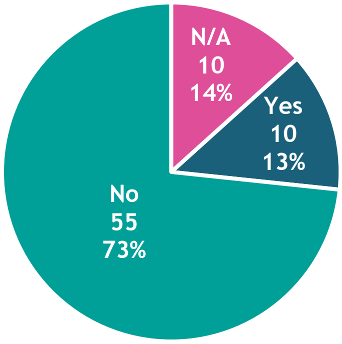


- 26 survey respondents explained more about how caring during the pandemic had increased their anxiety and depression, caused them to gain weight and exercise less, and how some of their medical conditions had got worse. Some carers also told us more about how they felt unsupported, neglected, isolated, tired and stressed. Increased pressure was difficult for some and other carers felt lonely.

> "I have pre-existing heart problems. Because I am so exhausted and stressed by my caring role, I have been eating terribly (comfort eating) so have put on loads of weight. I have just been told I am pre-diabetic. This is dangerous for my heart and stresses me further. I am a single mum so worry about my [child] if I died. Despite knowing all this, I still don't have the time, energy or motivation to address it. At the end of the day I just slump in front of the TV with junk food. Working, caring for my son and parents and home schooling has made this a very difficult year for me, both physically and mentally."
>
> "I am mainly tired… spend most of my day juggling priorities to ensure everyone gets the care they need - which leaves little time for me. My health has deteriorated."

Breaks

Able to take a break/enough breaks from caring role



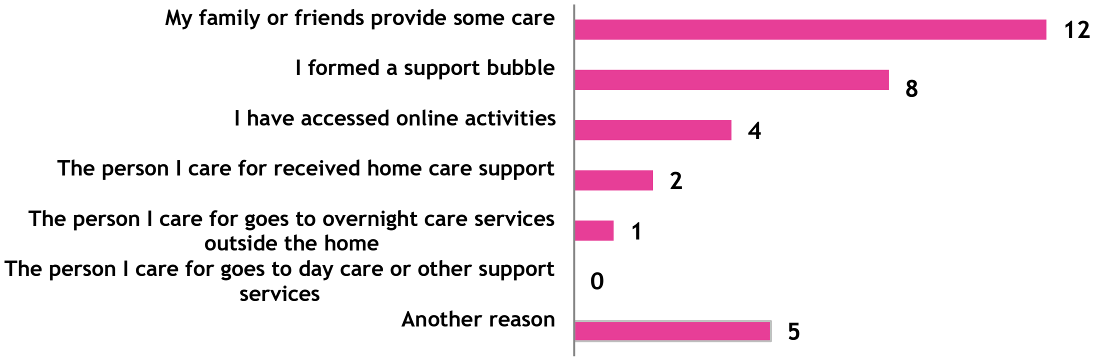
- Three-quarters (73%) of survey respondents had not been able to take any or enough breaks from their caring responsibility during the pandemic. The most common reason for this was there being no-one else who could take over the care, a difficulty enhanced by the travel restrictions, limits on who you could have contact with and the need for some carers or those they care for to shield. Some people added that the people they cared for needed constant support. The closure of day centres, respite service and schools prevented others having a break, as did the loss of usual informal support, such as visits from friends and family.

> "Due to lockdown, I have been unable to get anyone to help me support my mum or son. All responsibility has been left to me."
>
> "Day centres and Personal Assistants are all closed and so our son is home all day and night."
>
> "Less people who can step in and provide informal respite care/support. More stress."
>
> "Covering care and supporting self/family has remained a constant battle/balance; there is no opportunity to take a break."

Reason for not being able to take a break	Number of comments
No-one else	21
Constantly needed	7
Cessation of services	7
Cannot go anywhere	7
Loss of support	4
Shielding	4
Increased need of cared for	3
Supporting family	2

- 22 carers told us they had been able to take a break, mostly through having help from friends, family or support bubbles, with a few having support from paid carers or being able to access online support activities, such as those provided by Northamptonshire Carers.

Reason for getting a break



- The impact of not being able to have enough breaks was again felt by carers, with many describing the physical, mental, and emotional toll and how they had to take on more responsibility.

