



# Experiences of caring during the coronavirus pandemic

Full report  
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.”



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## 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 through 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<sup>1</sup>, 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.”**

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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 10-13.

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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<sup>1</sup> 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](http://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on)



“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 disproportionately affected by coronavirus, it provides useful recommendations which we will seek to deliver ourselves and alongside partners.”

*Gwyn 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

- 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.
- 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.
- 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. 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 or those they care for catching coronavirus.

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



- 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. 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. 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.

## 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.

### 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).
- 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.

### Breaks

- 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.

- 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.
- 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.

## 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.

### 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.
- 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.
- 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.
- 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.
- 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<sup>2</sup>.

### 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.

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<sup>2</sup> 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](http://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on), pages 23-27.





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<sup>3</sup> 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<sup>4</sup>.
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.
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.

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<sup>3</sup> [www.northamptonshire.gov.uk/betterhealth](http://www.northamptonshire.gov.uk/betterhealth)

<sup>4</sup> [www.northamptonshire-carers.org/gp-surgeries](http://www.northamptonshire-carers.org/gp-surgeries)



## 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 through 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.
- Reinstated 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.



## Background

During the coronavirus (COVID-19) pandemic there have been many changes to health, care and support services. The feedback received by Healthwatch Northamptonshire, Northamptonshire Carers, and Carers' Voice Northamptonshire earlier in the pandemic suggested that these changes have affected those who provide informal (unpaid) care to family and friends and that there has been an increase in the number of unpaid carers as a result of the coronavirus pandemic.

National research by Carers UK showed the majority of unpaid carers immediately took on more care for their older, disabled or seriously ill relatives through the lockdown<sup>5</sup>, and six months in (October 2020), four in five carers (81%) reported that they were still providing more care than before the lockdown<sup>6</sup>. In the survey of nearly 6,000 carers, two in five (40%) said they were providing more care because the needs of the person they look after had increased. Many cited the detrimental impact of the national lockdown on their relatives' physical and mental health.

A similar proportion of family carers (38%) were providing more care because their local services had been significantly reduced or closed. COVID-19 infection and control restrictions meant most day services were operating at a reduced capacity and some had not opened at all.

After many months of living with limited contact and support, the pandemic has had a devastating impact on carers' lives, causing them extreme loneliness, anxiety and exhaustion. Three quarters (74%) said they were exhausted and worn out as a result of caring during the pandemic and two-thirds (64%) told Carers UK they hadn't been able to take any breaks whatsoever between April and September 2020.

The Carers UK survey also showed that 58% of carers had seen their physical health impacted by caring through the pandemic, while 64% said their mental health has worsened.

Therefore, Healthwatch Northamptonshire teamed up with Northamptonshire Carers and Carers' Voice to find out more about the challenges being faced by unpaid carers in Northamptonshire and how services can adapt and improve to better support them and the people they look after.

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<sup>5</sup> Caring behind closed doors - Forgotten families in the coronavirus outbreak - April 2020: [www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-report](http://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-report)

<sup>6</sup> 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](http://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on)



## Method

### Project steering group

Healthwatch Northamptonshire put together a 'Carers experience during COVID-19' project team that consisted of Healthwatch Northamptonshire staff and volunteers, Northamptonshire Carers staff, Carers' Voice Northamptonshire representatives, a Northamptonshire County Council (NCC) engagement representative, and a representative from Support Northamptonshire. The project team discussed the issues that they knew were currently being faced by carers (in 2020) and agreed the best approach to find out more and how to reach these people, especially those who do not consider themselves carers. It was decided that we would use a survey and one-to-one telephone interviews or group calls, and to also utilise the Northamptonshire Carers AGM (Annual General Meeting) as a consultation event to gain as much feedback as possible.

### Survey development

The carers project working group decided that it was important to ensure that the survey was available in various languages, so we hosted the online survey on the Healthwatch Northamptonshire website, which has an in-built translation tool. Paper copies were made for those that were not online.

The survey introduction made it clear that the survey was intended for unpaid carers (and a definition was given) and not people providing care as part of paid work.

### Survey distribution

The survey was shared on the Healthwatch Northamptonshire and Northamptonshire Carers website, via their newsletters and social media channels and was also shared with members of both organisations, Carers' Voice and Support Northamptonshire.

A press release about the survey and carers consultation was issued and the project was covered by Heart, NLive and BBC Radio Northampton radio stations and featured in the NN Journal.

The survey was sent by email to a number of community groups and organisations and shared with community groups on social media. It was also shared on social media by other health and care organisations in the county.

Paper copies were distributed by Age UK Northamptonshire to clients they were supporting at home to help reach those not online.

### Interviews

To ensure we were able to engage with carers in a way that suited them, and that people had an opportunity to speak openly about their experiences during the pandemic, we conducted one-to-one interviews over the telephone and via Zoom.

Eight one-to-one interviews were completed. Online focus groups were also offered but telephone was the preferred format for all. This included one individual Zoom call. Most of those interviewed had also completed the survey and took the opportunity to tell us more through a conversation.

### Consultation event

Healthwatch Northamptonshire supported Northamptonshire Carers at their AGM and consultation event on Zoom, where carers joined to discuss their experiences throughout the pandemic. The event was attended by 56 unpaid carers, young adult carers and professionals.



Attendees split into breakout rooms to discuss three questions that complimented the survey before group facilitators fed back to the main group.

1. What challenges have been faced by Carers during the coronavirus pandemic?
2. Despite the challenges, have there been any positives this past year for Carers?
3. Looking forward, what support will Carers need post-coronavirus?

### Data analysis

Survey data was analysed using quantitative and qualitative techniques. Qualitative survey data and comments were coded and themed. The findings from the interviews and consultation event have been integrated with the survey findings where they support them.

### Limitations

As services and groups were not meeting and face-to-face engagement was not possible it was difficult to reach people that were not online and already aware of organisations such as Northamptonshire Carers and Healthwatch Northamptonshire.

### Previous coronavirus survey findings

During the early stages of the coronavirus pandemic, May and June 2020, Healthwatch Northamptonshire conducted another survey. The survey asked all people to tell us how they had found accessing health and care service during the coronavirus pandemic, including what they thought of the new ways of contacting GP practices, whether they have had any treatments delayed or cancelled and whether they have seen changes in home visiting services from social care workers or community nurses. The survey also asked how much of an impact the coronavirus pandemic has had on people's mental wellbeing and whether they have been able to get help with this. The findings were shared quickly with the health and care system to help them understand where services had improved identify those that were more difficult to use.

20% (62) of the 310 respondents to this survey said they were a carer and 25 of these (40%, 8% of all) themselves had a long-term condition and/or disability.





## What people told us - Findings in full

- 78 people answered our main survey and two young people answered a separate survey tailored for those under 18 years old. Three people had not had experience of caring for someone since March 2020 so were asked not to complete the survey. (All figures given are percentages of the answers received for each question, unless otherwise specified.)
- Eight carers were interviewed by phone or video call.
- 56 people (unpaid carers, young adult carers and professionals) attended the online consultation event held with Northamptonshire Carers and Carers’ Voice. The feedback sessions were recorded and uploaded to YouTube: <https://youtu.be/oNWG4RPxcKA>.

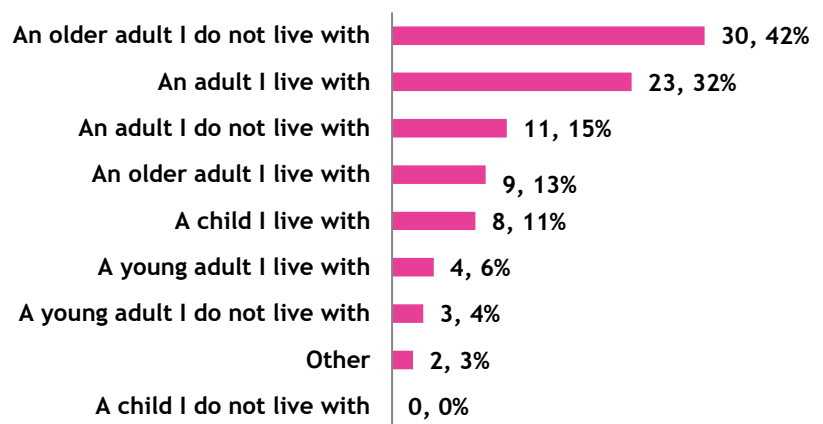
### About their caring

#### People they care for

##### Who do you care for?

Five people gave an additional comment (including the two who answered ‘other’), three of whom explained in more detail that they care for multiple family members. One explained their adult child is homeless but stays with them a few nights a week and one person said they were a Healthcare Assistant at a care home and that they took the job so they could see their parent who lives there.

Person/people care for



One quarter (35%, 17 of 72) selected more than one option.

The two young carers both care for a parent and one also cares for a sibling. Both said they cared for people with a learning disability and mental ill health. One also cared for someone with a physical disability and one with another health condition.

The carers who were interviewed cared for family members or friends with a range of needs, including Downs Syndrome, Dementia, Autism, a hearing impairment, and Leukaemia.

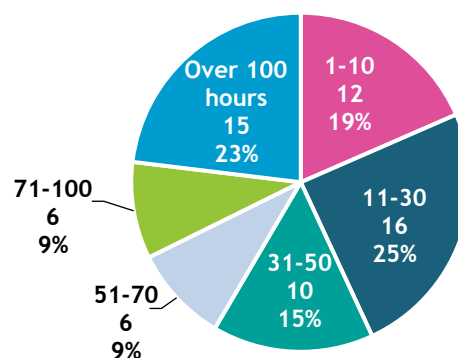
#### Amount of caring

##### Approximately how many hours per week do you provide carer for this person/people?

The answers to this question were given as free text and then coded into categories. Estimates had to be used for some and two people gave broad ranges.

12 of the 15 people who said they cared for over 100 hours per week gave comments such as “24/7”, “7 days a week” or “Every hour”. One person said they were “on call 24/7”.

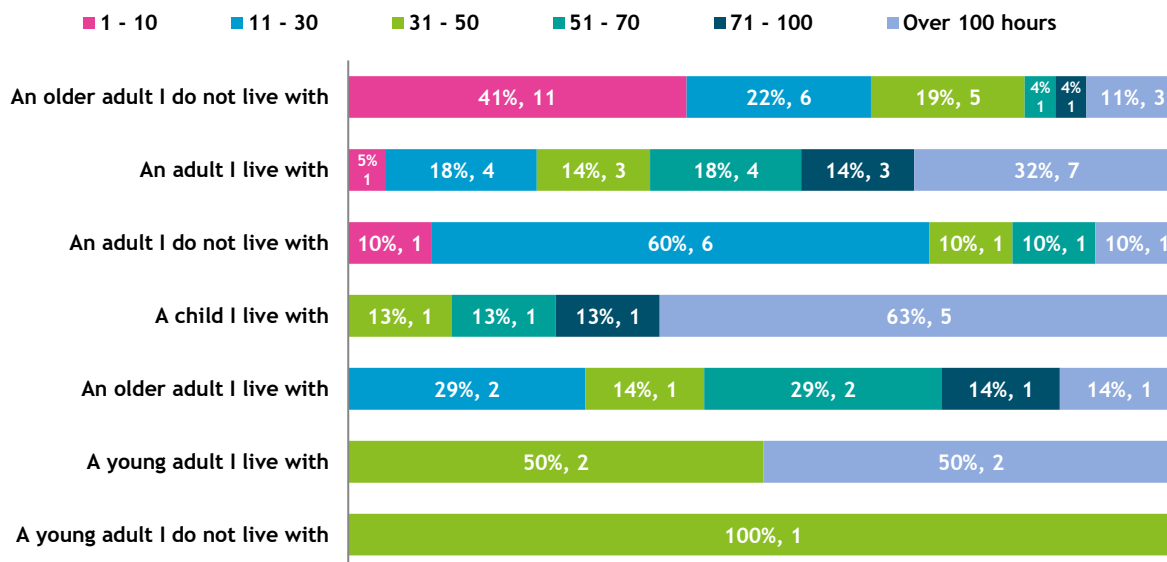
Caring hours per week





Unsurprisingly, those who lived with the person they cared for spent more hours a week caring, especially if they cared for a child. Those who provided care for an older adult they did not live with provided the least care per week, although 37% of these (10 of 27) still provided more than 30 hours of care per week.

### Hours caring per week breakdown by person care for



## Challenges of caring during the pandemic

### Changes in the amount of care given

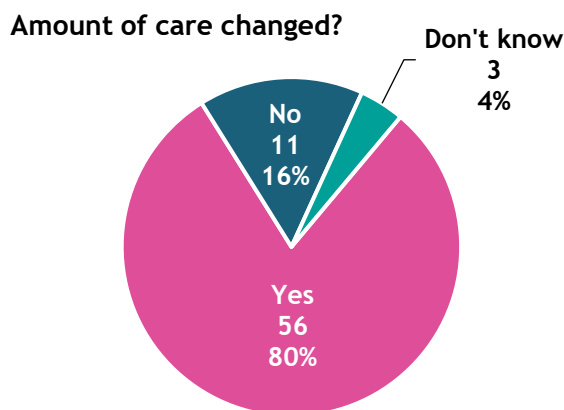
*Has the amount of care you provide changed as a result of the coronavirus pandemic?*

80% (56 of 70) told us that the amount of care they provided had changed because of the coronavirus pandemic.

One of the two young people said they were doing more to support the person they care for and the other was not sure.

#### Reasons for providing more care

Those who had provided *more* care were asked to select the reasons from a list. 55 of 75 people (73%) gave one or more reason for providing more care (33 of whom (60%) gave more than one reason).



Reason	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%

18 people told us more about giving more care for ‘**another reason**’ and a further four gave additional comments.

Eight people (11% of all 75 respondents) highlighted **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 might not be reversed as restrictions ease. Comments included:

“Elderly father-in-law is struggling to cope and has been less able to go out due to the pandemic and is upset he cannot meet or do the normal social things he would do.”

“More anxiety for person and less independence as cannot meet others. More shopping, more help with trying to keep occupied.”

“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.”

“As my mother has been shielding, she is less active and has become more disabled. At times it is difficult to get a supermarket delivery so I’ve been doing more shopping. I live in London and because of the lockdown I decided that it would be impossible to provide care from a distance; therefore I’m staying with her temporarily.”

“Shielding as classed as extremely clinical vulnerable so can’t have anyone in the home or go to day centre.”

“My father’s health significantly deteriorated during the pandemic and has now become very frail ... All this has led to my father who was very independent before the pandemic relying on myself for house cleaning, transport to appointments and looking after his healthcare needs.”

“Although living in sheltered flats, with 60 other people, she cannot have any contact with them which means the isolation is worse as she could mix with others but forbidden.”

Four people (5% of all respondents) mentioned providing more care because of **increased mental health or wellbeing needs**, in addition to the cases of anxiety mentioned above. Comments included:

“Their mental health has deteriorated; one son has suicidal thoughts and their anxiety has greatly increased. Their anger, etc. has increased due to being unable to access the outside world even less than normal. One needs a dentist but can’t access and is in great pain with toothache. My husband’s mobility and mood have drastically changed for the worse too. I am shielding too, so that’s a great impact on all of us.”

“As we cannot go out, this is impacting on wellbeing.”

Four people (5% of all respondents) mentioned providing more care because of **difficulties accessing health services**, including for diagnosis:



“Because I could not get a diagnosis for my wife who is suffering from dementia.”

“My grandson has mental health problems and all support for him has stopped.”

“Although under PCAT<sup>7</sup>, my [adult child] does not have an up to date care plan in place. [They are] very vulnerable and we are very limited on safe places for [them] to stay. [Their] mental health is not being managed effectively and services or support seem reluctant to help.

“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 ...”

Two mentioned having to do more caring tasks, in part because mainstream **schools were shut**, including:

“Shielding meant more caring tasks (like cleaning), no (mainstream) schooling and no help!”

One person explained the impact of a lack of schooling and family pressures in more detail:

“A combination [of reason]. During the first lockdown I had the offer from nursery for [child] to remain in but due to the risks and unknown element of cover at that time I took the decision to keep [child] at home. This was challenging as I had a very stressful job with long hours which meant I spent most of my day on Zoom calls. However, as [child] wasn’t yet at school there was no pressure to fulfil a home learning schedule, etc. and we found a rhythm that worked for us. [Child’s] toilet habits got worse over this [time] but [their] meltdowns reduced with being home more. The pandemic continuing to bring challenges and finding out I am pregnant led to me having to take early maternity leave as I was struggling to cope at work with the increased stress at home, etc. also. This unfortunately was shortly followed by my [parent] having a stroke which impacted the little help I do have at home. The schools shutting made things extremely difficult for me heavily pregnant and struggling with sickness and sciatica plus trying to maintain a now extensive home-schooling schedule was really difficult. My [child] struggled with the changes again, the ups and downs of things being open not, seeing friends then not, etc. which added to the care needed at home. As [they] started school without an official diagnosis in place and [the school] are still getting to know [child] they didn’t identify [child] as vulnerable and limited any space for [them] to two days a week which was only after several calls to the school to discuss. They have kindly increased this to three days a week ready for me have a c-section next week so [child] can have more stability. There is little consideration from the government on these types of situations. Regardless of [child’s] extra care needs... there is no help or provisions as to how to care for two plus kids whilst barely mobile and with a new-born on little or no sleep. How are parents expected to be able to provide an adequate environment for home learning during this period and support their child who will need their attention to fulfil the tasks set at school as at 4 [years old] they are not able to just log online and get on with it?”

In addition, one person said they had started working at their parent’s care home so they could see them, one person said it was “Hard to evaluate as live in and do everything so sometimes it seems endless” and one person commented on a “Positive response to healthy eating habits and how we can change our diet and healthy foods will help us improve our daily routine and improve our fitness.”

One of the respondents to the young people’s survey said they had been providing more care because they had not had a support worker visit and had been home more:

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<sup>7</sup> PCART - Planned Care and Recovery Treatment Service - [www.nhft.nhs.uk/pcart](http://www.nhft.nhs.uk/pcart)



“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*

### Reasons for providing less care

Nine of 75 people (12%) gave a reason for providing *less* care.

Reason	Number of people	Percentage of survey respondents
I am reducing face to face contact with the person I care for	3	4%
I am providing less care for another reason	3	4%
My employment hours/status has changed so I have less time	1	1%
The place where the person I care for lives is not allowing visitors	1	1%
Virtual or remote services (e.g. GP appointments) have made it quicker or easier for me to support the person I care for	1	1%

Two of the three other reasons given were because of the improved condition of the person they care for, for example:

“In 2020 I provided a lot of care to my [sibling] after [they] had a mental health episode and spent several months in Berrywood. Now that [they are] stable, [they] no longer needs a lot of care (though that may change during lockdown three).”

Another person said their relative had moved to a care home:

“Elderly relative finally had to go into a care home, but responsible for him still. Now caring for husband with complex health issues.”

One person explained that the reduction in visits to care home may be temporary:

“My mum is in a care home which is not accepting visitors as COVID is in the home at the moment although visits will start again in a week or so - not answering this question, just giving you an idea of my situation.”

### More about what has changed and the impact on carers

52 of 75 people (69%) told us more about what had changed and the impact this had on them, which can be grouped into the following themes (there was a lot of overlap with many mentioning more than one theme):

Theme	Number of people	Percentage of survey 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%
Other (“nothing has changed” and comment from a worker in a care home)	2	3%



### *Less support (23 people)*

23 people mentioned having less support from or access to health and care services (14 people) and/or from others (12 people) or felt unsupported by the government or financially (four people) (some mentioned more than one theme).