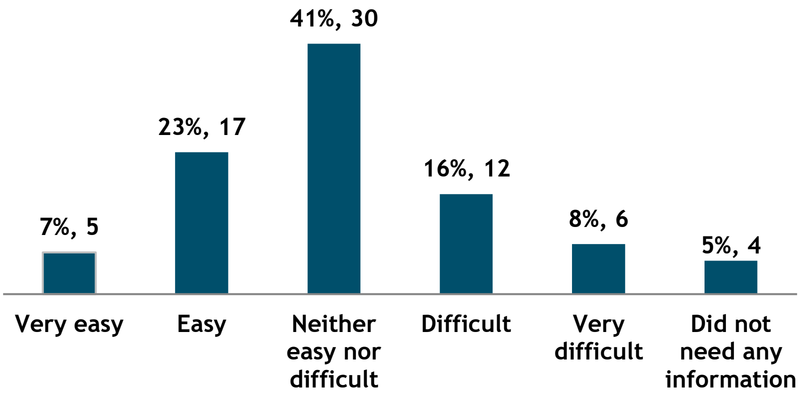
Impacts of not being able to take a break	Number of comments
Exhausted/tired/stressed/frustrated/worried	10
Impact on mental or physical wellbeing	6
More responsibility/more busy	5
Other	5
Keep going	*2*
Used to coping alone	*1*
Unfair on other family members/children	*1*
Guilt from cared for if went away	*1*

Guidance, information, advice and technology

Information

- Finding information was easy for some and more difficult for others. Most of those who found it difficult to get the information they needed as a carer mentioned that the information from the government was confusing, unreliable or inconsistent, and one person we interviewed gave an example of how they were told different things by different people at different times. Some carers were left questioning whether to break the rules to provide care, as well as having to determine who to choose to care for if multiple people needed them, while keeping themselves and the people they care for safe. A few struggled to find information about the risks to those they cared for, finding that there was more information for paid carers than unpaid (informal) carers, and some people were still unclear about access to vaccinations for carers at the time of the survey.

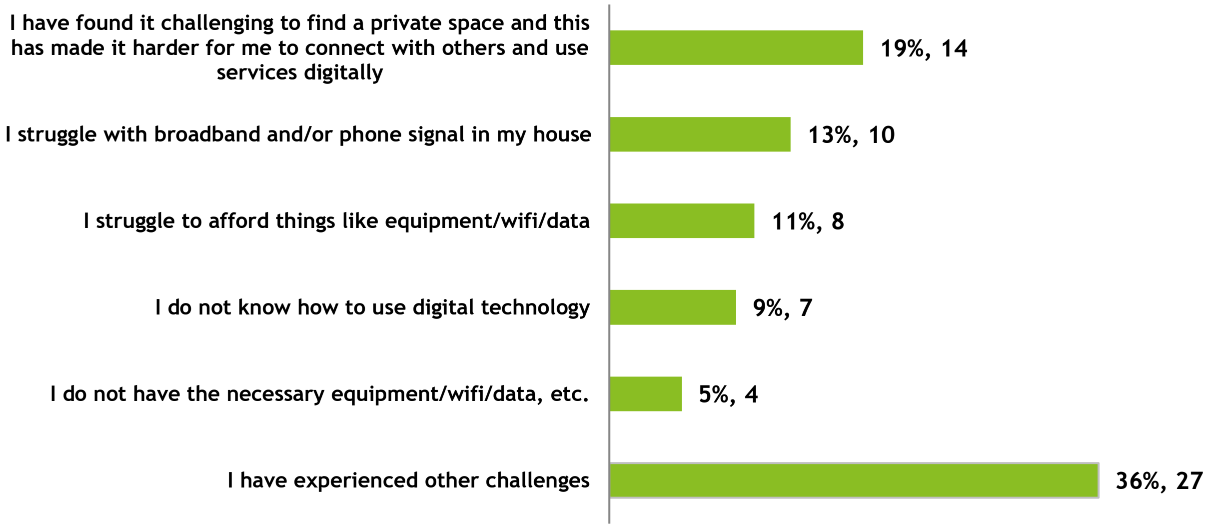
Ease of finding information about coronavirus needed as a carer



> "Most Government information on Covid have not included information specifically related to unpaid carers. It has been difficult to find the information I need, e.g. it is only by receiving the carers newsletter that I found out that unpaid carers were going to be included in the vaccine rollout."
>
> "Some services/departments closed or reduced services. Longer delays getting reply."

Technology

- Access to technology or knowing how to use it was not an issue for most carers, although these were all an issue for some. Half the survey respondents had experienced difficulties using digital technology, including finding it hard to find a private space at home to have a remote appointment or conversation, and struggling with poor internet or phone signal – or struggling to afford the technology altogether. In the survey comments, twelve carers highlighted that although they could use digital technology, those that they cared for but did not live with, such as elderly relatives, could not use it or did not have access to it. This presented some with challenges in communicating with the person they care for and in supporting them to use digital services, such as remote health appointments. Two carers mentioned the need for video calls and having to encourage the GPs to use video technology instead of phone. One highlighted accessibility issues for a person with hearing difficulties they care for and their struggle the increased reliance on phone calls.



Challenges using digital technology

"I have limited experience of technology which has made it harder, slower and more frustrating for me to get quick easy help."

"Rheumatology consultant used Teams online, but it was so slow on my phone, we had the picture of me but could not work it, so he rang me on my landline. We do not have access to iPad, iPhone, laptop and have been invited to Zoom meetings but just cannot do it and I have got stuck. It would make a big difference to us if we did have that."

"I have psychological therapy on Zoom, and it is tough to find a private space in the house."

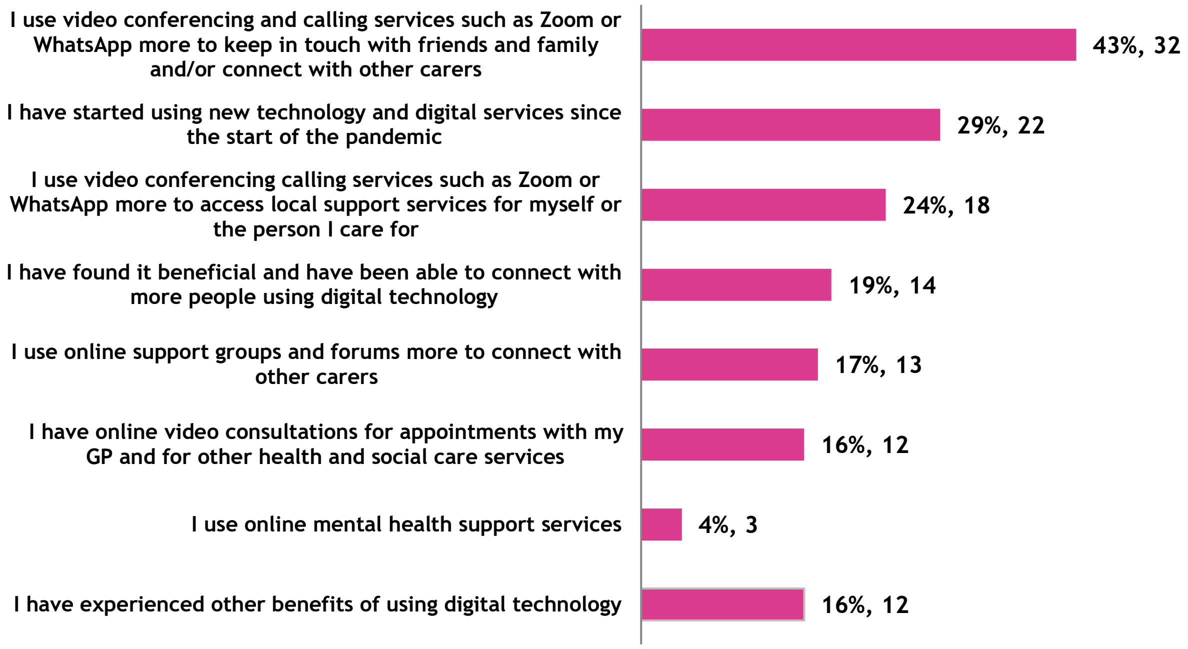
"My father will not have Wi-Fi, so we are unable to speak to him through digital technology. He also can't use a smart phone so online banking, etc. is not possible."

"My mother struggles with this so it requires me to be present when they offer her telephone or virtual appointments. This has caused increase in hours I care for her to help with this."

"The GP surgery had not used video calls until my mum was suicidal, and I asked them to try and use technology to talk to her."

- 43% of survey respondents had used technology more to keep in touch with friends, family or other carers and 29% had started using new technology or digital services during the pandemic. One quarter (24%) were using video calling services to access local support services for themselves or those they care for and 17% were able to connect with other carers through online support groups and forums. 14 people (19%) agreed that digital technology had been beneficial and helped them to connect with people. Others appreciated being able to do shopping online, etc. and get information.