#### **Less support from or access to health and care services (14 people)**

Nine people talked about **difficulties accessing health services, or health services not being available**, including for those that needed medical support and example of poor communication at the point of discharge from hospital, for example:

“My father was admitted into hospital with pneumonia in November, although care in the hospital was good, discharge was disgraceful. At no time was I contacted by hospital staff about my father health and whether I felt he was fit to be discharged, even though I had voiced my concerns to senior nursing staff on several occasions during his hospital stay. 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.”

“Secondary care services for my cared-for and myself stopped abruptly with the first lockdown. Apparently, telephone support can be accessed but I have not discovered how to do this. We have been managing with limited contact with her GP and what we can do for ourselves. My cared-for is waiting to be reassessed (again) by the NHFT Mental Health team - she lost access to services and her key worker in with the first lockdown in March, was reassessed in the summer and directed to Changing Minds, which was inappropriate for her and a waste of their time, and is waiting for reassessment. We are both angry about this, PALS have not returned phone calls or emails, but are not prepared to be put through the complaints procedure again ...”

“We have been unable to attend hospital appointments for my husband due to public transport issues and cancellations. My husband’s epilepsy nurse has been unable to visit due to covid. Her support has previously been invaluable to us ... Has been harder for him to get to his local GP for blood tests, etc. as no buses serve our area. Previously would have got a taxi but have found many taxi drivers not following covid regulations (wearing masks) and as he is on clinically vulnerable list this is not ideal.”

“My mother has become more ill during the Covid pandemic, unexpectedly. My brother has since moved to London so is unable to care for her. The GP referrals for her tests have been delayed so her condition is worsening and medication is not working because they are still unsure of what it is.”

“... I am unable to access local NHS services due to mask wearing and contact method is telephone only. I am deaf myself and lip read to communicate.”

Three people highlighted the **difficulties in getting domiciliary care staff**, for example:

“a) Personal carers self-isolating/shielding; b) NCC approved agency staff unable to accommodate times requested or provide service because of their own staff shortage and/or the reluctance of staff to put themselves in the front line; c) No response to advertising.”

One person illustrated the issues their homeless child faces:



“My [adult child] has been sofa surfing for over three years due to the council deciding they cannot help. The support from friends has drastically reduced due to the pandemic, which has left my [child] having to spend a lot of time in my adapted shed (they will not come into the house for long, as is unable to cope with [my children’s] ADHD [Attention Deficit Hyperactivity Disorder] and lack of space, etc). [They] also focus most of [their] anger towards me, so don’t like me most of the time. When [they] gets too distressed, [they] will go and stay with whoever offers, usually there is no food or anywhere proper to sleep, or they take advantage and [child] comes home more distressed. [Child] was being assessed by adult services for support and help with housing, but, as with the mental health team, they never seem to stay the course.”

#### Less support from others (12 people)

12 people highlighted how **service had closed and/or they were not getting as much support** from relatives or carers services as before, for example:

“All support stopped from anyone else, I am the sole care giver and have had to go into the flats with 60 other people/carers/delivery staff/cleaners, etc. so the pressure has been significant as I have no alternative but to put myself at risk as a nearly 60-year-old.”

“I got a new job so change but also day centres shut and one of my cared for people developed epilepsy. With no support for this during covid my caring role has increased.”

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

“Services more erratic and liable to short notice change. More difficult in regards to getting GP services. Church services/support decreased. Isolation of vulnerable person puts different strains on their needs.”

“Elderly relative (in 90’s) needs more care as health conditions worsen. Other adult’s mental health affected with increased anxieties over contracting COVID-19 and transmission to elderly relative. No breaks this year as other family members have not been able to stay with us to help ease the responsibilities for a short period in time ...”

“I care for my partner who is on the spectrum and I also care for my [child] who is diagnosed SPD [Sensory Processing Disorder] and is on the pathway for an autism diagnosis. Because there is no school [child is] home 24 hours a day hardly sleeps, and I get no support from anyone. My GP said they would support [child] going back to school through the lockdown but the school refused to take [child].”

Four people mentioned **struggling financially or feeling unsupported by other support networks**. Financial hardship was also mentioned at the consultation event, where carers said increased care and staying at home was costing them more, such as having to supply their own PPE or provide others with indoor activities. Others were doing more shopping for people they cared for, using their own money. Example survey comments:

“I’m unable to go out and get things like basic supplies and medicine and have had to spend much more money on food and fuel, I got into debt with gas and electricity as the first lockdown they credited my meter with advance payments which I am now paying back each week ...”

“I have had to care more for my disabled homebound mother since this pandemic begun ... living on £67 a week Carers Allowance is very hard. We need much more help financially, and for our own mental health wellbeing. We feel totally neglected by society.”



### *Extra strain on carer (23 people)*

In addition to the impact on carers already highlighted in the above comments, 23 people mentioned more about how the extra care demands had put strain on them.

Nine people mentioned how caring had been **tiring, exhausting, draining or stressful**, for example:

“... I cannot be with my [adult child] when [they are] in hospital as I usually advocate for [them] when [they are] hospitalised. The nurses were too busy to answer the phones so [I] was not involved in [their] care, although after every admission [child] had to stay with me as [they] required 24 hour care. Whilst this was going on I care for my [parent] who is shielding and becoming more forgetful. My other [child] is autistic and needs social support as well as physical health needs, one diagnosed and one waiting for diagnosis. [Their partner] has Asperger’s and had major surgery ... from which [they are] still recovering. I have found it more difficult and draining during Covid as a carer. There is no outlet for me and I feel very isolated sometimes. I have been exhausted as some points.”

“... I am exhausted mentally and physically and feel I have nobody to turn to. As a family we feel isolated and very depressed.”

“... I am tired to be honest, and often wish I could be somewhere else.”

“More time needed to support, I feel worn out. I have to do a round trip each time as we all live in different areas but I am the closest family member to provide that support.”

“... Try to work to two jobs from home and care for my daughter has caused stress and exhaustion.”

“My hours in my paid job have increased as I’m a registered care manager and have lots of staff off, the care I provide my parent has increased due to them shielding so I’m also doing their shopping and errands. I’m working 60-70 hours a week including both, plus caring for my children. I’m exhausted. My mental health has declined and I’m close to breaking point.”

“I have been shielding since March. Often feel exhausted by sheer stress.”

Five others mentioned other **impact on their wellbeing**, for example:

“Impact on my back - I have suffered back issues this year as I am doing all the care and she is severely physically disabled.”

“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.”

“Myself and my husband have no time together on our own. We cannot even go out for a walk. Our wellbeing has suffered immensely as a result.”

“... 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.”

Four people highlighted the **difficulty of having to emotionally support those they care for**:

“Spending more time helping to keep someone happy at home all the time as we both cannot go out ... I have to try and keep both of us happy and try not to let everything get to us, it’s hard some days.”





“... Emotionally it is even more hard for me as I’m managing all three of their moods and needs whilst being ill myself ...”

“I have been left providing the emotional support for three people struggling with Covid restrictions...”

“Cared for person is not able to get out and about as before, because friends cannot meet on ad hoc basis ... He needs more geeing up to get him out and about as he scared. This is difficult when you have friends the same as I seem to be continually trying to keep everyone positive ...”

Two people mentioned **doing more** and three specifically talked about the doing additional food shopping, for example:

“Because both parents were shielding I became the sole contact with outside world. The impact was huge in all areas.”

“My husband has a long-term health condition of COPD [Chronic obstructive pulmonary disease] and has been shielding. My father is [elderly] and has mobility problems. I have been responsible for doing shopping and driving them to health appointments and any errands that need to be done outside the home.”

“Because the person I care for was not put into the shielding category, despite having several underlying health conditions, it still meant I had to go to supermarkets and could not get on the list for deliveries.”

Two people highlighted how it can be **difficult when the person they care for lacks understanding** of the situation:

“The person I care for has no concept of Covid. Hence is anti when it comes to wearing a mask, washing hand frequently, etc.”

“The pandemic has made us more worried as the elderly are vulnerable and do not understand the situation ...”

One person mentioned the **impact caring had on their work**:

“... I have had to reorganise my work with the change in arrangements.”

A respondent to the young people’s survey also explained how helping their family had been easier in some ways and harder in others:

“It’s harder as my [sibling’s] routine is all out of sync and I’ve not had any time off since March. I can’t go to my best friend’s and university is usually my break but I haven’t been physically there - though in some ways virtual working has helped be a bit more flexible around needing to juggle care needs last minute.” - *Young carer*

### *Impact of lockdown on person being cared for and their needs (16 people)*

16 people highlighted the issues the pandemic had caused for those they care for. Mostly they commented on how their **needs had increased** or they had become more isolated or how not being able to go out resulted in a decline in independence. For example:

“Concern that because I have not been able to visit as a result of restrictions, my mother is more isolated and in danger of becoming institutionalised as a result.”



“His memory has deteriorated because we cannot mix with other people to stimulate him. He has to be reminded of everything, even taking medication when he thinks that he has already taken it. I can’t leave him safely.”

“I am now doing all the housework/paperwork/gardening/ordering medication for my mum as she is concerned about having carers come into the house. I am fully supporting my son and his mental health has deteriorated during Covid lockdown.”

“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 ...”

“My mother’s health has deteriorated increasing her care needs. My other family members mental health has been problematic so they have required more help. I have spent more time meeting the varying needs of my family ...”

“Parent who lives with me is progressively becoming more frail and increasingly less mobile and therefore unable to do much for themself.”

“Cared for person not able to get out and about as before ... Needs more help with shopping as I need to make sure he is safe and socially distancing, using hand sanitizer, reminding about things ... Not able to get out on own so much as cannot access anything.”

“As I care for my nan and granddad a few hours a day most days, I’ve seen a big change. Mainly due to them not being able to go out anywhere and being scared to literally leave the confines of their own home they have become more isolated which also concerns me. I imagine for a lot of people in the similar situations ...”

### *Anxiety about carer or carer for catching COVID-19 (12 people)*

12 people mentioned the **worry they or their family and the people they care for had about catching COVID-19** and how this impacted what they could do, for example (in addition to examples above where this has been mentioned):

“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 ...”

“I have found it very difficult to balance the need to reduce contact with my mother during the pandemic. I have continued to work full time, and although my workplace is Covid secure, the more people you come into contact with on a daily basis, the more risk there is for you to take the infection to the person you are supporting ... I have reduced down the time I spend with her, drop shopping on the doorstep for my dad to put away, and only spend short bursts of time helping with hair washing and exercise ... Mum is very sad that I don’t spend more time with her, but I think she understands that it is safer this way. It has been heart-breaking not feeling safe enough to carry on as before. Roll on the Vaccine.....”

“... I have spent more time meeting the varying needs of my family. Covid has made everyone more concerned about seeing anyone outside our immediate household/bubble as we can control our risk of infection if we stay locked down with little or no external interaction.”

“... her personal care has become so much more difficult with the risk of Covid infection. That is to me and to her and my wife too ...”



### *Having to do things differently (six people)*

Six people highlighted ways they had been having to do things differently, such as **having to find alternative activities or visit care homes differently**. Two people found it hard not being able to provide as much care or having to provide it remotely. For example:

“Visiting times for Mum have gone from call in whenever you want, to make an appointment to see her and special measures in place to no visitors at all. My mum has gradually deteriorated as she has dementia. When she first went into the care home about four years ago, I was able to take mum out for little trips and for meals and to visit other family members. This was lovely and gave us both quality time together away from the home ... Now when I see her, it’s only for very short periods of time. The staff have to bring her to a special safely prepared room, which is confusing for Mum, and often I spend half our time calming her down. Usually, I would be able to sit with her in her room or sit in the main lounge area, where she would be settled. I can’t take her out anymore, due to the pandemic, the time of year and generally she’s not up to it anymore.”

“Concern that because I have not been able to visit as a result of restrictions, my mother is more isolated and in danger of becoming institutionalised as a result.”

“... We are trying to fill gaps normally filled doing other activities ...”

“Had to provide more support via virtual means.”

### *Lack of or confusing communication (five people)*

Five people mentioned issues **with poor communication or find messages confusing**, for example:

“More anxiety and change in rules and lockdowns. Very uncertain times for all. No support from local authority and lack of communication from departments.”

“... I cannot be with my [adult child] when [they are] in hospital as I usually advocate for [them] when [they are] hospitalised. The nurses were too busy to answer the phones so [I] was not involved in [their] care.”

“I get confused about “bubbles”. Do I bubble with my sister or with my son, or both? I am sure I may have broken rules somewhere along the line in the past year. Although we are all extremely careful regarding mask wearing, handwashing and social distancing ...”

### **Additional themes from consultation event**

#### *Isolation*

When asked what challenges carers had faced during the coronavirus pandemic, the group highlighted that more should have been done sooner to address **social isolation** as they were unable to visit or communicate with loved ones. This was reported to have more impact where people were in residential care or in/admitted to hospital without knowing the outcome of their care and no communication regarding their circumstances.

“...dropping your cared for person off at casualty sometimes not knowing if you would see them again.”

Isolation especially had an impact on people with **mental health** needs as the ‘new normal’ during the pandemic increased their anxiety and was reported as ‘terrifying’.



Northants Parents Forum Group also said that most parent carers were feeling isolated and there has been a general lack of response from services, and those that are still supporting have extended wait times.

### Bereavement

The lack of normal routines around death and bereavements were noted, including the difficulty arranging funerals, with limited numbers allowed to attend and no wake. This had an impact on the normal grieving process and people felt alone and isolated without the usual support offered by visits from family, friends or neighbours.

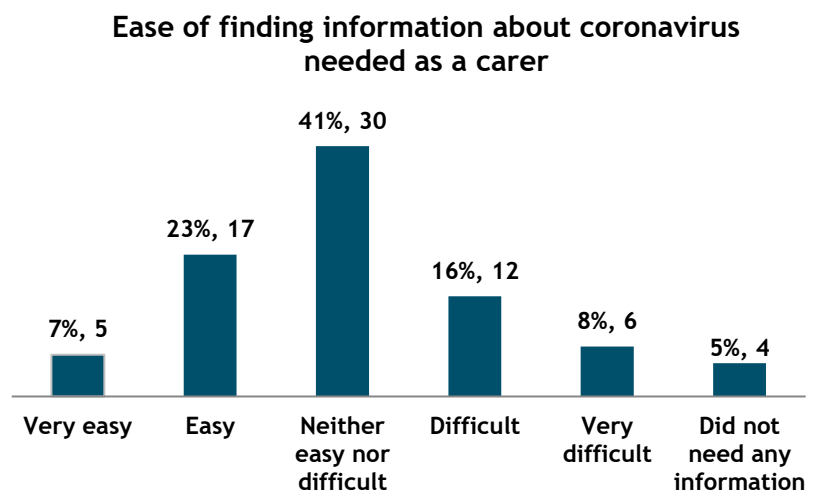
“A friend was left with the ashes but unable to carry out the persons wishes as they could not travel to scatter them.”

## Guidance, information, advice and technology

### Finding information about coronavirus

*How easy/difficult is it to find information about coronavirus/COVID-19 that you need as a carer?*

Almost half the carers (46%, 34 of 74) did not have a strong opinion on how easy or difficult it was for them to find the information they needed about coronavirus as carer, with 41% saying it was neither easy nor difficult and 5% not needing any information. 30% (22) found it easy (23%) or very easy (7%) and 24% found it difficult (16%) or very difficult (8%).



One young person also found it difficult.

Those who found it difficult to get the information they needed were asked to tell us more about the information and why it was difficult. 19 people gave comments (including six who had said it was neither easy nor difficult).

14 people found the **information from the government difficult** in some way. Nine said it was either confusing, unreliable or inconsistent, for example.

“The news is very unreliable and causes people to panic. It’s also based on political agendas. The info we do get is very confusing.”

“The principal difficulty arises from very frequent changes, and very frequent reversals of regulations, etc.”

“Nobody is able to help support us as carers, and the information about the actual virus seems to differ depending on the sources you use.”



Attendees at the consultation event also commented on this and felt the information available caused confusion. Difficulties were expressed about understanding what was right or wrong and worrying about what to do and what not to do. Better advice was requested as the contradicting information and ‘conspiracies’ caused further anxiety. Carers were left questioning whether to break the rules to provide care, while having to determine who to choose to care for if they usually cared for multiple people/family members, and keeping themselves and the people they care for safe.

Three people had **struggled to find information about the risks** to the person they cared for and two commented that there was information for paid carers but not unpaid carers. Two people who responded to the earlier survey in May and June 2020 also would have liked more advice about what to do as a carer, two others struggled to find information about local services and one pointed out the need for Easy Read information.

One person struggled to find information about access to **vaccinations**, and some of those at the consultation event was also confused by being offered a vaccination before the person they care for.

One survey respondent who is clinically extremely vulnerable struggled to find out how to get support, and another struggled to find information about support/childcare bubbles. One person disagreed with the government information as they felt the government didn’t see mental health as a priority, for example:

“The information surrounding Covid, risk management, support/childcare bubbles has been inconsistent and not trustworthy.”

“I have not been able to find any information on access to vaccinations - apart from the age-related info on the Government websites.”

“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.”

“Mostly it talks about paid workers rather than unpaid and vague information regarding use of direct payment and Northamptonshire County Council don’t seem to know either.”

“There was no information to start with, for example from the GPs, regarding the virus itself, how it would affect the person I care for, if that person was classed as extremely vulnerable and if so how to get on a priority list for shopping delivery. The list is endless.”

“The person I care for has mental health problems, and that is not a priority according to the Government.”

“I’ve found it easy enough to find info about own health but not as a carer. At best the info is vague and advice contradictory.” *Feedback from May 2020*

“Needed easy read versions local charities posted them out to us and put them on websites and social media. NCC failed to support us.” *Feedback given June 2020*

Three people found it **hard to get information about the care or support** the people they cared for needed because services were closed, delayed or changed. Another person also felt carers were not supported.

“Some services/departments closed or reduced services. Longer delays getting reply.”

“It has been difficult not knowing the procedures for A&E visits. I was challenged by a nurse for taking a patient to hospital as I did not know I was supposed to phone 111 first during the first



lockdown. The follow up care needed for the people I care for after hospital admission are/ were not in place. Physio needed to mobilise has not been available. In the end I contacted ICT<sup>8</sup> myself to arrange for support in one case. If I had not known that I could do this it would have put even more pressure on me. This has been compounded by the paid care for my [adult child] being inconsistent throughout Covid, with many visits just cancelled.”

“Because my [child] is undiagnosed which ultimately has been due to the delays from Covid, what I feel was a completely inadequate assessment and the change from nursery to school which means I have to now wait for the school to gather evidence to support an appeal ... most information and support is only there if an EHCP<sup>9</sup> is in place so this leaves a lot of children falling through the gaps.

One person felt it was harder for them to get information because they didn't use the internet and another struggled because the increased use of phone calls, video call and masks made it hard for them to lip read.

“No broadband and everything seems to be digital this and digital that. Feel forgotten and ignored. Listen to radio or watch TV for info.”

“Unable to hear on telephone, people wearing masks unable to lip read, and video calls not a great method when trying to lip read.”

One person said they only had information through the carers newsletter and a respondent to the young carers survey said the only support they'd had was from the Young Carers team:

“Apart from the Young Carers team who have been amazing, Covid and lockdown has left me feeling more isolated in not being able to see my best friend who was the thing that kept me going and also not having face to face hospital appointments has been harder in terms of [parent] as [they've] been quite poorly and I think it might help for [them] to be seen.”