Increased use of digital technology



"Felt closer to family and friends in that I can meet on Zoom whereas as before I had to make complex arrangements to leave the house and meet."

"I can buy stuff online without going out unnecessary."

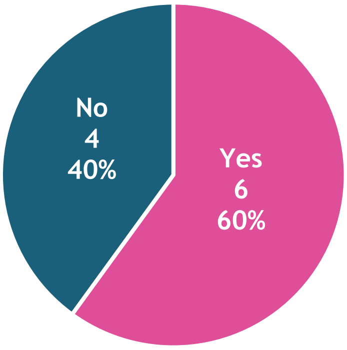
"I have taught my dad how to use WhatsApp so I can be sure he is ok as he would have said he was fine without me being able to see him/my mum for myself."

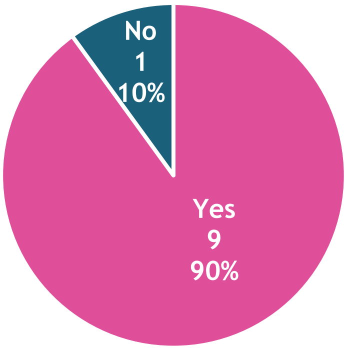
"Time saved going to appointments and finding a parking space, and generally less stressful (i.e. when it works!). No parking/petrol/wear and tear costs."

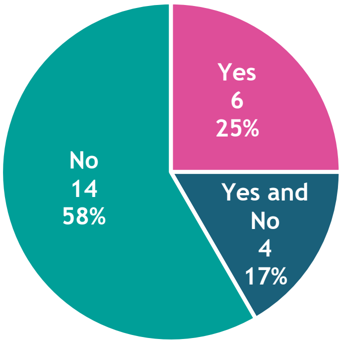
- The risk of digital exclusion was also highlighted at the consultation event. Carers explained more about how video meetings/appointments over platforms such as Zoom are not easily accessible for everyone, particularly for older people and those who do not have the knowledge or desire to use technology. It was also pointed out that those with mental health needs often prefer to speak to someone on the telephone or face-to-face as it can be hard to understand gestures on virtual platforms.

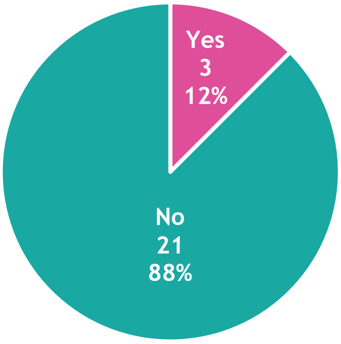
COVID-19 testing and Personal Protective Equipment

- Getting a test for COVID-19 had been more difficult at certain points of 2020 so we asked carers in the survey if they'd had any issues. Most had not but four had needed a COVID-19 test but could not get to a testing site, three had needed a test but could not get an appointment or home testing kit, one could not use the testing kit or had difficulty with it, and one was unsure about whether they needed a COVID-19 test. Six of the ten who had tested positive felt they were given sufficient information and advice about self-isolation and nine out of ten found caring more difficult following a positive test.


Sufficient information?


Caring more difficult?