Two people explained how they could easily access information, one because they worked in healthcare and one person explained that carers services made finding information easy:

“Keeping up with current Government guidance has been tricky but once we established the support bubble things became easier as it provided exemptions. Carers services have kept me updated regularly.”

One of the eight people interviewed told us more about the inconsistent messages and confusion they experienced about whether their child needed to shield:

“We started off being told as he has Downs Syndrome he had to shield. We found ourselves religiously wiping everything down, remaining in quarantine and isolating our post, etc. because of his diagnosis. It turns out it was not necessary, he didn't need shielding, we only found this

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<sup>8</sup> Intermediate Care Team - The team aims to provide rapid assessment, treatment and monitoring of patients who have experienced a recent trauma or deterioration in their physical health and are at risk of admission to hospital. This is achieved by supporting people in their own homes or facilitating early discharge from hospital where a health monitoring or rehabilitation need has been identified.

[www.nhft.nhs.uk/ict](http://www.nhft.nhs.uk/ict)

<sup>9</sup> Education, health and care plan - An education, health and care (EHC) plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs. [www.gov.uk/children-with-special-educational-needs/extra-SEN-help](http://www.gov.uk/children-with-special-educational-needs/extra-SEN-help)



out at the start of second lockdown, when the decision was made by his consultant instead of the doctor.

It was scary and onerous, we created holding area for post and shopping etc it made things too real but in a positive way helped him understand the situation. The mixed information from the GP was most annoying. One minute keep him at home because he has asthma and to start him on antihistamines but he said he’s okay to go outside, the next lockdown he wasn’t allowed.

A phone call from his consultant initially told us, don’t let him out and no contact with others so much stricter but conflicting information from different professionals made things harder for [our son] and our family to understand. A letter through the post also then gave more conflicting information - the government isolation letter. It is only because we’re quite confident as parents that we have managed [our son] and his condition. Consistent messages would have made things easier. ...

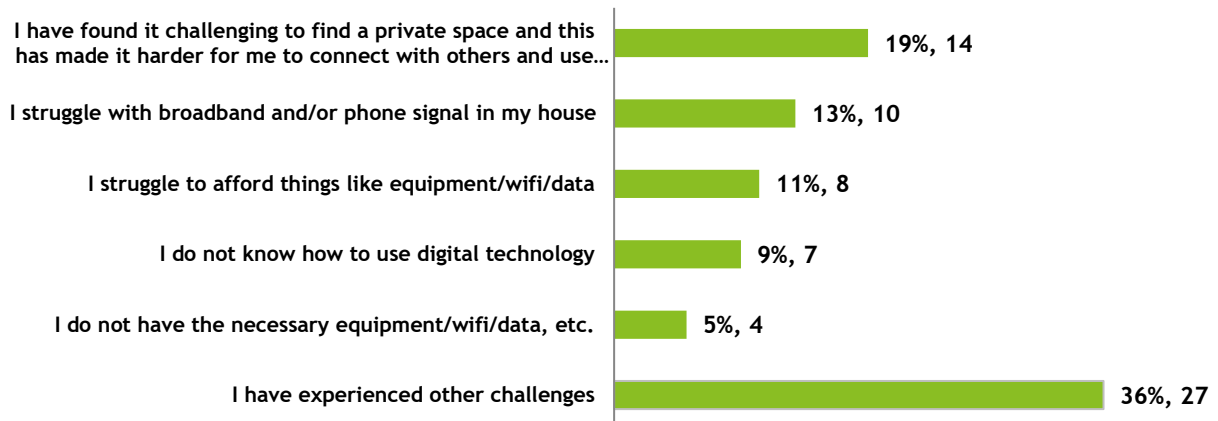
It would have been more comforting/reassuring to have a message for parents to say that it is okay to balance what you are being told with what you believe is right/best for your child when they have a disability and think through the information you are given rather than getting hung up on the guidance. It became easier after we made this decision for ourselves, if we were less confident as parents then this could have been a really terrible time instead.”

## Digital technology

### *Have you experienced any challenges using digital technology?*

Since the inability to meet face to face during the coronavirus pandemic has led to an increase in the use and reliance on digital technologies, such as video calls using computers and smart phones (e.g. Zoom and WhatsApp), website and social media, we asked carers to tell us if they had experienced any challenges using digital technology.

#### Challenges using digital technology



51 of 75 people (68%) had experienced one or more difficulty, and nine people selected two or more from the list.

Access to technology or knowing how to use it was not an issue for most carers, although these were all an issue for some. A few carers gave additional comments, for example:

“I need help with things like Zoom.”

“I don’t struggle to afford them I just can’t afford them.”

“There have been multiple occasions when our phone line has been inoperative. BT make temporary fixes which last approximately three months and then fail - on average we are



without a phone for a week each time. When the phonenumber becomes inoperative it has a knock-on effect on our broadband.”

One of the people interviewed explained more about their difficulty with remote hospital appointments when they lacked equipment:

“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.”

The challenge of finding a private space at home where they could use services and connect with others (such as care support) was an issue for more people - 19% (14 of 75), and was also mentioned at the consultation event, for example:

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

“The upstairs room I use is not ideal, but I don’t want the person I care for to wander in on work meetings.”

The largest number of people, over one-third, (36%, 27 of 75), told us they experienced challenges other than those we listed. Twelve of these people 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 and online banking. Example comments:

“I find supporting someone else who does not use technology a challenge.”

“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 father does not use digital technology, it [remote health appointment?] is okay for specific health concerns but not for elderly decline in health possibly due to dementia or Parkinson’s.”

“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.”

“I’ve had to teach my 83-year-old mum from standing outside her house and writing down instructions on how to use a tablet so she can make and receive FaceTime calls. I’ve had to verbally guide my severely disabled son on what buttons to press so that he can see me.”

“My parents can’t use digital technology despite being shown several times. My mother’s dementia stops her from being able to use the phone now.”

“Zoom, Skype, etc. are all great but it’s very hard communicating with mum through it as she seems confused about what’s happening at times and her eyesight isn’t so good anymore. Also, in the care home the Wi-Fi connection is very poor in the residents’ rooms, so often when they take the iPad or phone down to my mum the connection is so poor the whole thing is a waste of time, but very frustrating too - especially when I haven’t spoken to Mum for a while.

I’ve often thought what a good idea for people with dementia would be to have a large screen on the wall (that they can see but can’t access). When I want to talk and see Mum, I can connect to her via an app or Zoom and speak to her, so we can both see each other and talk to each other through the screen. To be able to have regular contact with Mum, on a daily basis - even just a quick conversation to say hi and how are you, would really make the difference to her and





her mental well-being. She may be confused and anxious a lot of the time because of the wrath of dementia but she always recognises me when she sees me and becomes calm very quickly.”

“Mum cannot operate equipment easily and my dad is from the Stone Age, so hands free telephone chats are as good as it gets. Mum has limited communication skills since the stroke, so this is very difficult. You rely on facial expressions and gestures to pad out what Mum cannot say, all of which is lost over the telephone.”

Five people commented that they **did not have much experience of using digital technology** but had learnt:

“I have had to learn how to shop online bank online and Zoom. It has taken time patience and persistence.”

“I do not fully understand how to use it. Trying to access lessons, etc. for my son has reduced us both to tears.”

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

Three people mentioned that it was **hard to use digital technology** while also caring for their children and one also found virtual conversations difficult because of their mental health:

“I have mental health problem and find it difficult to talk on Zoom, etc. plus my daughter would not cope if I was not giving her my full attention.”

“I am fine with using digital technology, but it has been difficult to do this and leave my daughter unsupervised.”

“With two young boys (ASD) and my adult daughter to care for, I struggle to get any time to myself and or the rare times I do, you can be sure a crisis will develop.”

One person highlighted the difficulties their daughter had with remote schooling and one person highlighted the difficulties the person they care for had with virtual appointments:

“Hospital letter didn’t have the right info on so spent ages waiting in the wrong virtual waiting room. All support services have provided appointments by video or phone, but he gets really bored so only partially successful and impossible to talk if he is.”

Two people mentioned **technical issues** with their smartphones which meant they couldn’t use apps, such as the NHS COVID-19 app, and they couldn’t afford a new phone.

Two others 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 with the increased reliance on phone calls:

“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.”

“GP surgery took ages to use video calls, my mum at 94 was the first person to encourage the GP to use it, her GP was surprised that she could use it (but the 300 residents in care homes that they have as patients can’t use it). This should have been in place for all GP surgeries where the patient had access to email. My mum is 94 she uses video call to lip read and the iPad is digitally connected via Bluetooth to her digital hearing aids, so this was more about her disability of hearing impairment than Covid but usually it would be a face-to-face appointment and I take her.



The consultant at Northampton General Hospital said it was not possible to video call. The social prescriber did not use video call until I insisted. The pharmacy can no longer take her order as she cannot hear on the phone and they refused to video call, so I have to take the call and do the order, we now pay £60 for six months of medication delivery, this was free.

Family contact has been improved through facetime as the younger 20-30 age group find this easier to communicate than telephone.”

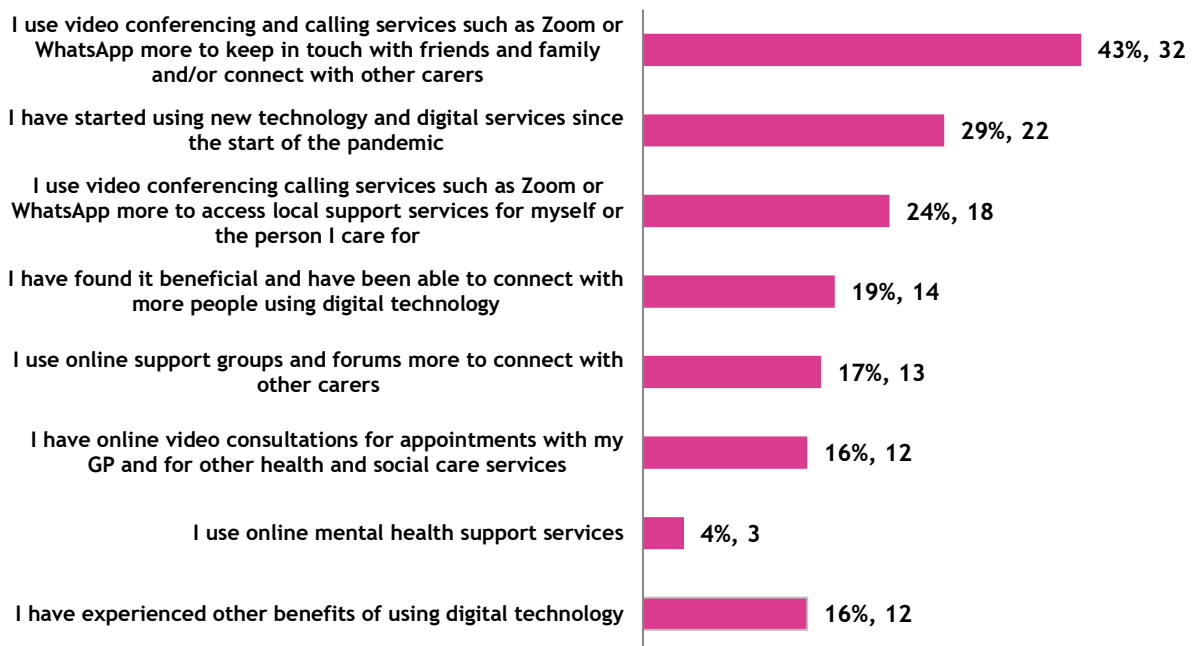
One person chose to keep in contact with the person they care for by phone or visiting as neither liked to use digital technology, and one person pointed out that physical care needs could still not be provided by digital means. One person commented on how some services lacked technology.

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. Others do not like talking in a group and it was felt a choice of ways to be contacted should be offered. Online provision of services can be helpful but there is a need to find the right balance so that people’s needs are met. The example of telephone care assessments was given - these may not identify all the person’s needs, which can lead to a crisis later.

*Have you been able to use digital technology more during the coronavirus pandemic?*

We also asked carers to tell us more about the ways they had been able to use technology and any other benefits from this.

**Increased use of digital technology**



59 of 75 (79%) selected one or more option (28 people (37%) selected two or more). 16 people did not select any of the options.



Nearly half of carers (43%) had used technology more to keep in touch with friends, family or other carers and 29% (22) had started using new technology or digital services during the pandemic. One quarter (24%, 18) were using **video calling services to access local support services for themselves or those they care for** and 17% (13) 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. A few carers gave additional comments, for example:

“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 am trying a lot of new things online but not very confident and need help of family.”

Eleven people (15%) told us about other benefits of using digital technology they had experienced. Three mentioned the benefit of **online shopping**, for example:

“Shopping online has been of benefit, although I still do mine and my sister’s weekly shopping myself. I found it very difficult to get delivery slots when first lockdown started, and my sister doesn’t trust the supermarkets to send the correct items. Also, any problems that have arisen can usually be dealt with online quite well.”

“I can buy stuff online without going out unnecessary.”

Two people were **able to get information online**, including from the Northamptonshire Carers website. Two also mentioned how it helped them to **stay in touch with the people they care for** and for leisure - while also pointing out the downside of social media:

“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.”

“I don’t have broadband at home but have upgraded my monthly mobile data allowance... This has allowed us to spend more time online and watch more TV programmes on iPlayer etc. I’ve used WhatsApp more to keep in contact and share content with my cared-for when I can’t physically be there. Following the first lockdown I’ve given up using most social media and am feeling better for it.”

One person appreciated the **convenience** of virtual appointments (when the technology works) and the benefit of video appointments for lip-readers was again highlighted as above, and one person valued being able to use technology to work from home:

“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.”

“Digital technology has been invaluable in allowing me to do my job and work from home.”

Two people told us again that they were **unable to use technology** and one person could not attend a carers support group online during working hours:

“I have been unable to use support from work as the carers group meet during work hours.”

“Not applicable as I lack the technology my phone is android but unable to run Zoom, etc. My Wi-Fi is also poor.”

“I cannot afford internet therefore I don’t have it.”



## COVID-19 testing, information and caring

*If you or the person you care for has needed a COVID-19 test, have you experienced any difficulties getting tested?*

We were keen to know whether carers and those they care for were able to access COVID-19 testing when they needed it (whilst being aware there were issues for everyone accessing COVID-19 testing in the autumn of 2020). Getting to a testing site and getting an appointment or home testing kit were the most common difficulties faced, although the majority had not difficulty getting tested.

37% of carers (28 of 75) and 63% of those they care for (47 of 75) had not needed a COVID-19 test.

80% (37 of 46) of the carers who'd had a COVID-19 test had not had any difficulty getting tested.

Of the nine people who had some difficulty, four had needed a COVID-19 test but could not get to a testing site, three had needed a COVID-19 test but could not get an appointment or home testing kit, one needed a COVID-19 test but could not use the testing kit or had difficulty with it, and one was unsure about whether they needed a COVID-19 test.

69% (18 of 26) of the people cared for who'd had a COVID-19 test had not had any difficulty getting tested.

The difficulties for the eight who had some difficulty were the same as for the carers - three needed a COVID-19 test but could not get to a testing site, two had needed a COVID-19 test but could not get an appointment or home testing kit, two needed a COVID-19 test but could not use the testing kit or had difficulty with it, and one was unsure about whether they needed a COVID-19 test (or the carers was unsure).

Some carers commented on their difficulty or ease of getting a test in the following question comment box:

“I was on meds and couldn't drive so ordered a home test that never arrived. Eventually I got a walk-in test.”

“My husband's condition (epilepsy) means he lost his driving licence and employment, so we do not have a car. This means we have been reliant on the home testing kits, some of which have taken up to three days to reach us. This has actually negatively impacted our children more than ourselves, as they were unable to attend school while we were waiting for the tests and the results, resulting in them unfortunately missing more school than necessary.”

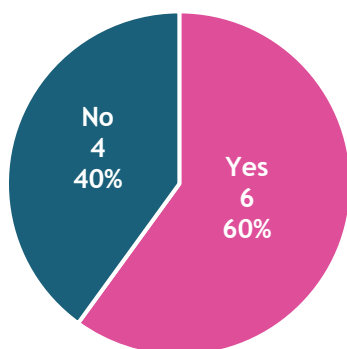
“My COVID-19 test was required for my hospital day appointment. As this was a hospital requirement before I could have my day surgery there was no problem obtaining a test. I have not needed or tried to obtain a COVID-19 test for any other reason.”



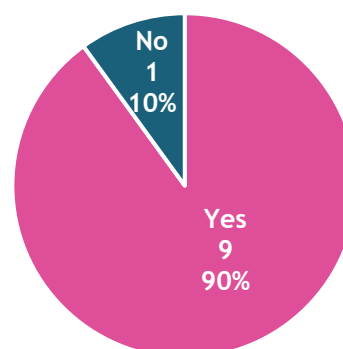
*If you or the person/people you care for have previously tested positive for COVID-19, were you given sufficient information and advice about self-isolation?*

This question was not applicable to most. Ten people who'd had a positive COVID-19 test answered - six felt they were given sufficient information and advice and four did not.

**Sufficient information?**



**Caring more difficult?**



*If you or the person/people you care for tested positive for COVID-19, or had symptoms of COVID-19, was it more difficult for you to care for them as normal?*

A positive COVID-19 test, or symptoms of COVID-19, made caring more difficult for nine of the ten people this question was applicable to.

Four people explained that this was because they **could no longer see the person they cared for**, including one who had earlier highlighted the impact of not being able to see their parent with dementia in a care home. Two highlighted that someone else had to, or would have to, care for that person, for example:

“I had to self-isolate due to symptoms at the very beginning of the pandemic (before testing). As I am the only one my grandson (who doesn't live with me) interacts with it was very hard to support him.”

“If my father had COVID-19 it would mean I could not visit as my husband is shielding. It would require services to provide input for the time he was isolating.”

“I had to self-isolate which resulted in her partner having to stay off work and care for her.”

Two people commented on how they **still had to look after the people in their household, despite being unwell**:

“We all had Covid as a family and I still had to continue my caring role although I was sick. This is hard and makes one feel very sorry for oneself.”

“There is only me at home with my child. It was so scary in case I became very unwell and could not care for him. As it was, when I had Covid, we had to rely on lots of takeaways and living in joggers, etc. My son spent a lot of time on his technology.”

One person mentioned a **lack of information from the hospital**:

“They caught Covid in hospital and then the information from hospital was restricted despite there being power of attorney.”

Six people who said the question was not applicable gave us other comments, three of which were about getting a COVID-19 test (see above). One person felt they had **no choice but to continue caring** while their household self-isolated:



“My adult children who live with me had to isolate but I had no choice but to continue to go to her flat as I am the sole carer and all other support had stopped.”

One person highlighted the **issues they would face if they had needed to self-isolate**:

“If one, therefore both of us, had to self-isolate I think it would be very difficult to care for them as normal. We’ve tried to keep life as normal as possible. I think if we were stuck indoors for 10 days we’d go nuts.”

One person talked about the fear of their father having to stay on a ‘COVID ward’ in hospital:

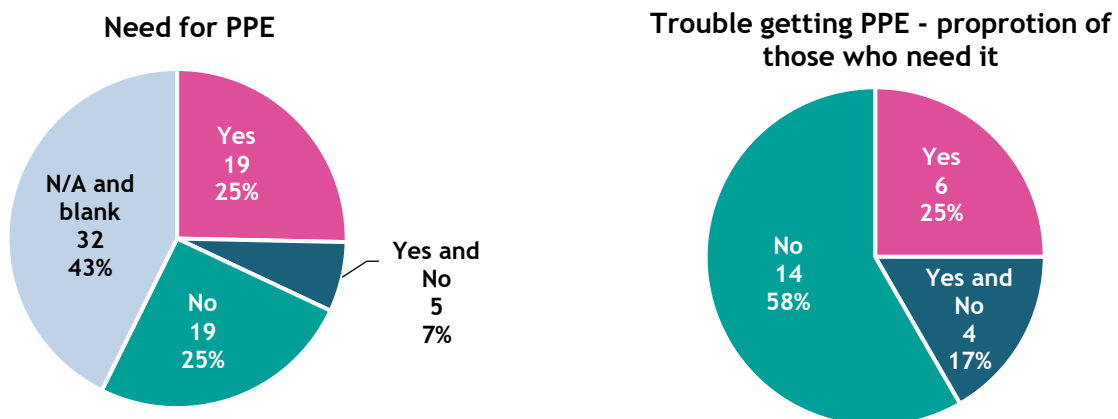
“Dad has been hospitalised twice during COVID and had to stay on a COVID ward despite not having it. He was tested regularly but this was a huge fear for me.”

## Access to Personal Protective Equipment (PPE)

### *PPE availability and guidance*

Carers were asked about their experience of obtaining or using PPE (e.g. face masks, aprons or gloves) during the pandemic to see if they had any difficulty.

24 of 75 carers (32%) said they need PPE to carry out their caring duties at least some of the time. 42% of these (10 people) had trouble getting PPE to help them care at least some of the time (plus two others who had not said they needed it in the previous question, 12 in total).



Four people (5% of 75) had been asked by a service if they needed PPE, two who did need it and two who did not.

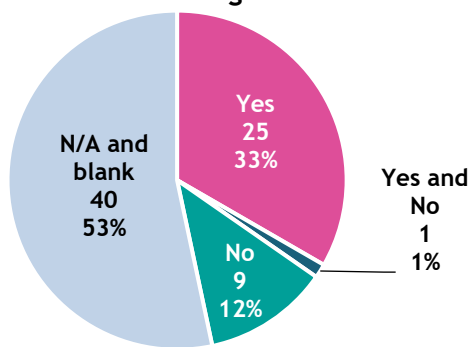
26 of 75 carers (34%) said they’d had to buy PPE themselves specifically for use when caring.

Four people had been given advice on the most effective way to use PPE as part of their caring role - three of the 24 who said they needed PPE (13%) and one who hadn’t. A further 15 people who had not said they needed PPE were also not given advice, a total of 36 (48% of 75).

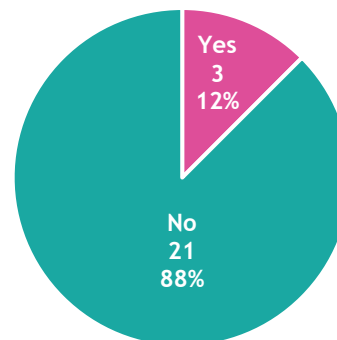
Four people said they had been given advice on safe disposal of PPE if they had been using it (14% of 30 answers) and 26 said they had not (87% of 30 answers).



Had to buy PPE specifically for caring



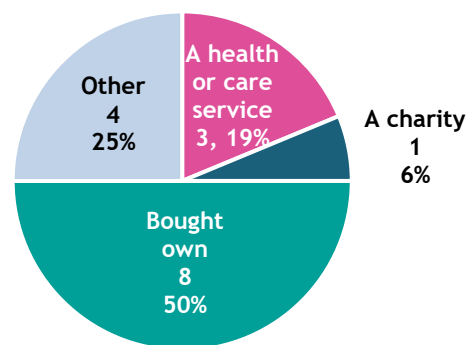
Given advice on the most effective way to use PPE- proportion of those who need it



### PPE providers

Those who were provided with PPE were asked who provided it. 16 people answer, half of whom had bought their own.

PPE provider



The four other answers were:

“Neighbour.”

“Have used masks and gloves provided from work.”

“Local Rotary club I belong to; a friend.”

“The local council who supports us with employing carers.”

Three people gave other comments:

“My son will only wear N95 Masks but has refused to go out now. My other son never leaves home, and my husband has a specific mask.”

“Person being cared for has recently (within the past month) been provided with some PPE.”

“I only use disposable masks.”

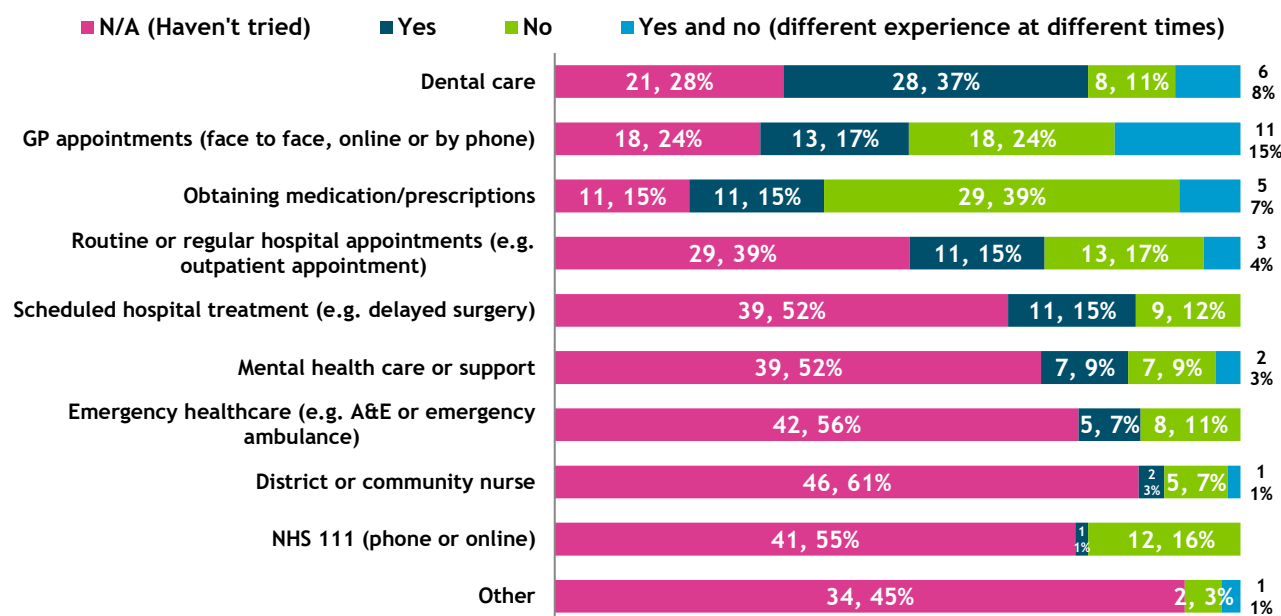


## Experiences of accessing health services

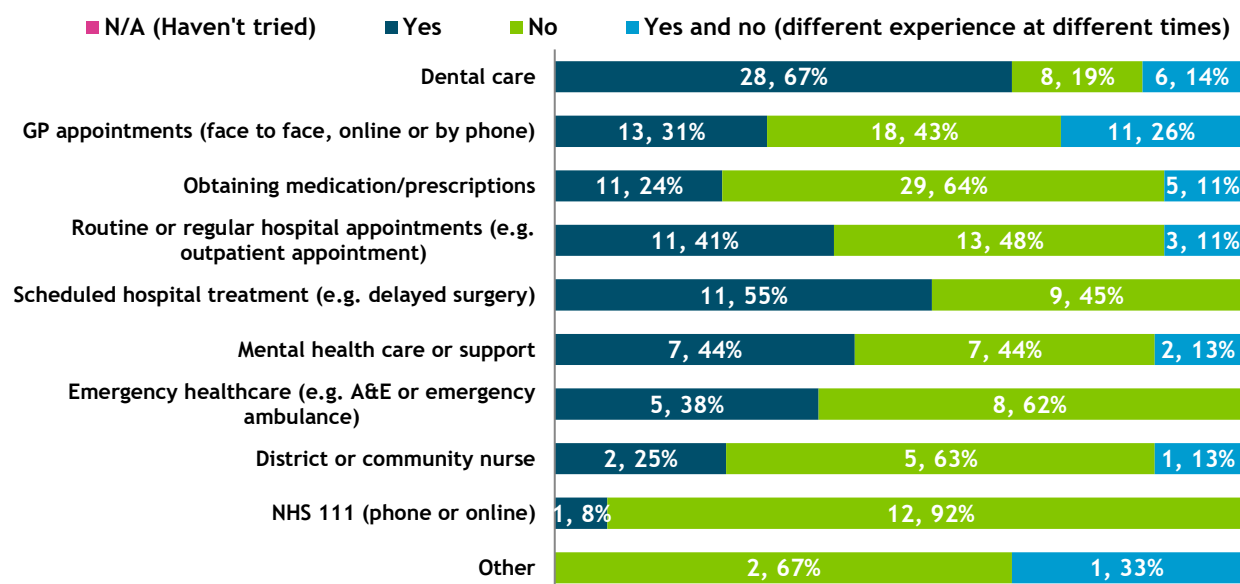
### Experience of carer

*Have you had any difficulty accessing health services for yourself during the coronavirus pandemic?*

#### Difficulty accessing health services for self during pandemic



#### Difficulty accessing health services for self during pandemic - proportion of those who had tried



**At least one-third of all 75 carers (37%) had difficulty accessing dental care during the pandemic**, with a further 8% having difficult some of the time. Discounting those who had not tried to access dental care, this rises to two-thirds (67%, 28 of 42) who had difficulty and 14% (six) having difficulty some of the time. This high proportion is not a surprise as access to NHS





dentistry has been an issue for many people during the pandemic<sup>10</sup>. Eight people (19% of the 42 who had tried to access dental care) had no difficulty.

**Scheduled hospital treatment was the only other service where more people who had tried to access it had difficulty** (11 of 20 who had tried to access it, 55%) than had not had difficulty (nine of 20, 45%).

Those **trying to access GP appointments had a mixed experience** - 13 of 42 (31%) who had tried to access a GP appointment had difficulty and a further 11 (26%) had found it difficult some of the time. 18 of 42 (43%) had not had any difficulty access a GP appointment when they tried.

People who **had tried to access mental health care or support also had a mixed experience**, with seven of 16 (44%) having difficulty access support and seven (44%) not having difficulty. The same was true for those accessing routine or regular hospital appointments, with 11 of 27 (41%) having difficulty.

Most were able to easily access medication or prescriptions, but 11 of 45 (24%) had difficulty. Access to emergency healthcare and advice and district or community nursing was less affected for those who needed it for themselves.

One person who listed another service had found a consultant appointment difficult to access. Two gave further insight about access issues they had faced:

“No GP face to face appointments but prompt response on phone. I had to call 999 once because there was no response from 111. I did not like having to do this. I had to switch to an online medication delivery as I was shielding but the GP made this difficult.”

“Mental health care and support. Accessing the hub if fine, but actually getting help is very difficult.”

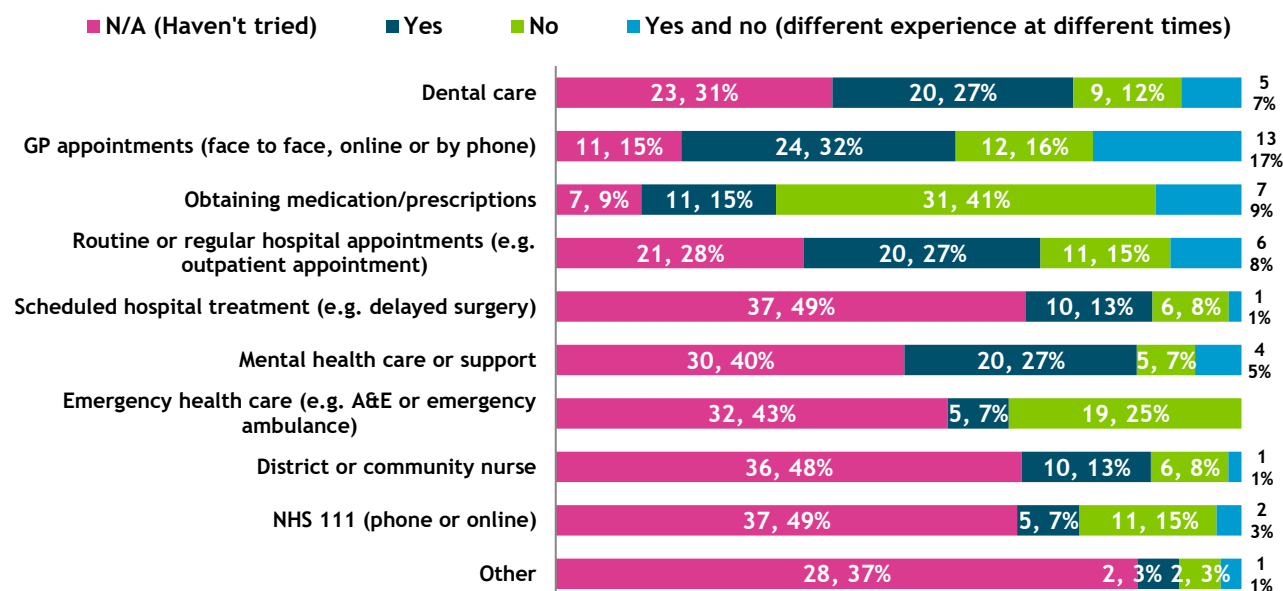
<sup>10</sup> [www.healthwatchnorthamptonshire.co.uk/news/2021-05-26/twin-crisis-access-and-affordability-calls-radical-rethink-nhs-dentistry](http://www.healthwatchnorthamptonshire.co.uk/news/2021-05-26/twin-crisis-access-and-affordability-calls-radical-rethink-nhs-dentistry)



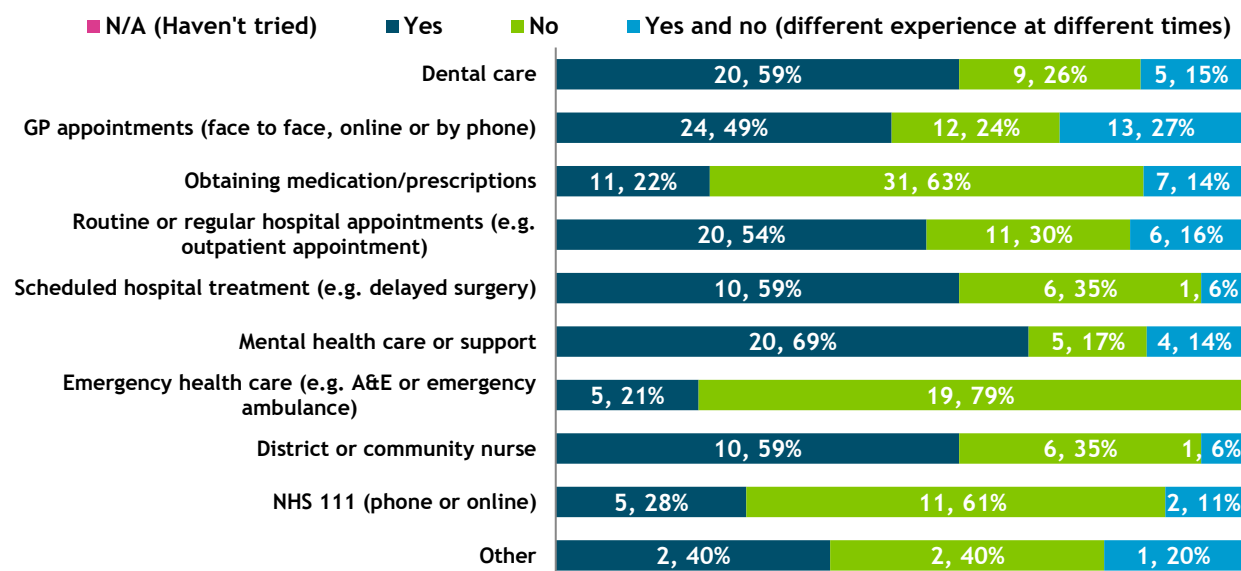
## Experience of cared for

Have you had any difficulty accessing health services for the person/people you care for during the coronavirus pandemic?

### Difficulty accessing health services for cared for during pandemic



### Difficulty accessing health services for cared for during pandemic - proportion of those who had tried



The proportion of people having difficulty accessing health services for those they cared for was similar to the difficulties faced by carers for themselves for some services. **Services where accessing them was more difficult for the cared for were GP appointments, mental health care or support, district or community nursing, routine or regular hospital appointments, and NHS 111.**

**The service most difficult to access for the person cared for was mental health care or support, difficult for two-thirds (69%, 20) of the 29 who needed it, compared to 44% (seven) of carers who found access difficult for themselves. Scheduled hospital treatment and district or community nursing was difficult for ten of the 17 who needed it (59%) and dental care access**



was difficult for 59% (20 of 34), similar to the difficulty carers found for themselves. 49% (24 of 49) had difficulty accessing GP appointments, almost double the number of carers who found it difficult accessing appointments for themselves.

One person who listed another service had found pharmacy difficult to access, one mentioned physiotherapy and one said the foot clinic was closed. One person expanded on the issue accessing medication:

“Could not get some of the medication or it was delayed.”

Eight people gave further insight about access issues they had faced:

“GP won’t take bloods or blood pressure, so I’ve had to buy a BP machine. I do not want to risk taking Mum to hospital just for a routine blood test. Pharmacist has been amazing and supports my parents brilliantly. Paramedics have been called a few times and have been amazing as always. However, hospital didn’t allow visitors and wouldn’t give phone updates due to confidentiality. Dad went in on emergency and didn’t have phone, so we had no news of him for a week. Very distressing. Mum’s tooth fell out and after lockdown, dentist saw her and replaced tooth immediately.”

“Blood tests, some difficulty arranging but straightforward getting it done.”

“GPs have just given my mother different medication rather than getting her the referral she needs sooner, and consultant appointments continue to be months away.”

“Mental health support vanished overnight. Routine hospital appointments moved to telephone consultations.”

“Someone rang my parent from the local Health Centre 11 weeks into lockdown and asked her how she was feeding herself or being fed and if meals were being prepared from scratch. ELEVEN WEEKS BEFORE ANY CONTACT FOR AN 89-YEAR-OLD!”

“She was referred by the GP to an audiologist for hearing aids but never got an appointment. We had to pay £1700 for private hearing aids. Also, she was referred to the memory clinic for a diagnosis of dementia, but we are still waiting. Which means she cannot get prescriptions for related medication.”

“Getting services to communicate with each other.”

“The care home organises all this for Mum now.”

## More about access experiences and impact

We asked carers to tell us more about any difficulties they experienced, or things that worked well, in accessing health services for themselves or the person/people they care for and the impact this had on them as a carer. 42 people gave comments, 64% of which were negative (36% of all survey respondents).

Sentiment	Number of people	Percentage of comments	Percentage of survey respondents
Negative	27	64%	36%
Positive	4	10%	5%
Mixed (from save service)	7	17%	9%
Both (from different services)	4	10%	5%



### Positive experiences

Four people had a positive experience of accessing health services and four others had a positive experience of some services and negative experience of others.