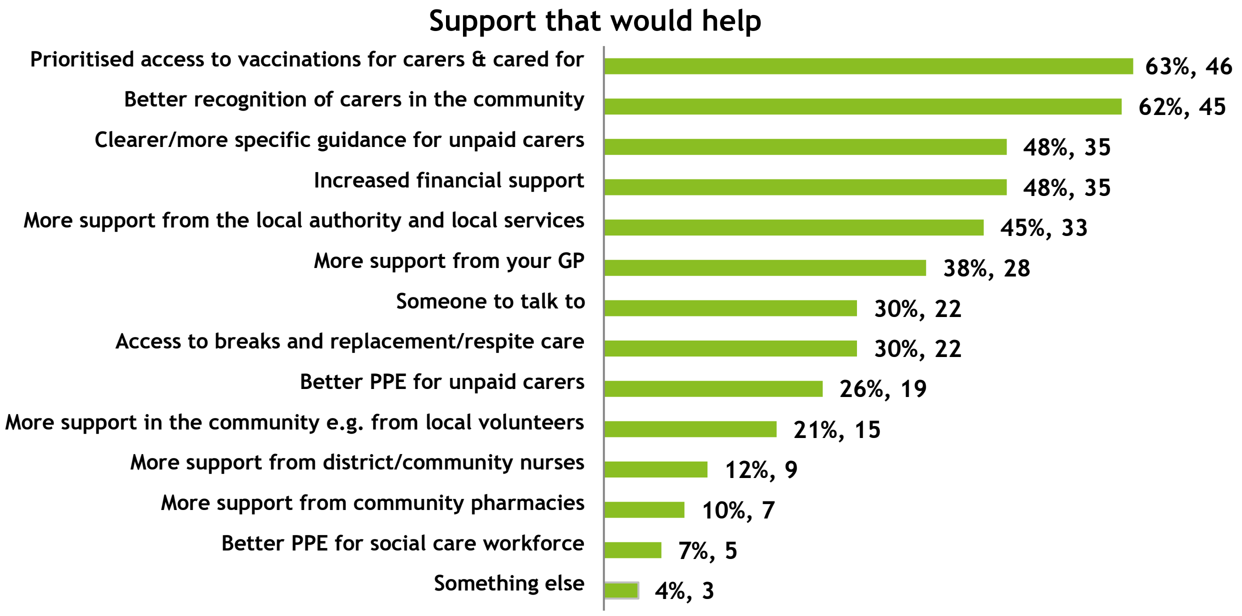

Trouble getting PPE - proprotion of those who need it


Given advice on the most effective way to use PPE- proprotion of those who need it

- One third (32%) of survey respondents needed Personal Protective Equipment (PPE) to carry out their caring role at least some of the time during the pandemic. Most were able to access the PPE they needed, but ten people had had some difficulty. Most carers who needed PPE brought their own.

Future support and changes that should continue

- When presented with a list of support that may help them during the pandemic, prioritised access to vaccinations for carers and the people they care (63%) and better recognitions of carers in the community (62%) were the most selected options by survey respondents. Almost half (48%) would like clearer or more specific guidance for unpaid carers and increased financial support, and 45% would like more support from the local authority and local services. Over one-third (38%) agreed that more support from their GP would help and 30% would benefit from having someone to talk to and/or access to breaks and respite care.



"Why is Carer's Allowance ONLY £67 per week for my 120 hours? … Carers are so under paid for the amount of work we do - we do not do 8 hour shifts and then go home; our shifts are 24 a day"

"Especially better recognition of Carers in the community."

"It would be a great support to talk to other people who have relatives with dementia."

"Not having to feel you are having to fight all the while for help, I have been reduced to tears on many occasions just to speak to doctor (not GP)."

- Carers at the consultation event talked about the support carers will need after the coronavirus pandemic, including phone and digital services blended with face-to-face, new services for carers and increase in the services for carers currently being offered, and increased awareness of carers. Most of those we interviewed also felt that a mixture of virtual and face-to-face appointment would be helpful in the future.
- Four survey respondents highlighted positive changes they would like to continue – the convenience of phone or video appointments, benefits of online support and shopping and prescription deliveries.

Recommendations

Based on the feedback we have received the following recommendations should be considered by service providers to help support carers and the people they care for during and after the pandemic. We also support the recommendations made by Carers UK in their report[2].

Access to services

1. Maintain a combination of telephone, digital and face-to-face health and support services, whilst giving people the ability to choose the route to access appointments that best suits their needs and access requirements.
2. Remain aware of those who struggle with digital access and seek ways to support them to become more digitally literate if they would like to, but continue to offer alternative ways to communicate, such as letters and booklets.

Support for carers and cared for

3. Promote Public Health Northamptonshire services[3] that can support those who have lost independence or become more frail during the pandemic, such as the Supporting Independence Programme, and other wellbeing services that could support carers who want to lose weight or exercise more.
4. Increase support to help people transition back into 'normality' and to overcome the trauma experienced, especially for those who are anxious or who have suffered loss during the pandemic.
5. Improve access to mental health support for those being cared for as many carers struggle to support their loved one who are waiting for professional help.