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 <sup>11</sup>
Phone and video appointments worked well	6	14%
Good and efficient treatment	5	12%
Good support	2	5%
No delays	2	5%

Six people thought that **remote appointments** (phone or video) worked well, for example:

“The one time, at the beginning of the pandemic I needed advice about my sore joints I had a phone call with a physio which was really helpful, and they sent me some information in the post. The second time was to talk to a doctor over the phone about HRT and they were very helpful too.”

“Epilepsy nurse really accessible can call her any time.”

“Important hospital medicals done on the phone.”

“Worked well - doctors via phone call and photo, PD check-up via video call.”

All those we interviewed expressed a degree of positivity about the availability of health appointments/services in a virtual format, as this meant they did not have to support the person they care for to access various health appointments, for example:

“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.”

Most of those interviewed agreed that in the future appointments should be a mixture of virtual and face-to-face appointments. Some people did prefer face-to-face appointments, but they considered this was because of their specific health need or condition and would like appointments to return as they were.

Five people mentioned how they had been **treated well and things had gone smoothly**, two that there were no delays, and two felt they got good support, for example:

<sup>11</sup> Some answers came under more than one category.



“March 2020 my wife had a finger broken during a minor fall. This involved A&E and outpatient appointments. All went smoothly and successfully.”

“Warfarin services were excellent with INR testing; I cannot praise them enough.”

“Normal appointments with NHS have run smoothly. The mental health team for my younger children have been great.”

“I have had help from pharmacy and GP to ensure repeat medication has continued.

“Age UK been very good.”

More than half of those interviewed told us that even though they had health appointments cancelled during the pandemic, when they were able to attend their appointment at the hospital or GP surgery, their appointment was efficient and the treatment they received was good.

### *Mixed experiences*

Services with mixed experience	Number of people	Percentage of comments
GP practice	4	10%
Hospital	2	5%
A&E	1	2%
Pharmacy	1	2%

Most mixed experiences involved aspects of **communication** that could have been better. One person found the treatment of their son in hospital to be good, but it was difficult not being able to have more than one person stay with him, and another person found the treatment in A&E to be good until the point of discharge, where they were not given much information or follow-up support:

“There were exceptionally long waits on the phone to arrange appointments for my father. A positive outcome happened when we attended a routine GP appointment for my father. He was going to have to return for his ordinary flu jab two weeks later, but the nurse offered to do it as part of his routine appointment, so we did not have to make a separate journey.”

“My son had planned major surgery in August 2020, and all went to plan - no delays etc. More difficult as a carer as only one parent allowed to stay with him in hospital.”

“Not had any real problems myself, just one telephone consultation with my own GP, can't afford to be ill. My sister has had numerous tests, scans etc., over the last year, which I have accompanied her to. Mostly all went off smoothly, with occasional delays, e.g. she has rheumatoid arthritis and the Rheumatology Dept cancelled her routine appointment with the nurse and have booked her in for a telephone consult next April (that's April 2022)!”

“Elderly relative (90s) developed gall bladder problem. No problem getting emergency assistance and looked after extremely well in A&E although could not be accompanied. Problems encountered when A&E doctors decided should be sent home for “safety”. No information given on discharge or what to do if another flare up occurred. No follow up appointment. Contacted normal doctors on several occasions over next few days asking for help without success except to be told DO NOT phone NHS 111 service again must go back to doctor. Muddled through best we could. Very worrying time - had to research condition on internet and try to follow any practical advice found to ease pain and discomfort.”

One interviewee told us more about the ‘pros and cons’ of their son’s virtual medical appointments:



“[Our son] has had one medical appointment a month since March all have been conducted 50/50 virtual/in-person. I am worried that he hasn’t had a hearing test for a year, and he definitely needs one but in general, I am happy with appointments this way as I feel he doesn’t need to go in every single time, going forward this would be preferred and that every other appointment to be offered in person.

They also found the information they were given about which ‘virtual room’ to enter was not clear.

### Negative experiences

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%

Self-care refers to a comment where the carers explained they prioritise their caring over their own health:

“Accessing healthcare for myself is always last on the list, my tablets are always sitting waiting for my collection, same with repeat prescriptions, this last year I have left things that I probably should have addressed with GP, but my focus is on my mum’s health and wellbeing.”

Negative overarching themes	Number of people	Percentage of comments <sup>6</sup>
Lack of treatment/care	19	45%
Communication	13	31%
Lack of support	11	26%
Direct impact of COVID-19	4	10%
Other	5	12%

### Lack of treatment/care

19 people told us that they had been **unable to get treatment or care or a diagnosis**, either because of **delays** (nine), a **lack of follow-up** (three), **not being able to get an appointment** (three) or a **service being unavailable** (two), for example:

“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.”

“Every day is a struggle for my mother and as she has not yet been properly diagnosed, we cannot get her any paid care. She is now also unable to work because of her condition yet PIP



won't accept her application as she has no diagnosis. She has now been this way for a year with no support of money or care. Universal credit gives her £241 to live for the month and all of this now falls on me who also has another family to care for.”

“During the first lockdown I could not get anyone to visit my wife for a diagnosis.”

“Delayed hospital appointments for both orthopaedic and mental health appointments.”

“I hurt my knee in February 2020. Due to it not being an emergency, I have not been able to get any contact with a GP. I now struggle to get up and downstairs.”

“No dentist for a while and parent broke her false teeth plate and had to live with it like that for five months.”

An interviewee told us how they did not get the support they were meant to:

“I have a shared care plan with my rheumatoid consultant, people were supposed to ring to see how my health is, nobody has rung, it is a 12-week plan and just reaching the 12-week period.”

Two people experienced **delayed care because they or the person they care for were not willing to be treated** while there was a risk of catching COVID-19:

“Have refused learning disability assessment this year due to concerns regards coronavirus by person I care for.”

“Also needs cataract implant correcting but not prepared to go to hospital during the pandemic to have done so very limited sight in one eye.”

One person was unable to complete their dental treatment, and another had difficulty getting medication. Two carers who were interviewed expressed **difficulty arranging review appointments and assessments**.

The attendees at the consultation event also highlighted a **lack of access to healthcare and other services**, for both themselves and the person they cared for. A **lack of access to mental health support and primary healthcare** were particularly highlighted. Carers said that their calls to services were not always welcomed, they struggled to get appointments and were turned away when they needed to speak to someone.

GPs were found to be the hardest to contact and some were unwilling to speak to carers who are not living in the same place as the person they care for.

### Communication

13 people, plus one from the 2020 survey, mentioned issues with **communication, including struggling to get through to a service** (e.g. GP) (six) and various examples of **poor communication** (five), for example:

“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.”

“GP surgery not using video call quickly enough. Social prescriber had to be called as didn't call when they said they would.”

“Main problem has been getting past our doctor's "gatekeeper", i.e. their reception staff. One receptionist is particularly unhelpful and will not allow you to speak to a medical professional - instead she tells you what to do. We now terminate our phone calls to the doctors if she answers the phone. Getting advice and information on new health conditions - what care should be given, dietary adjustments/changes etc.”



“Mental health for my son would only speak with my son directly, not me, he has severe learning difficulties.”

“Difficulty getting Adult Social Services agreement to accept Agency costs above their standard rate, even though the charge would be fully covered through their client’s personal budget. This caused anxiety, frustration and stress not only to me, but even more so to the person being cared for.”

“Our GP picked this time to remove one of my daughter’s medications from her repeat list meaning that I need to try to get an appointment to discuss this. I’m sure they have better things to do than this, but explaining why they removed it and discussing it with me might have been a better idea. This could have been done by a receptionist.

“The impact is great as it always is, doctor doesn’t listen, nurses says they will make appointment but don’t, so as always you have to plod on. We did after 8 months have an appointment by Zoom and the doctor (consultant) wore a mask for 50% of the meeting! Did not speak to me separately, then wrote to GP saying everything fine, when not - it’s all a battle.”

“We have needed to speak to a doctor concerning a medication change and prescription for a vulnerable adult with long term severe mental health condition and have had to wait over a week for a phone call with a doctor to discuss next week.” *Feedback given July 2020*

Half of the carers interviewed mentioned having had difficulty accessing virtual appointments, sometimes due to lacking the necessary information to log in correctly.

One person implied that having a telephone conversation rather than face-to-face led to difficulties, and one highlighted how phone calls were difficult for people with communication difficulties:

“Routine hospital appointments moved to telephone consultations then due to a false positive X-ray without appropriate referral procedures anxiety levels were raised unnecessarily.”

“Telephone calls have worked okay. GP follow ups when son was suicidal. The others refuse to call as phone calls are difficult with autistic people.”

### Lack of support

Eleven people experienced a **lack of support**, including six who were referring to **mental health** issues, for example:

“Doctor did not support with mental health anxiety to do with COVID.”

“I have struggled to get the help and support from the Mental Health services for my son and this ended up with him being admitted into Berrywood Hospital.”

“Mental health support vanished overnight and no one has bothered to chase up since.”

“My son who has Asperger’s Syndrome and co-morbid depression, has been waiting for an assessment from the Adult Social Care Mental Health team since January 2019 (I know I can’t lay the blame on Covid-19 for that one) with no mental health support. He is finding it very difficult to get a medication review, having been on anti-psychotic and anti-depressant tablets for two and a half years with no review. So I do get really fed up sometimes, then feel guilty as there are others coping with far worse than me.”

“Prescriptions are less reliable than previously. Both dentists have not been taking regular appointments. Secondary Mental Health services are near to non-existent. I have not been able to see or talk to anyone since the pandemic began. My cared-for lost services and has then been





given the run-around and shunted from one place to the next. Her GP has contacted secondary services and she is awaiting reassessment.”

“My only issue is the lack of support for my adult daughter, who warrants a stay in St Mary’s Hospital (as is supposed to be part of her care plan when necessary) and should be in supported accommodation. It is always left to me to keep her safe and cared for, to take the abuse when she is not coping of off meds. The mental health team need to listen to parents and carers more. My relationship with my daughter has been destroyed by the extra pressure.”

“Getting a fact sheet would have helped. We did not realise the havoc that can be caused by a UTI: extreme confusion. We are now not sure at what point she should go to a home (or even hospital) and whether anyone else could cope with her. Her behaviour is unpredictable, and she needs a lot of support. We are stumbling from one drama to another - while trying to work from home.”

“I have had no support from my specialist ADHD/ASD team other than one phone call. Even though I was struggling nothing led on from it. Due to the impact of no support, I have started to need to claim PIP for myself.”

“No physiotherapy which impacts on my daughter’s health. No dental support.”

Phone calls to the Northamptonshire Carers support line have also revealed that some **social care self-funders** felt unsupported, dismissed and isolated. Instead of support they were provided with the care directory to review and had to contact appropriate services themselves.

Two respondents to the 2020 survey told us that the people they cared for had hospital treatment, which was fine, but they had **difficulties when the patients were discharged** having contracted COVID-19, for example:

“The care in hospital was fine. However, my father was sent home after eight days having tested positive for COVID-19. After four days at home, with two falls, trying to keep distant from him by my mum 78, his carer, he became very ill again necessitating close contact by her (he had 24 hrs of diarrhoea), fever and paramedics came and took him to hospital. My mum was given a couple of masks when he left hospital but no real guidance. I was told the district nurses are too busy and working for people who ‘really need more support and don’t have anyone to care for them’. I am very worried my mum has been exposed to Covid-19 virus now, so we now have to wait and see if she contracts it. I live 3.5 hours away and she would not let me come to help as she now needs to self-isolate for 14 days. Plus cleaning a house covered in body-fluids.”

*Feedback given June 2020*

### Direct impact of COVID-19

Four people mentioned the impact of COVID-19 more directly, including those who **chose to delay their appointments to avoid the risk** (see above) and another who experienced secondary effects:

“Experienced family fall outs due to fear of COVID so not taken son for his MRI.”

### Other difficulties

Other difficulties mentioned included the **limit on the number who could visit** a child in hospital, having **less time for self-care** (both examples given above), and how the lack of services can result in **people becoming reticent to attend** appointments:

“He is scared to go dentist at best of times so will not go at all now. He also scared of needles and doctors so this needs to be managed by myself as best I can.”



One person highlighted in detail the **transport and logistical difficulties** people with long-term conditions can face, especially if appointments are constantly rearranged and another mentioned other physical access issues:

“My husband has been due an inpatient telemetry appointment since last year, which have been cancelled several times. When dates have been offered, he has been unable to attend these due to the logistics of the Covid test he needs to have three days before attending. As we do not drive we are reliant on public transport, and to get to his neurological department means a 60 mile round trip, using bus, train and taxi. Obviously, this means it isn't impossible for him to self-isolate between the time of his covid test and attending the appointment. This is frustrating for us as the reason we have this problem is due to his epilepsy, and so his condition directly affects his ability to attend these healthcare appointments for his condition and shows a lack of accessibility due to his disability.

We have asked if he could attend a testing site closer but have been told the hospital trust (Oxford University Hospitals) insists all covid tests are carried out at the Churchill Hospital, which is over 30 miles away from where we live.

Our main issue during covid has been accessibility, and the fact that the rural village that we live in has no public transport. As my husband cannot drive due to his epilepsy this causes us problems with travelling out of our area, in particular for his many healthcare appointments, and causes him great expense as he is reliant on taxis to take him to these appointments. Just to visit the doctor or have a blood test will cost him £26 in taxi fare, which is a lot especially as he is already on a low income due to the fact he cannot work due to his disability. This makes healthcare appointments inaccessible to him at times.”

“The person I care for uses a scooter and could not get to a hospital appointment when there was a minor fire as lifts were closed and there were only stairs available. No ramp access to the floor for his appointment, which has to be re-scheduled.”

In the May-June 2020 survey, five people mentioned how extra **pressure was put on them as carers** of people with a long-term condition, for example:

“I was given a box of plasters, packing, non-sterile gloves and told I was to do my daughter's complicated dressings myself by the medical centre. I had to insist on a referral to the catch nurses who have been wonderful.” *Feedback given May 2020*

“Only heard from GP once to check on my mum (luckily she's got me as an older young carer to look after her) but pharmacy have been the same with meds.” *Feedback given May 2020*

“I chase all prescriptions and appointments on their behalf.” *Feedback given August 2020*

“Our adult daughter is under a secondary care provider for severe mental health conditions and is on a substantial number of medications. We are her carers. She also has autism. We had absolutely no one contact us from either secondary or primary care during the lockdown to check on how things were. Thankfully with the support of ourselves and her social care setting providers she coped fairly well. We eventually had to chase up a review with her consultant. She has had two different locum consultants since hers left in October, so we didn't even have an assigned consultant during lockdown. Thankfully she has a social care personal budget in place and those support services turned out to be very good during that time.” *Feedback given July 2020*

One interviewee mentioned difficulty caused by the pausing of a service's complaints procedure - the delay resulted in their complaint being difficult to be continued, which in turn had a



knock-on effect as their condition worsened and consequently led to a new complaint being submitted.

### Negative impacts

Negative impacts overarching themes	Number of people	Percentage of 31 comments including impact <sup>12</sup>
Impact on health or care of cared for	20	65%
Emotional impact on carers	18	58%
Other	4	13%

Many of the comments above illustrate the negative impacts of the difficulties people faced, both on the carers and the people they care for. Two-thirds of the comments mentioning an impact highlighted the effects on the **health of the people cared for**. Six people mentioned that appointments had been missed and four people explained that not being able to get a diagnosis led to the person they cared for not being able to get other treatment or support, including one who also explained the financial impact of this. Other said more about the impact on the health of the person they cared for or themselves, including having to cope longer with certain conditions (three) or having complications from not being treated (one), being admitted to hospital, now needing further benefits (Personal Independence Payment, PIP), having mobility issues and pain, and not being able to complete dental treatment (all one person each).

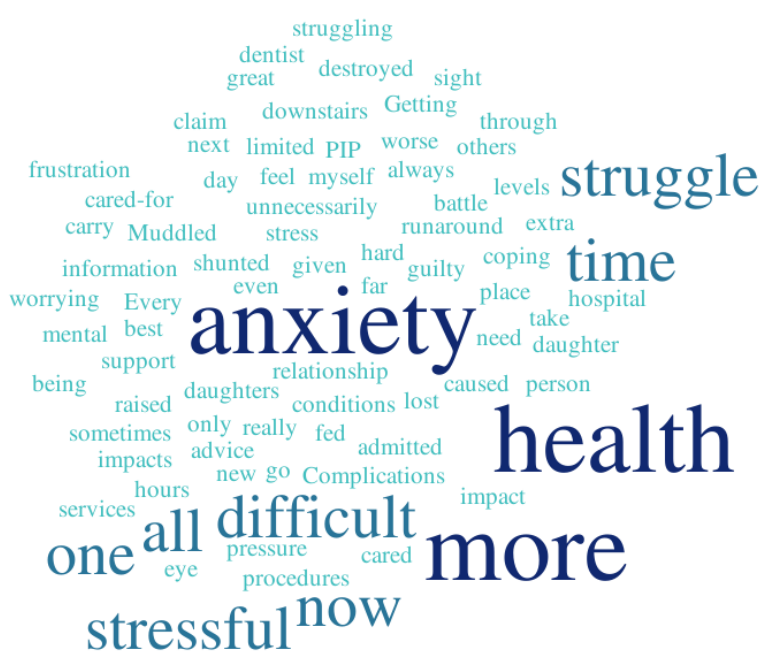
18 people (58%) told us about the **emotional toll** the difficulties had on them, mentioning anxiety of worry (four), stress (four), frustration (three), increased pressure on the carer (two), having to spend more time chasing (one), ignoring their own health needs (one), and three just mentioned how difficult it was.

This was also a theme highlighted at the consultation event. The unavailability of services, even for short periods, has resulted in carers being tired while also having their own health conditions to manage, impacting on the carer as well as the person being cared for.

“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.”

Other impacts included the increased financial strain, having to get private treatment, the cared for being more reluctant to be seen and finding a lack of information.

A word cloud on comments about impact:



<sup>12</sup> Some answers came under more than one category so the total is greater than 100%.



## Other support services

To find out more about carers experiences of different support services for both carers and the people they care for we asked them if these services had resumed, if they were receiving the same level of support as before, and they had started using new services. 37 people answered this question, and 38 did not, which may imply that around half of those who took the survey use the below services. 19 people answered about one service, eight about two services and nine about three or more services.

	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
<b>Total</b>	<b>15 (20%)</b>	<b>10 (13%)</b>	<b>7 (9%)</b>	<b>2 (3%)</b>	<b>18 (24%)</b>	<b>23 (31%)</b>	<b>75</b>

The services used by the most people were **day services** (11 people), **Northamptonshire Carers** (11), **NHS or council-funded carer workers** (10) and **self-funded care workers** (10) (four people had used funded and self-funded care workers, so 16 people in total had used care workers).

The most common answer was that **services had not reopened or resumed** (31% of all answers), especially before or after school provision and day services. 18 of the 78 answers (24%) said that a **service had reopened/resumed but the person was not using it**, particularly specialist schools, sitting services, activities or support provided by local charities, and residential care.



15 activities (20%) were started during the pandemic, particularly support from the local community or NHS volunteers with shopping, prescription, etc., which fits with this sort of support becoming much more common during the pandemic. Two people had also started using care homes and/or residential care (one had used both).

Few services, except those provided by Northamptonshire Carers, continued throughout the pandemic. Only two people said that a service had resumed and was providing the same level of support as before the pandemic.

One young person had used CAMHS (Child and Adolescents Mental Health Service) and the other had used Northamptonshire Carers Young Carers service, which they rated very highly. They were looking forward to one-to-one support starting back up but still appreciated the virtual check-ins. These were also the only services to have checked how they were during the pandemic.

## Impact on carers of the changes in services

Carers were asked to tell us any more about the impact on them of the changes in services, including any difficulties or improvements.

### Difficulties

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

The difficulties faced due to changes to services and the impacts on carers were similar to those highlighted earlier in the survey, where people told us the impact of having to do more.

Ten of the 22 negative comments highlighted that they either had **no support** or help (six people), including some who said they did not use any services. Others had **struggled to access** support in some way (four people), for example:

“No consistency in Social Workers. Lack of communication and support from Adult Social Services. Reluctance to understand individual circumstances and needs. Emphasis appears to be based on closing the case as soon as possible.”



“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.”

“Tried repeatedly to get council older adults’ assessment and was fobbed off every time. Ended up doing privately.”

“Carers started again in November face to face which I can only access but stopped again in December with tier 4.”

“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.”

“We don’t get help or support from anyone.”

“I have never been offered any support.”

One person we interviewed explained how they were not able to access support while they were struggling to get a diagnosis of autism for their child. They felt as if they had been left alone and that there should be more support given to help whilst awaiting assessments, especially during times like these:

“As my [child] is not diagnosed, [they are] seen as ‘normal’ so do not qualify for help and I am not considered a carer until [they have] a diagnosis.”

Five people told us that there were having to **do more and/or had less help**, for example:

“I am almost 60 and I work two jobs. On top of this I have had to step back into a fulltime caring role for my daughter, including when I was ill myself. It’s very hard to do this and makes life very demanding. I don’t consider myself to have mental health issues as such but this has given me an understanding of what it is like to struggle. The first lockdown was incredibly hard. I over-ate out of frustration and sadness and put on weight. I became tearful and depressed and was worried all the time about what might happen to my daughter if she caught Covid.”

“Break required exhausted due to relentless caring and ongoing needs and concerns of person I care for.”

“Shopping from Age UK stopped. Cleaning agency stopped so more work changing bed, washing, etc.”

Interviewees also told us they struggled when support services and respite services were not available to support them, and which resulted in further pressure on them and their families.

Two people highlighted the impact on their loved ones of **not being able to visit care homes** - one who earlier highlighted the impact on how their parent’s dementia, and one who had to delay admission to a care home:

“We cannot visit care homes to check them out. Once she is admitted, we would not be able to visit her because of the pandemic, which makes us hesitant about having her admitted. It might be the last time we see her when we take her in. She is close to 100 years old and frail.”

Two people found **virtual support was not as good**, for example:



“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.”

Two people said they or the person they cared for were **not accessing service because they were shielding**.

“Childcare not possible when shielding and potentially unsafe at the moment.”

“Day centre is closed no PAs coming into home. College is open but we are shielding.”

Other difficulties:

“Cannot use any services as cared for not interested.”

“I am volunteer for Age UK and MHA and my old folk that live at home have had every activity stopped: lunch club, day centre, volunteer friending visits. In fact everything! Mega isolating.”

One young person struggled because of their mental health. This person found coping with caring during the pandemic easier when school was open. The other person found that it was easier to provide care while they were not at school but that also meant they did not get a break:

“It was easier in the fact I’m at home more so there’s more time to do things like washing, dinner etc, but harder in the fact I’ve literally not had a break and that’s been quite a lot on my shoulders.”

### *Improvements/positive comments*

Two people commented on how they’d had some support, two on the support from **Northamptonshire Carers** and one was grateful to have had some brief respite support:

“We are still able to contact my husband’s epilepsy nurse via telephone and email if needed, which we are grateful for but it’s not quite the same as seeing her in person.”

“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.”

“It’s nice to know that Northamptonshire Carers are there if I ever need them.”

Some of those interviewed **discovered additional support services they could access online** to support their own health and wellbeing. Those at the consultation event also had found that some of the services accessed remotely provided valuable support:

“The telephone befriending has been great, really a life saver.”

### **Changes that should continue**

The survey also asked carers if there were any changes in services that they would like to see continue. Twelve people commented, with four highlighting positive changes they would like to continue and eight again highlighting the services or support they were missing.



### *Changes that should continue (improvements):*

Two people appreciated the **convenience of phone or video appointments**, and one mentioned the benefit of **online support**. One person found **prescription deliveries** really useful, and another said the Age UK **shopping service** was a lifeline for them, but that it then stopped with little notice. One of those interviewed would also like 'VIP' shopping deliveries to continue:

"Online support is valuable."

"Some hospital and community services by video or phone (maybe every other appointment?). Prescription deliveries really useful."

"My husband prefers telephone appointments with his neurologist, and this actually works better for him than travelling over 60 miles for a routine appointment, unless of course he needs physical examinations or assessments."

"The Age UK shopping service was a lifeline for me, it lasted briefly throughout the pandemic then [with] a weeks' notice and it stopped."

### *Things people still want changed (challenges):*

Five people wanted **more support or for services to open**:

"Open day centres for elderly who have been vaccinated or pay for care visits to isolated elderly."

"Please start to offer before and after school activities again so I can work."

"More wellbeing services for carers who don't live with/or close to the person they care for or you find you slip through a net but still have the same stress/worry but nobody to talk to about it."

"Appointment of social worker for duration giving support and guidance covering all aspects of needs."

"It's difficult to change something that is practically non-existent."

Two people talked about **COVID-19 testing and mask-wearing**:

"It would be good in people who have an exemption certificate to not wear a face mask were advised/told to wear a visor."

"Test your District Nurses for Covid and vaccinate them ASAP as they are the spreaders in the care homes as carers are tested three times a week."

One person suggested that virtual tours of care homes and advice forums would be useful:

"For care homes to arrange virtual tours. We have spent a lot of time looking for resources and discovered the existence of a bath lift, plastic bowls for visibly impaired people, the frame around the toilet (to prevent soiling), a light wheelchair. I wish there was a forum where we could exchange questions and answers about what equipment to buy."

One person wanted to be listened to and engaged with more:

"Yes consultants to listen and engage with carers, I understood that NHFT pride themselves in speaking to carers separately, they don't."





One person who was interviewed suggested more online ‘drop-in sessions’ for carers could be useful.

### Positive changes consultation event discussion

One of the questions discussed at the consultation event was whether there had been any positives during the past year for carers, despite the challenges. The challenges faced during the pandemic were contrasted with reports of positive experiences. Many of the new ways of supporting carers were appreciated. New skills, hobbies and support activities, including choir, mindfulness, art, cooking, accessing online music, virtual tours of the country and book clubs, were available for carers and those being cared for, which was especially helpful for those who don’t drive or cannot get out and are usually isolated.

“Something awful gave birth to something nice.”

Peer support included WhatsApp groups providing messages of support, laughter, photos, encouragement, and telephone calls between carers. Befriending calls were launched quickly and provided support to so many isolated carers and those being cared for. People appreciated having a choice of activities.

“The WhatsApp group was wonderful and supportive.”

The wellbeing packs that were dropped off on doorsteps also caused a tearful but happy response from carers.

Northamptonshire Carers has been able to support carers with the technology (although there is still some need for training) and the IT equipment provided has meant people have instant access and were able to embrace the technology and improve their knowledge and confidence. People reported increased levels of participation and building resilience and appreciated the increased diversity of activities to include online/armchair options. It was felt that these options would still be helpful in the future but that it was important to find the right balance and it was important that carers still had the choice of face-to-face support.

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

“I had just plucked up the courage to go to a carers group in Towcester and then it switched to online, my daughter makes me log on and it has been wonderful, hope it continues online.”

Other organisations were also reported to diversify their support, taking action to promote a more accessible and approachable choice of support, including a blended model of some support online, some with befriending calls, some doorstep calls, etc. Face-to-face activities arranged in the parks in the summer were reported to be better, especially as this included exercise, was cost effective and was outside.

Video calling technology was reported as a positive experience, enabling people to access GP appointments without travelling and an easy way for people to access a veterinary appointment for their pets too.

The pandemic has shown the resilience of carers as well as increasing awareness of the needs and isolation of carers. Northamptonshire Carers have been able to reach and support people that they never did before; including those who did not consider themselves to be carers before.

Even though things have gone wrong during the pandemic, and it has been an awful experience for many, it has also highlighted serious issues and forced people to implement change.



The shift to employers and employees being used to working from home may improve the flexibility for working carers in the future and the increased awareness of disease transmission may encourage people to stay at home when they are sick.

Some people highlighted financial benefits from being able to save money - where people were spending money on going out or taking the person they cared for out, the pandemic has forced them to stay in ultimately saving money.

There were reports of the development of community spirit with people offering to help each other, from the generosity of people and businesses offering food parcels, money, delivering supplies and wellbeing packs, church steps becoming libraries and jigsaw exchanges.

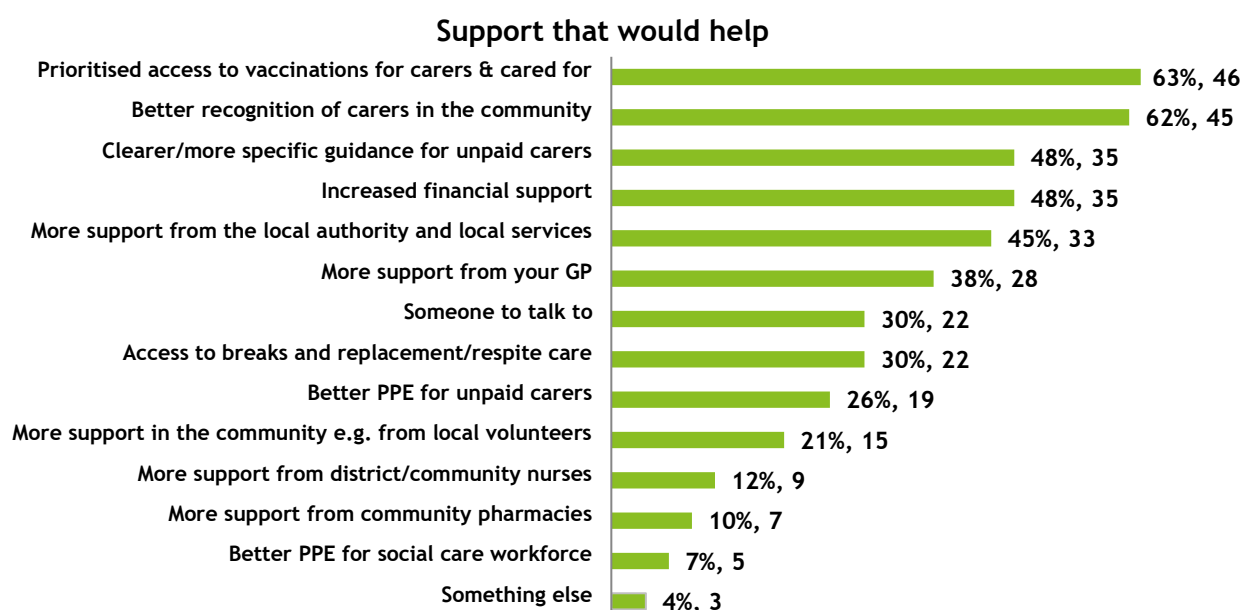
Carers reported people have had more time to stop, think, and reflect; the pandemic has made people realise what is important, with relationships growing stronger and a spotlight on the newfound appreciation of the NHS.

Whilst some people had found being at home put strain on relationships, others had found that family relationships had strengthened through being able to spend more time together. Others had benefited from getting outside more and cooking better meals - although some survey comments highlighted this was a struggle for others.

## Views on other support

Carers were asked which support, from a list of suggestions, would help them the most in the near future. 73 people responded to the question. The only options with over half selecting them were **prioritised access to vaccinations for carers and the people they care**<sup>13</sup> for (63%, 46 of 73) and **better recognitions of carers in the community** (62%, 45).

Almost half (48%, 35) would like clearer or more specific guidance for unpaid carers and increased financial support, and 45% (33) would like more support from the local authority and local services. Over one-third (38%, 28) agreed that more support from their GP would help and 30% (22) would benefit from having someone to talk to and/or access to breaks and respite care.



<sup>13</sup> The majority of survey responses were received in January, when the guidance about vaccination of carers was unclear.



Three people said 'something else' would help them:

"It would be useful for me to have some form of identification to say I am a carer, which could be used in shops, etc. e.g. a lanyard and badge."

"Knowing when it's okay to raise non-urgent but worrying issues with my GP again (like tests and preventative cancer action)."

"A better government!"

The two young carers thought that **being able to talk** to someone face-to-face (one), being able to talk to someone in their situation (one) and being able to have time to themselves (one) would have been helpful for their emotional wellbeing or mental health during the pandemic.

Eleven others used the survey box to comment on their answers.

Three people commented on **COVID-19 vaccinations**:

"It was a shame that when I took my mum for her Covid injection that they couldn't give the carers their injection at the same time. It just seems a waste of my time and the GP's time that I will have to eventually go back for my injection."

"Actually, I am getting vaccinated soon but my partner - who is in the same bubble with his mum - was NOT offered a vaccination! Why was only the woman in the household offered a vaccination, when my partner also cares for his own mum? It does not make sense and also impacts on our mental wellbeing that we will still be anxious."

"That said, my mum has had both of her vaccinations and I have an appointment for mine as a key worker."

Other comments included views about **Carer's Allowance, the recognition of carers, access to support and breaks, digital systems** and the Age UK **shopping services**, for example:

"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)."

"More support for my sister and son from anywhere. If I collapse in a big heap there is no one to look out for them."

"All health and social care staff to get modern with digital systems to facetime/video call patients."

"Occupational Therapy waiting times too long, waiting for a full assessment only to be told it is shower only and have to refer back in for anything else, needed the whole flat, when we were waiting in all day, nobody came, they rang to say they couldn't find the address, needs some user survey of what they are doing in Millbrook as they are now assessors and providers."



### *Comments from consultation event about what support carers will need post-coronavirus*

#### **Phone and digital services blended with face-to-face**

New remote ways of accessing services and receiving support, should continue, but alongside the face-to-face support that used to exist. For example, giving people a choice of an online meeting, a meeting at home or over the phone. Being able to register a death over the phone rather than having to do so in person was appreciated. Actions should be taken to address the 'digital gap/divide' and phone access should be used alongside online access to help those less able to use technology.

"A blended approach of online and face-to-face would be great, I was fearful that the online might end."

#### **Increase of current services for carers**

Services that are currently being offered should remain and increase, including more carers assessments and telephone befriending should continue. Carers should be supported to look after themselves and be encouraged not to put things off when it comes their own health and care. Some carers have delayed resolving their own health issues because their focus has been on the person they are caring for. Wellbeing support for carers is going to be critical

Northants Parents Forum Group commented that parent carers felt the things they would most benefit from post-lockdown were mainly related to wellbeing, building social networks and respite breaks.

#### **New services for carers**

Carers felt that additional services and support for carers will also be needed, including bereavement support and support for carers and those they care for who are affected by 'Long Covid'. As people's lives will have changed, such as through job or housing changes and bereavement, new life coaching, confidence building, and other support and guidance packages may be needed.

It was felt that returning to normal life, while living with the risk of contracting COVID-19, could be difficult for some and they may need reassurance or mental health support to help them. There will also be carers that have lost family members or those they cared for who will need support with bottled up grief and guilt and help finding new routines and ways to cope.

It was also felt that services should start making plans for supporting those with needs or crises that may have been missed while services were shut and/or contact was remote, and some carers may need to be encouraged to plan ahead having got used to living moment by moment and giving up planning since plans have had to change so much over the last year.

It was also important to continue to ask carers what they need and what support is missing.

#### **Services for cared-for people**

Carers felt that the package of support and care provided by services had reduced, without the agreement of carers or regard for the strain on them, and that more advocacy to represent the cared for person and the carer's rights was needed.

Many of those with anxiety about going outdoors and going back to services or healthcare appointments may need additional help and encouragement.

#### **Awareness of carers**

It was felt that carers rights have been eroded and that there should be more campaigns to raise awareness of carers views. Support for working carers was also discussed, including encouraging



employers to continue to offer flexible working and working from home, so carers who want to work can.

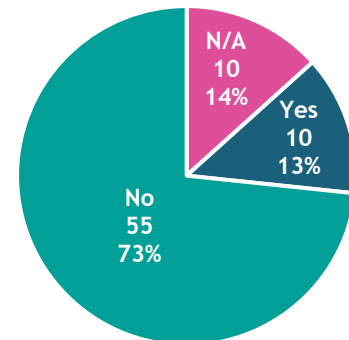
## Other impacts of the pandemic on carers

### Breaks for carers

*Have you been able to take a break/enough breaks from your caring role since the start of the coronavirus (COVID-19) pandemic?*

All 75 people answered this question, 10 of whom said it was not applicable to them. Of the remaining 65, 55 people (85% of those the question applied to, 73% overall) said they have not been able to take a break, or enough breaks, from their caring role since the start of the pandemic.

Able to take a break/enough breaks from caring role



*Please tell us why you have been unable to take a break/enough breaks and the impact this has had on you*

We asked people to tell us why they had been unable to take a break, or enough breaks, and the impact this had on them. 50 people commented.

### Reason

48 people gave a reason for not being able to take a break.

Theme	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

The most common reason (21 people) for not being able to have a break was that there was **no-one else** who could provide care, including because of travel restrictions and bubble arrangements, so others could not visit, for example:

“I have no family who live near me. They used to be able to travel from the various areas of the UK they live in but have not been able to do this during the pandemic. In some instances, this is because the area of the UK they live in have banned all but local travel or they rely on public transport (trains) and we had concerns how they could travel to us safely. No one would be able to self-isolate when they came to our house and the risk of them contracting COVID during their long journeys to us was too great. Just have to soldier on and look forward to having a break when everyone has been vaccinated and can travel again.”

“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.”

“Because I live nearby my role is main carer. My brother does very little to help. I have learnt to be very strict on self-care and only visit twice a week. I still have many panicked phone calls



though and have to run errands constantly. I managed to employ different carers for each parent but find I have to manage their needs as well (food supplies, last minute equipment replacements etc). I moved in with mum for a month whilst dad was in hospital as she can't be left alone. I had to send my young son away to relatives as my mum found him too stressful. That was unbelievably hard. My son is [young] and I'm a single mum with [health] problems so the additional caring pressures weigh heavily on me."

"I am the only person providing care once I return home from work. I cannot take a break unless the person is resting."

"My husband and I have looked after a parent who lives with us 7 days a week since the start of the pandemic in order to maintain our support bubble of three. As a result, other members of the family have not been able to provide us with any breaks."

"I visit every day, facetime every day and always have something that is outstanding be it glasses broken, dentures broken, chiropodist not coming affecting walking, shopping service stopped, cleaning service stopped. No wider family visiting, just me."

"We are a multi-generational household living under the same roof. We cannot self-isolate from each other. As the main carer for the entire household I am "on call" 24/7. I have no family who live close to me."

Seven people highlighted how the people they cared for need **constant care**, for example:

"My husband needs 24/7 supervision as his seizures are uncontrolled and require first aid. This means that he cannot be left alone and so my caring role requires I am with him all the time unless I have another responsible adult to take over. We have been unable to do this due to lockdown restrictions."

"I live with my wife, I will not go out just in case she falls over, trips. We cannot go out in the car as we are in lockdown. All our booked holidays have been cancelled until sometime in 2021."