Specific support for carers

6. Recognise the contribution of carers and respect their ability and willingness to provide care and knowledge of the person they care for and their needs. Ensure they are well supported by local authorities, local services and financially. Continue to promote the needs of carers to health and care services, such as through the Northamptonshire Carers Investing in Carers GP accreditation scheme[4].
7. Be aware of the increase in the number of carers due to the impact of the pandemic on people's conditions and those who have developed long-term effects of COVID-19. Support will be required for these people and those they care for.
8. Ensure that carers are able to take breaks, that there are sufficient respite services, and that the return of essential services is prioritised.

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[2] Caring behind closed doors: six months on - The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers - October 2020: www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on, pages 23-27.

[3] www.northamptonshire.gov.uk/betterhealth

[4] www.northamptonshire-carers.org/gp-surgeries

9. Maintain and expand support services that have been introduced, such as befriending and peer support groups and telephone ‘check-ins’.
10. Provide carers with clear advice about the risks of COVID-19 and any contagious diseases or endemics and ensure carers are prioritised in future vaccination programmes.
11. Provide more support for carers of ‘self-funders’ who have to arrange the social care of those they look after with minimal guidance.
12. Encourage employers to offer flexible working to support carers and maintain an increased awareness of how diseases are transmitted to help protect carers and the people they care for - people should be encouraged to stay at home if they are unwell.

Responses to the report and recommendations

Northamptonshire Carers

Coronavirus has impacted everyone in Northamptonshire and beyond. For unpaid carers and young carers though, this impact is twofold: not just are they concerned about their own health, wellbeing and in many instances finance but they are also having to consider the person they care for. Our Carers Support Line received many calls from carers who had very complex, risky or worrying challenges. For example, carers who had to juggle working with caring for a loved-one who was clinically vulnerable – if they themselves were vulnerable then their employer would have let them shield from home, but this was not possible to protect the cared-for person. Carers of people with dementia called us in crisis after respite and day care was cancelled or felt nervous about care workers visiting their home when there were concerns about PPE supplies. Parent carers and young carers were disproportionately affected when schools were closed and even when reopened, we spoke to many who were anxious due to health conditions within the family.

This report demonstrates this impact and also highlights what support is needed. Some of this is already in place with a popular menu of online activities to provide a break from caring. We are planning on keeping much of this whilst reopening face-to-face support in-line with guidance. As the report finds, flexibility suits many carers whether it be in the workplace or in terms of delivery of services. This allows an individual approach which best suits a caring role – there are 70,000 carers in Northamptonshire, each with their own circumstances who would benefit from this approach.

Supporting carers is a team effort involving health services, social care, employers, voluntary sector, education and the wider community. In doing so each of these partners also benefits such as reduced reliance of statutory services or absenteeism at school or work. Northamptonshire Carers support the outcomes of this report and will work with partners to deliver upon it.

We would like to thank Healthwatch Northamptonshire, Carers’ Voice and everyone who contributed to this comprehensive and insightful report.

Public Health Northamptonshire

This report highlights the disproportionate impact of Covid-19 on carers as they provide support and manage their own wellbeing alongside those they care for. Earlier in the pandemic, Public Health Northamptonshire completed a Covid-19 Equality Impact Assessment, reviewing the evidence base on disproportionate impacts across different population groups. One group highlighted within the evidence base was carers, and the evidence resonates with the findings from this report.

Therefore, it is important we collectively utilise the report’s findings to support carers as we begin to learn about and adapt to living with Covid-19. The report highlights clear, realistic recommendations for local organisations to take forward, one of which specifically addresses the promotion of Public Health services (recommendation 3). We will take this forward to work with local carer organisations, identifying ways to promote services addressing the concerns raised - such as the Supporting Independence Programme; the Falls Management Service; promotion of physical activity in general and the participation in strength and balance exercise in particular; healthy eating and Weight Management; and promotion of mental wellbeing and access to Mental Health services.

The full list of recommendations should be collectively considered across the Northamptonshire Health and Care Partnership and Public Health Northamptonshire will support in considering these.

We'd like to thank Healthwatch Northamptonshire and partners for the insightful report which will support our work going forward. We'd especially like to pay gratitude to the many carers who have inputted into the findings to help us plan and adapt to local need.

West Northamptonshire Council

West Northamptonshire Council are in the process of pulling together an action plan in response to the report and would welcome the input of both Healthwatch and other stakeholders in how we develop and take this forward for carers in West Northants.