"I am with my partner and daughter 24 hours a day I am tired lonely depressed."

"Cannot leave the person I care for. Exhausting, tired and frustrated."

Seven mentioned the **cessation of services, including respite care** services (three people), for example:

"Day centres and Personal Assistants are all closed and so our son is home all day and night."

"No respite or day care or carers in the home."

"With the cessation of secondary services, I have had to provide almost everything. I don't have the time or resources to take a break. I'm not sleeping or eating properly and am totally knackered. On the occasional evening I get to myself I drink myself to sleep which allows me to switch off temporarily but is not helping in the long run. I see no change to this in the foreseeable future."

"Cannot get Respite Care service. It is wearying."

This was also highlighted at the consultation event - respite services are not always available, and carers would often get short breaks while the people they care for attend day centres, so the closure of day centres had an impact on both carers and the people they care for.

One person who was interviewed explained how they struggled to access respite services as their children with Asperger's could not be supported by mental health or learning disability as both services said it was the other they should be supported by, so they fall through the gap. Due to



increased anxiety from the pandemic, these young adults no longer go anywhere so the carer has no breaks.

Seven people told us they could not have a break because they **could not go anywhere**, for example:

“I don’t take breaks. I couldn’t afford a holiday, and where can you go at the moment? My son would be very hurt if I went away without him, and my sister would make me feel so guilty that I could even think of going off somewhere, I just carry on.”

“Unable to with current rules and physically not capable of exercising myself so housebound for months on end.”

“We cannot go anywhere ... We would really like to see our friends in Wales but we are stuck with mum-in-law here. She is so difficult and infuriating and we don’t dare to trust a paid carer, because she would soon exhaust their patience.”

“Unable to go away due to lockdown, feel more stressed and tired.”

Four people highlighted how they had **lost their usual support structure**:

“I cared for my wife all through the first lockdown without any breaks as I could not get a diagnosis for her until July 2020. In August, I got her into a care home.”

“Usual support is school, parents, my best friend. School shut/reduced. Stepdad suffered stroke so if anything I needed to help them more and they couldn’t care for my daughter. Nothing open so hard to go get a break anywhere away from things. Friends have had their own stresses balancing home working with home learning, etc. Also, exposure for my friend’s family left them isolating too, which impacted plans for breaks.”

“Due to lockdown unable to visit friends and family that are my support.”

“Less people who can step in and provide informal respite care/support. More stress.”

Four told us that this was because of **shielding** by the carer or cared for, for example:

“I was shielding both parents during the first lock down and so therefore I was shielding also. My relationship with my partner was put on hold which had a huge impact on my mental wellbeing.”

“Because he is shielding, no-one can visit. We are constantly bickering.”

“Initially shielding, now don’t feel able to leave for any amount of time. Every year my husband and I have a weekend away because of the stress etc, not in 2020. Also don’t feel able to put the responsibility on anyone else. We have a support bubble for informal care but haven’t used it yet.”

Three people explained that the **needs of the people they cared for had increased** and two had added **family caring or home-schooling pressures**, for example:

“My father’s health has declined rapidly during the pandemic and have been unable to access physical GP appointments who could see my father’s decline in health.”

“Due to severity of ill health, hospital admissions and surgery for the four people I care for it has meant I have not had time for a break. I have been exhausted and had to stop for a week, as I was in bed ill myself.”

“My husband has worked right through the pandemic, so I have been home schooling two children. He does help with care when he gets home from work.”



“Covering care and supporting self/family has remained a constant battle/balance; there is no opportunity to take a break.”

Two who said they had been able to take a break gave caveats:

“But have to be available to give emergency support and holiday/sickness cover even though we actually live 90 miles away.”

“Not much going on during the first lockdown, but it got better during the last lockdown!”

### Impact

As illustrated in the comments above, most of those that mentioned the impact that not being able to have a break had of them highlighted the mental and emotional toll on them.

Theme	Number of comments
Exhausted/tired/stressed/frustrated/worried	10
Impact on mental or physical wellbeing	6
More responsibility/more busy	5
Other	5
<i>Keep going</i>	2
<i>Used to coping alone</i>	1
<i>Unfair on other family members/children</i>	1
<i>Guilt from cared for if went away</i>	1

Two people who did not explain why they could not have a break did highlight the impact on them:

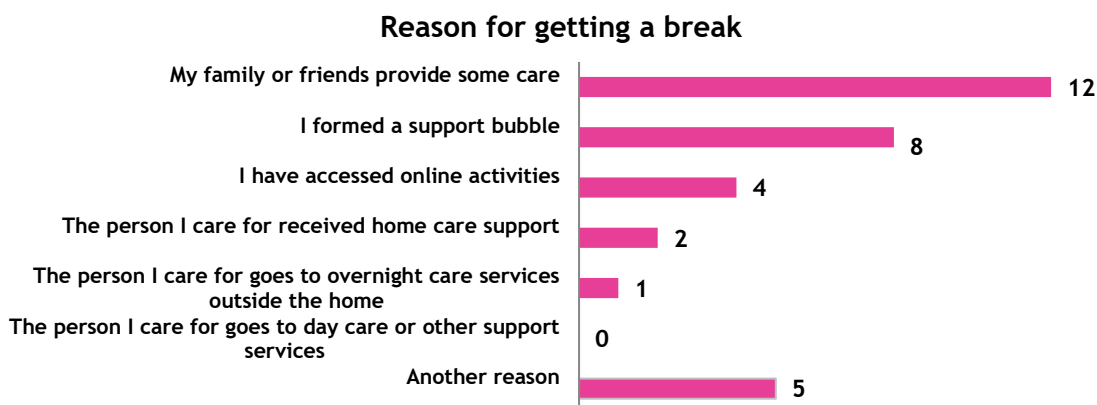
“I had hoped to take a proper break this year. I have had to make the best of things but have felt trapped and sad from time to time.”

“I only take a break to work within the hospital. Always on the go and worrying how family are caring for my son.”

### Reasons for taking a break

Carers were given a list of options to choose from to tell us why they had been able to take a break, if they had.

22 people gave one or more reasons, with the most common reasons being because friend or family had helped and/or they had formed a support bubble.



The other reasons given were:





“I do not live with the subject. Also the subject stayed four weeks with another family member for respite and monitoring.”

“My son went back to school so I’ve had a few hours off, but not a proper break.”

“Volunteering for a local homeless charity helping to write for a support programme of groups.”

“When the person I care for has a rest, I can take a break then.”

“During times that are covered by paid carers.”

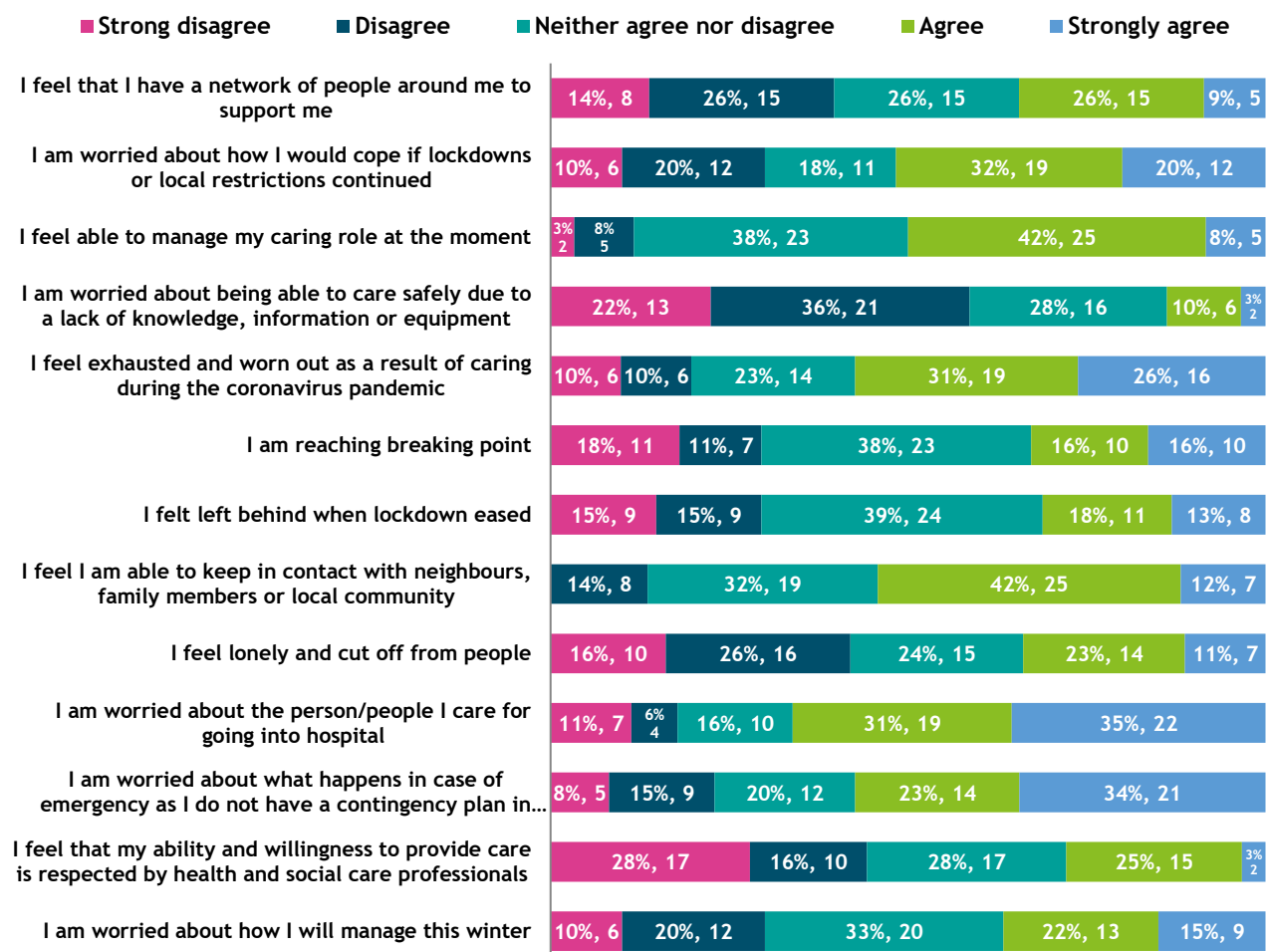
Another carer said they “take daily walks if possible” and one explained how most of the care is provided by another family member.

## More about carer wellbeing

### Feelings during lockdown

Carers were asked to tell us how they were feeling at the time by agreeing or disagreeing with a series of statements. 65 people answered one or more statement.

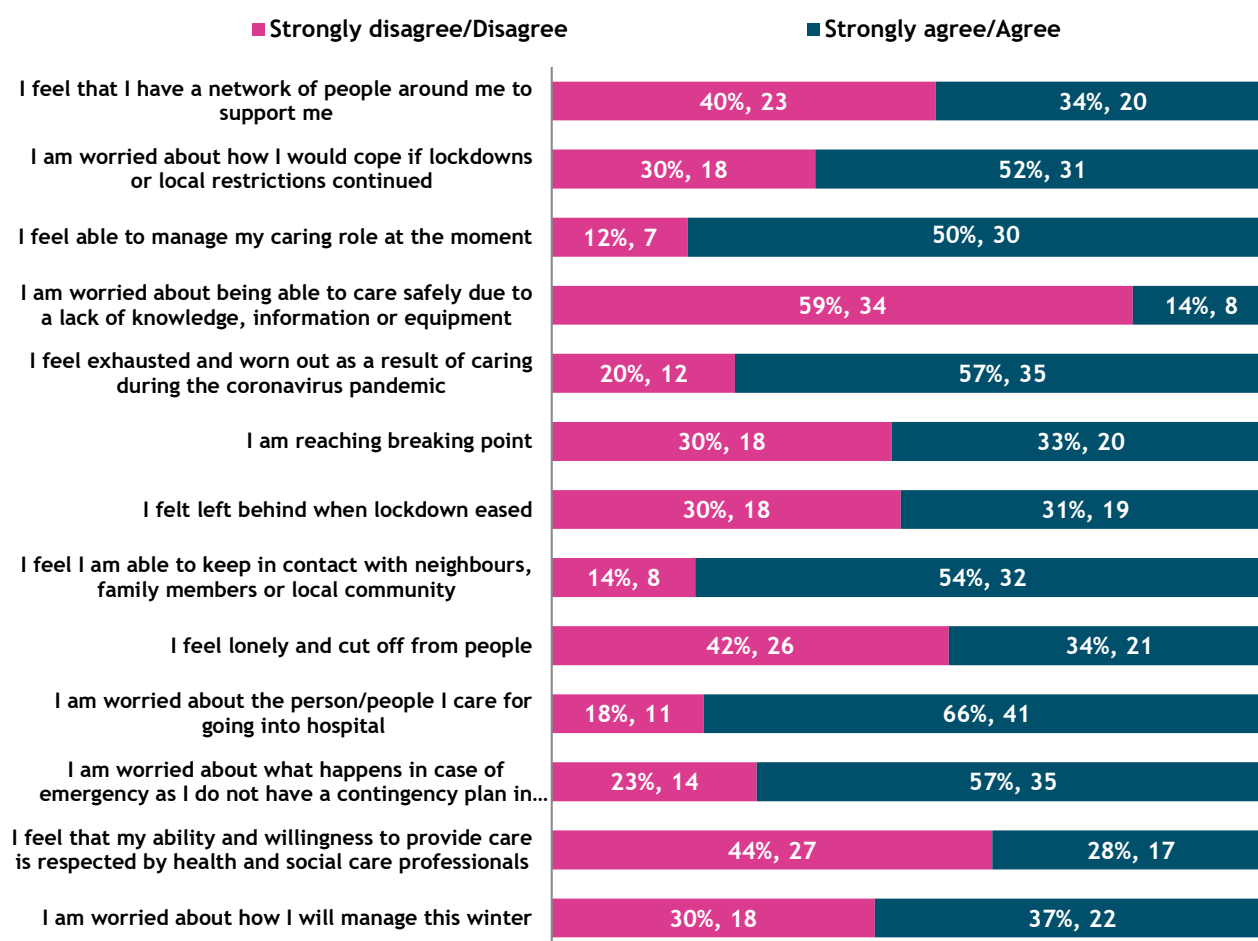
How carers have been feeling



The above graph can be simplified by removing the ‘neither agree nor disagree’ responses and combining ‘strongly agree’ and ‘agree’, and ‘strongly disagree’ and ‘disagree’.



### How carers have been feeling (simplified)



This shows that **carers were most worried about the person or people they care for going into hospital**, 66% (41 of 62) agreed or strongly agreed with this statement. 57% (35 of 61) agreed or strongly agreed that they were **worried about what would happen in the case of emergency** as they did not have a contingency plan in place.

57% (35 of 61) agree or strongly agreed that they **felt exhausted and worn out** as a result of caring during the coronavirus pandemic and 52% (31 of 60) were **worried about how they would cope if lockdowns or local restrictions continued**, compared to 30% (18) who were not worried about this.

54% (32 of 59) felt they were **able to keep in contact with neighbours, family members or the local community**, and no-one strongly disagreed with this statement.

A majority, 47% (27 of 61) disagreed or strongly disagreed that **their ability and willingness to provide care was respected by health and social care professionals**.

More positively, **fewer people were worried about being able to care safely** due to a lack of knowledge, information or equipment - 59% (34 of 58) disagreed or strongly disagreed with this statement. Half (50%, 30 of 60) **felt able to manage their caring role** at the time (compared to 12% (7) who didn't, 38% gave a neutral answer to this statement).

The results for the other statements were more mixed, but it is still concerning that 40% (23 of 58) disagreed or strongly disagreed about **having a network of people around them to support them**, 34% (21 of 62) felt **lonely and cut off from people**, 33% (20 of 61) felt they were **reaching breaking point**, and 31% (19 of 61) felt **left behind when lockdown eased**.



Carers were again given the opportunity to tell us more, which 17 carers did.

Five people talked about feeling **unsupported, neglected or isolated** and four people commented on how they felt **tired or stressed**:

“Although I can provide the care needed, I am tired quite a lot of the time. I work part-time then go home to be a carer.”

“I am tired.”

“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’m worried about everyone’s mental health and can’t carry it on much longer.”

“There is no support for carers.”

“I look after a [over 90] year old as a volunteer now and I feel isolated and unsupported.”

“Neglected.”

“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.”

“It is very isolating living rurally with no public transport, and whereas before we could ask for lifts from friends/neighbours if needed now we are unable to due to lockdown restrictions. We had to use food parcels delivered from the local community to feed our family when we were struggling to get shopping delivered during first lockdown.”

Three people explained their **worries about what would happen if they could not provide care**:

“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.”

“I’m worried about what might happen if I get Covid.”

“My main concern is obviously the fact I go into hospital in just a few days the impact for my [child] and the risks of cover. Also, how I will balance a new-born with the care of my [child] as a single parent. Whilst we have a provisional plan extended school closures, any exposure leading to isolation of my support bubble could leave me in a very difficult position post-op so lots of concerns.”

One person explained more about the difficulties of living in a multiple-occupancy house and not being vaccinated sooner:

“Caring is tough. We have no contingency plan as we cannot self-isolate in our house. With three generations sharing the house and its facilities we are all concerned if one of us were to get COVID-19 how it would spread throughout the house. It was difficult for us to obtain flu jabs this winter so the opportunity to get everyone in the house vaccinated quickly/timely is vitally important to us. Unfortunately, all the information/guidance states vaccines will be given in set patterns and carers to not feature in these. If unpaid carers were included with social carers who provide domiciliary care we would have access to the vaccine sooner - instead we just have



to continue to isolate ourselves for as long as possible as this is the only way we have to keep our household safe.”

Another person explained the stress caused by their loved on being in hospital:

“My worse nightmare has happened and my husband [is] in hospital ... The hardest thing is not being able to visit him and finding out what is going on with him! I am ringing three times a day but do not feel I am being kept informed as to what is going on with him! I am finding this most stressful and horrific after [many] years of marriage, and just want him home with me!!!”

One other person commented about their mixed experience of healthcare professionals:

“Some health care professionals respect care I provide others don’t. I’m lucky I have a supportive GP.”