NHS Northamptonshire Clinical Commissioning Group (also on behalf of Primary care and Northamptonshire Health and Care Partnership)

It has been said many times, but our experiences throughout the pandemic were, and continue to be, truly unprecedented. The role of, and pressures on, carers during these challenging times has also been something we have collectively recognised across Northamptonshire Health and Care Partnership (NHCP) and that carers are one of the population groups that have been disproportionately affected.

So as Northamptonshire Clinical Commissioning Group (NCCG), and on behalf of NHCP, we welcome this report and the detailed insight it provides. We thank Healthwatch and Northamptonshire Carers for their thorough and robust investigation into this vitally important issue.

From the outset of the pandemic health and care providers, as well as wider public services across the county, worked closely together to provide a coordinated response to support our community, including our carers. As we move towards recovery taking our learnings from Covid-19, Northamptonshire Carers are working closely with us in a few areas including our Integrated Care across Northamptonshire programme (iCAN) which focuses on improving patient and carer experiences of care as people age and become less independent.

We welcome the clarity of the recommendations in this report, in particular we are reassured to see that recommendation one, regarding retaining a combination of access routes to services aligns well with our forward planning for services across our GP surgeries through to hospital care.

NCCG will continue to work closely with our GP, community nursing and mental health provider colleagues on our recovery and response to Covid-19 as we move forward, and this report provides valuable insight into how we can better support carers though this journey.

The twelve recommendations and the rich verbal feedback gives a clear signal on what matters to our carer community. It provides a strong grounding for priorities to take forward in our collective planning. We are extremely grateful to Healthwatch, Northamptonshire Carers and the many carer responders to this report, for the opportunity to address these findings across our services as we move forward together

Northamptonshire Healthcare NHS Foundation Trust

Covid has brought incredible challenges to our wellbeing and how our communities function and this is particularly noticeable for carers. The increase in caring due to isolation and Covid restrictions is immense and we are aware many would not cope without their carers. Throughout the pandemic we have been considering how we support carers and have increased our carer support for those who have had patients on the wards, with a Carers Group run by a Consultant and carer representative. This proved to be a supportive space and has fed back to us at the Patient Experience Group to inform planning as Covid has unfolded. We are now looking to replicate this support in other areas and are also training some carers who wish to have support roles within our organisation to ensure that we continue to grow our carers' support as we come out of pandemic.

We recognise that the biggest barrier during the pandemic has been how people access support for their health, we have all been challenged by the changes here. In mental health services we maintained services to a level of contact by telephone and online support, which was new for staff and those accessing our services, and face to face for emergencies. We have completed a review on the benefits and barriers to this through the Patient Experience Group and the feedback has been really varied. As we move through the pandemic more services have come back to face to face (with PPE) and we are listening to people's view about online/telephone consultation and considering how we give a mixed approach to meet people's preferences. In particular, we recognise the challenges this raises for our older people's population and are glad to have resumed a lot of our older persons face to face and group services. We have also increased their funding to enable more staff to be available in particular to work on diagnosis pathways for dementia.

We are still challenged by our ward environments and how to maintain the balance of keeping people safe in relation to Covid, but still keeping in contact with family members. This has certainly been easier in the summer months. We take on board feedback and will continue to work on improving contact with loved ones, in particular for older people, who we managed to maintain a level of contact with as the main carer through care planned activity, but recognise this has been so hard for many families.

In addition we have our 24 hour telephone line, which is self-referral for service users and carers which is open 24/7 and takes in the region of 8000 calls a month and navigates through a range of services including voluntary sector support in the community. This will continue as Covid reduces and sits alongside our crisis cafes run with MIND, which have been open throughout the pandemic and increased in their sessions to allow for 12 noon – 11pm access across county.

Joint response from Northamptonshire's acute hospitals – Kettering General Hospital and Northampton General Hospital

The Covid-19 pandemic has had a major impact on acute hospitals and – in order to keep patients safe – we have had to change many ways of working which we recognise has had a significant impact on patients and their families and carers.

Necessary changes have included restricting visiting to inpatients, significantly reducing face-to-face outpatient appointments and increasing the proportion of hospital consultations carried out by telephone and video link. We have also had to rearrange routine waiting list procedures while continuing to provide emergency medical, surgery and cancer care in the most difficult of circumstances.

We are very aware of the impact these changes have had on patients, families and carers and have been carrying out work throughout the pandemic to mitigate this. This has included:

- Enabled Virtual Visiting - using computer tablets and phone apps – so that patients, families and carers can continue to see and speak to one another during those periods when visiting was not (in most cases) allowed in our hospitals.
- Looked at new ways of keeping families connected by using dedicated email accounts and postal services so that letters, pictures or videos can be shared with patients in our care (Our Letters to Loved Ones and Thinking of You Service) – This has included establishing a Relatives Helpline to ensure families and carers can receive regular updates on their loved ones.
- Initiated a patient property drop off and collection service so that essential items and home comforts can be brought into patients in a safe way.
- Enabled appropriate, where safe, visiting for patients at the end of their life by family members or carers.
- Reinstituted limited, booked, visiting for family members and carers once the peaks of the pandemic had passed. Maintaining the highest safety standards to reduce the risk of Covid-19 being brought into the hospital.
- Our ward and spiritual and pastoral care (chaplaincy) teams have supported families who have lost loved ones in the pandemic.
- Worked hard to maintain the principles of John’s Campaign which means, where possible, we now support and facilitate carers remaining with patients that have a diagnosis of dementia.

We plan to maintain a combination of telephone, digital and face-to-face services, and, where possibly, will tailor these to meet the needs of our patients, families and carers.

We have an ongoing survey – supported by Healthwatch and Northamptonshire Carers - which is monitoring access to digital services and are feeding this information to our patient forum and quality and safety committee so that we can respond to people’s needs appropriately.

We understand the concerns people have raised about catching Covid-19 in hospital which is why, throughout the pandemic, we have maintained the highest safety standards and infection control procedures in our wards and departments.

Although many national restrictions on movement and face coverings have been relaxed within the hospital itself we ask all of our staff, patients, volunteers, carers and visitors to continue to wear masks, wash their hands and maintain appropriate social distance. Also for everyone to follow the rules specified in each department.

We have recognised the importance of involving and working closely with patients, carers and our external partners such as carers groups during the pandemic. For example Healthwatch and Northamptonshire Carers are represented on a number of forums within our hospitals which enables them to contribute to shaping the way we deliver services.

We understand the concerns raised in Healthwatch’s survey about waiting times and this is a key priority for us as we reset services.

We are working hard – including at weekends – to continue to progress our plans to support patients, families and carers in getting the medical attention they need.

Acknowledgements

We are very grateful to all those who took the time to share their views and experiences with us – thank you.

We would also like to thank all who worked with us to develop and share the survey, especially:

- Northamptonshire Carers
- Carers' Voice Northamptonshire
- Support Northamptonshire
- Northamptonshire County Council (now North Northamptonshire and West Northamptonshire unitary councils)
- Age UK Northamptonshire
- and Healthwatch Northamptonshire volunteers

Thanks too to all the community groups and online pages that shared the link to our survey.

About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as "Enter and View") health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

Find out more at www.healthwatchnorthamptonshire.co.uk

healthwatch
Northamptonshire

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About Northamptonshire Carers

Why we do, what we do

Northamptonshire Carers aim to offer a comprehensive support service to Carers within Northamptonshire and in collaboration or close partnership with organisations that complement the service we deliver. We recognise the vital contribution Carers make to society and we will work to empower Carers in improving their health, wellbeing and quality of life, alongside raising awareness with all stakeholders with the aim to create Carer Friendly Communities. We recognise the diversity of our communities and are committed to supporting all Carers. The organisation is Carer-led and our developments will be a response to Carers future needs.

About Northamptonshire Young Carers Service

A young carer is aged between 5 and 17 years old. A young adult carer is aged between 18 and 25 years old. They take on responsibility for helping to look after someone (usually a family member) who has a long-term illness or disability. This could include a physical disability, learning disability, mental health problem or substance misuse issue.

The Young Carers Service will assess a family on an individual basis taking into account that the impact of the young person's role may differ depending on age and other family circumstances. The Young Carers Service offers one-to-one support, social activities, groups, advocacy and family support (such as signposting to relevant agencies). See 'Our Support' page for more information.

It is important to differentiate between young people who are affected by the impact of living with someone who has an illness and those who are actually in a caring role. The Young Carers Service is a service for those who have a necessary caring responsibility.

Find out more at: www.northamptonshire-carers.org

Northamptonshire
Carers

About Connected Together

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Northamptonshire.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures

Connected Together
First for Community Engagement

Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

Find out more at www.connectedtogether.co.uk

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