One person felt they had good support and one was used to coping alone:

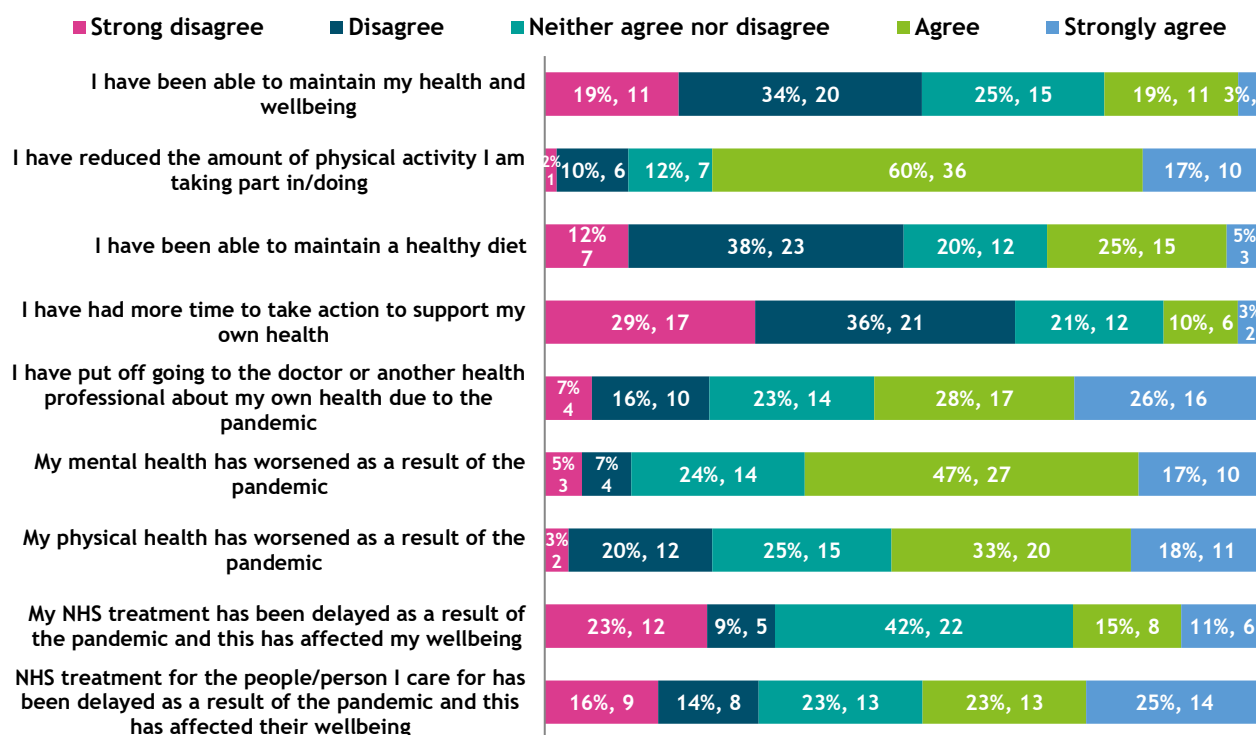
“I have good support from family and friends, and I am busy enough doing voluntary work from home.”

“I’m used to coping by myself so makes no difference to me.”

### Impact of caring on health and wellbeing

Carers were asked to tell us whether caring during the pandemic had affected their health and wellbeing by agreeing or disagreeing with a series of statements. 63 people answered one or more statement.

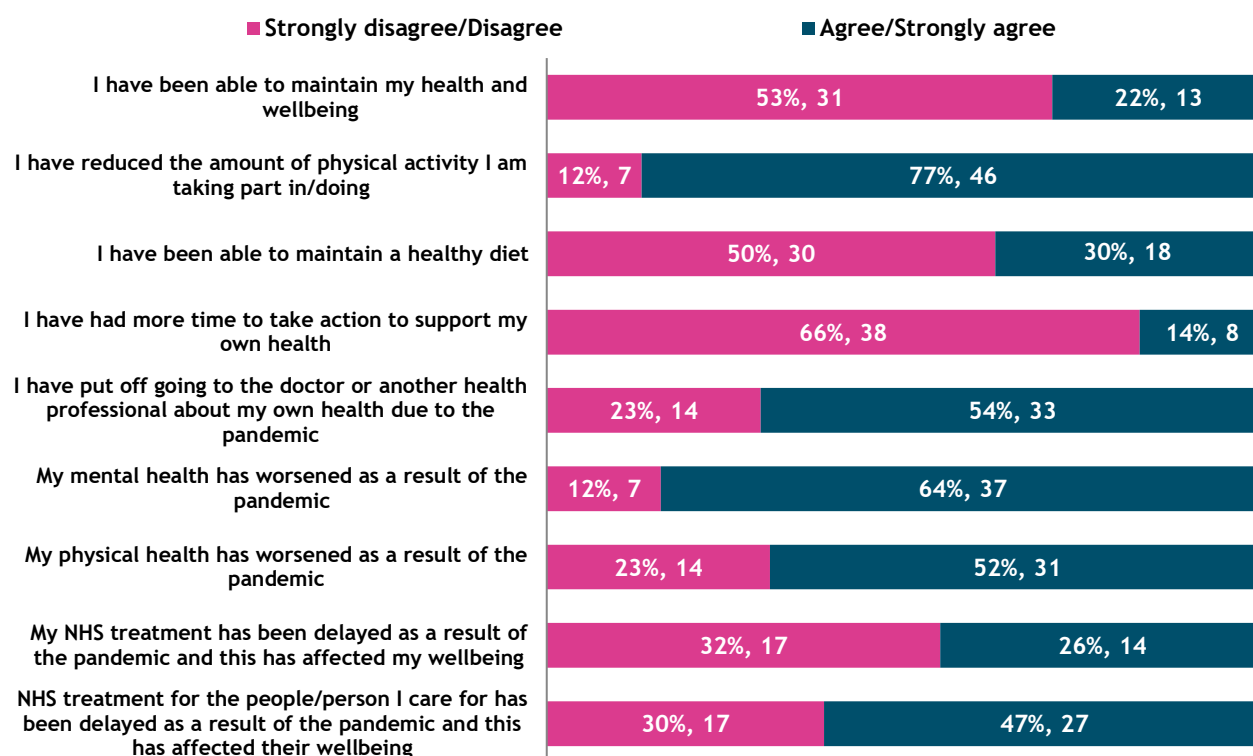
Effects of pandemic on carer health and wellbeing



Again, the above graph can be simplified by removing the ‘neither agree nor disagree’ responses and combining ‘strongly agree’ and ‘agree’, and ‘strongly disagree’ and ‘disagree’.



## Effects of pandemic on carer health and wellbeing (simplified)



This shows that carers have felt many impacts on their health and wellbeing. More people disagreed/strongly disagreed (53%, 31 of 59) that they **had been able to maintain their health and wellbeing** than agreed/strongly agreed (22%, 13).

77% (46 of 60) agreed or strongly agreed that they had **reduced the amount of physical activity** they were doing and 66% (38 of 58) disagreed or strongly disagreed that they had **more time to take action to support their own health**.

64% (37 of 58) agreed or strongly agreed their **mental health had worsened** as a result of the pandemic and 52% (31 of 60) said the same about their **physical health**. 50% (30 of 60) disagreed or strongly disagreed that they **have been able to maintain a healthy diet**, compared to 30% (18) who felt they had.

54% (33 of 61) agreed or strongly agreed that they had **put off going to the doctor or another health professional about their own health** and 26% (14 of 53) agreed or strongly agreed that their **NHS treatment had been delayed as a result of the pandemic** and this had affected their wellbeing. This was more of an issue for the people they cared for, with 47% (27 of 57) agreeing or strongly agreeing.

Carers were asked to tell us more about how the pandemic had affected their health and wellbeing, and the impact this had on them. 26 people commented.

Eleven people explained the impact on their **mental health**, such as increased anxiety and depression. Three people felt both their mental and physical health had been affected, for example:

“More mood swings, sleepless nights with worry, anger and frustration at delays in getting help with subject, not always able to exercise in my usual manner to improve mind, body and soul.”

“I feel more anxious, more angry and less hopeful than at any other time I can remember. I go to bed tired and wake up tired, and I need the mental energy to look after my cared-for. Since the end of second lockdown my cared-for and I had managed to increase our outdoor activities -



walking, birdwatching, etc. but with a new limitation on how often we can go out I don't know what we're going to do. I don't see an early way out of this situation.”

“The pandemic has caused my generalised anxiety disorder to get worse.”

“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.”

Seven people explained the impact on their **physical health**, such as increased weight or deterioration of conditions, and five also mentioned a **lack of access to healthcare services** (GPs had four mentions and dentists had two), for example:

“My weight and pain levels have increased whilst my ability to exercise and mental health have declined. This has made me fat and unhappy. Also as [a number of] close relatives all suffered related inheritable cancers in the last few years, I was going to request a mammogram and ovarian cancer scan this year, with a view to having preventative double mastectomy, hysterectomy and oophorectomy in the next few years but haven't seen the GP about it due to Covid. And my skin tags have got worse, ditto. And my annual colonoscopy has been delayed, which means they're less likely to catch my colon cancer while it's treatable. So basically fat, unhappy, in greater pain and with less chance to delay or prevent my inevitable death from cancer.”

“I have put on weight during the pandemic, comfort eating I suppose. I don't take as much exercise as I used to. My sister and son both live within 15/20 minutes' walk away, but I find I would rather take two buses than face walking. I have arthritis in my knees and walking can become quite painful, so I walk as little as possible when I have a flare up. Have become so unfit I get out of breath walking, and if faced with a slope, feel half dead by the time I get to the top.”

“I have essential tremor and my tremors and ticks have increased during the pandemic due to stress and anxiety. My GP has increased my medication slightly to help with this. I have also taken up Mindfulness to help.”

“My health deteriorated and the hospital discovered I had hypertension during my day surgery admission. I was told to contact my doctors on discharge - give them my blood pressure readings taken in the hospital, and to request 24-hour monitoring to establish I was suffering from hypertension. Duly did this only to be told by my doctors they were not doing this monitoring due to the pandemic. Told to purchase a blood pressure monitor and keep an eye on it myself. Feel totally alone with no support from our doctors.”

“I have had hospital appointments all cancelled for last year for my treatment for osteoporosis and also dental care. I was unlucky in breaking my wrist bang in the middle of lockdown and didn't have an operation I probably needed because they were not doing many at the time! I had to keep going for X-Rays and in plaster for six weeks, it has healed quite well considering.”

One other person was concerned about the progression of health conditions.

In addition to the above, three people said they had been **less able to exercise** due to coronavirus restrictions or worries, for example:



“I could take him out for short walks or drive to a country park before Covid. But now he is not to mix with anyone, so we are stuck indoors 24/7.”

“Reduced walking so I can protect my husband from getting infected.”

Four people mentioned the **pressure** they were under or that they were struggling:

“I am struggling to cope caring for two people. The pandemic has made this even more difficult. I need help.”

“Having to spend nearly 24 hours at home with one person. Having friend also scared and needing support, I cannot keep everyone cheerful. Having brother who lives on own and working through pandemic and of obese. Too much pressure all time.”

“I am stressed and over worked, but also can't help but continuously feel sorry for my mum. The worry is the worst, she is clearly very ill but if it was not for me calling the doctors everyday we wouldn't be getting anywhere. I'm at a dead end and don't know what to do if this were to continue for much longer.”

“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.”

One other person talked about work stress and another the impact of not being able to socialise.

One person felt they were well supported but did still experience some mental struggles:

“I am a positive upbeat person and work hard at maintaining this. Lockdown has brought its own challenges. I'm a [profession] and have been told by the government I can't work. So I've had worries over finances and paying the bills. I have a good support network around me and the government grants have helped to keep me afloat along with any savings I may have had. However mentally, sometimes it has been a struggle to keep upbeat everyday, especially with us being in the middle of winter and the grey dull days. Summer lockdown was much easier to cope with.”

One of those interviewed explained more about they struggled and did not have enough support, despite having tried to access help:

“As for emotional support I have nothing, not sure what I would do if I were in crisis, I have got to the stage where there is no point asking as the emotional drain of building up to asking for help to see them come through the door and know nothing will change. ... Basically, the mental health of all of us has deteriorated, the autism means they overact to the fear of the pandemic, they were already isolated and do not socialise anyway, but this has made it worse.

No external help at all coming in, I am supposed to be shielding, so I did manage to get the VIP rolling slot for food delivery which takes the stress out of food shopping. ...

My mental health is now suffering, in the beginning it was ok, we were grateful for the garden and sunshine, but now there is no end to it.”

### *Themes from consultation event*

People at the consultation event also mentioned wellbeing issues as challenges they had faced. Some said they were fearful and anxious and felt that “‘propaganda’ in the news has added to people's anxiety, every day” and others had anxiety about them or the people they care for contracting COVID-19. Some people cared for had become more unwell during the pandemic and had increased needs, which was more demanding for carers.



Caring was described as physically and mentally draining leading to exhaustion, particularly with support services being unavailable and with some people afraid to go out. It was also felt that carers were suffering in silence with their mental health and that winter and lockdown had been really hard on people's wellbeing.

“An elderly person said she was pleased it snowed, so she didn't have to go out with her grandson and dog to the park, as she was scared.”

Carers reported being unable to stay well mentally and physically, having no routine, no exercise and a poor diet due to being unable to secure basic provision, especially in rural areas. Some carers physical health will have declined, especially when their health was not always attended to prior to pandemic, and this could impact on their ability to cope with their caring role in the future. One carer was suffering with 'Long Covid' symptoms and there was concern about a whole new group of people with 'Long Covid' that may need care in the future and not be able to return to work and normal life.

Some working carers were also struggling, having been forced back into work against their wishes because they did not want to lose their job. Some had been becoming more confident to tell their employers they were a carer but other were not so confident for fear of losing their job.

Loneliness was also an issue - online meetings and groups had been important support, but it was hard not seeing wider family and some are so desperate to see people they would rather risk getting Covid than to “die of isolation”.

There was also concern about the pressures carers and services may see in the future due to the deterioration of older people, such as an increase in frailty, and those with long-term conditions - with the example of someone who had lost skills and independence because services have remained closed, and a concern that these changes will be permanent.

Seven respondents to the 2020 survey also told us about how caring during the pandemic was causing them extra stress or affecting their mental health.

### Final comments from carers

At the end of the survey we asked carers if there was anything else they would like to tell us about the impact or difficulties of caring since the start of the pandemic. Eight people commented, and one young carer. Comments mentioned more about how people had **struggled, difficulty accessing services or a lack of support**, and included **suggestions**:

“I'm expected to cope as I do this for a living, so doing it for family is easier!!! That is not the case at all, you cannot turn off when it's family.”

“It feels like every household for itself. If my mum-in-law goes into care, it will also start to cost a lot of money and the pressure of getting her house emptied/cleaned/put on the market involves a considerable source of stress. Getting a lasting power of attorney took way too long!! We did it ourselves to save money, but it took many months. A solicitor would have costed a lot of money. People need advice with that. Now the bank still wants my partner to go in with his frail mum.”

“Lack of services has impacted on the physical and mental health of those I care for, causing slower recovery and in some cases worsening conditions. Appointments have been cancelled and particularly mental health services just seem to have disappeared. This has made it more difficult for me as I have had to do more myself to support them. I am on 24-hour call.”





“Still enduring, mental health is not recognised.”

Two people mentioned the loneliness of those they care for, at home alone or in supported living:

“Just address the loneliness of people still living in their own homes.”

“In supported housing there could have been more mixing for those who have nobody at all visiting them, they could have been advised to mix more together or with a buddy.”

One person suggested a carers ID card would be useful:

“I felt nervous driving, in the first lockdown to support my mum, as we were not meant to be out of the house on the roads, I needed something to take that anxiety away like a carers card or something.”

One person commented on the pandemic:

“Actions of others not helping the situation, but we have no control over that!!”

The young carers highlighted the need for awareness of young carers as well as the isolation they feel and the difficulties with going back to school:

“I think it’s important for hospitals to still think Young Carer, it was hard to be recognised before Covid let alone now when most appointments are telephone appointments or even if they are face to face it’s the patient only (which I get why Covid- wise but we also know our family members best!).

Covid has also increased the feeling of isolation as at least at school we got to see our friends and it was kind of a mini break even though I always worry about home, but now we’ve not had that break.

I think we need to be considered in terms of going back to school too because my family member is clinically extremely vulnerable and I’m really worried about catching something at home and bringing it home to Mum.”

One person thanks us for doing this research.

“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.”



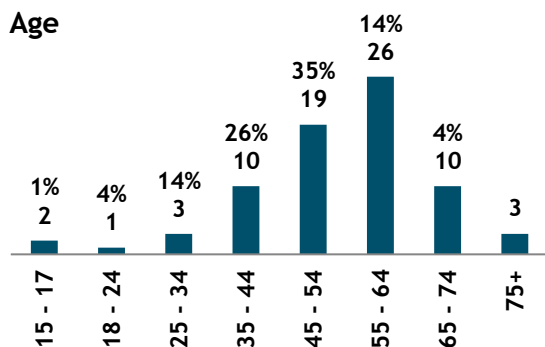
## Demographics

### Age

The majority of survey respondents (78%, 58 of 74) were age 45 or older. The two under 18s completed the young carers version of the survey.

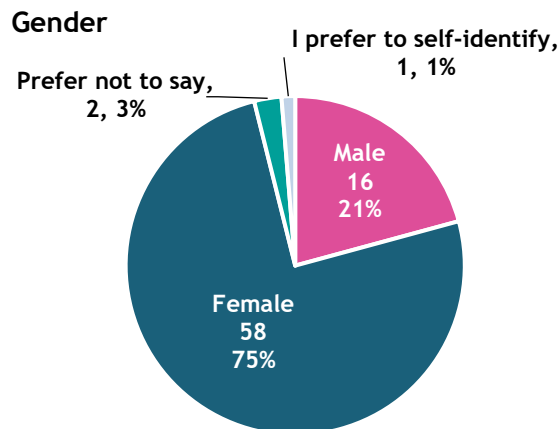
### Location

Over one-third of respondents live in borough of Northampton (39%, 30 of 76), including the two young carers. The rest were spread across the county. Two people lived in London, one of whom explained that they cared for two people in Northampton.



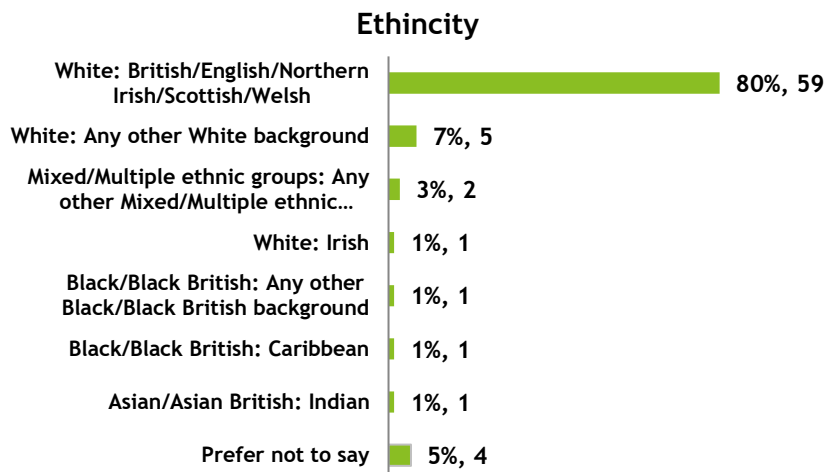
### Gender

Three quarters of the survey respondents were female (75%, 58 of 77).



### Ethnicity

80% (59 of 74) said their ethnic background was White British and a further 8% (6) were from another white background, including one White: Irish.



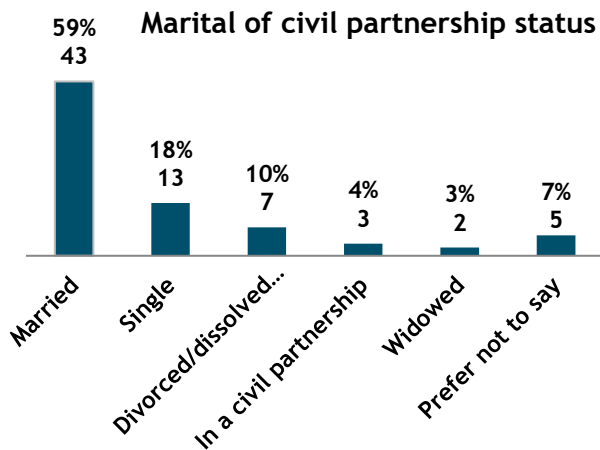


### Marital status

63% (46 of 73) were married or in a civil partnership.

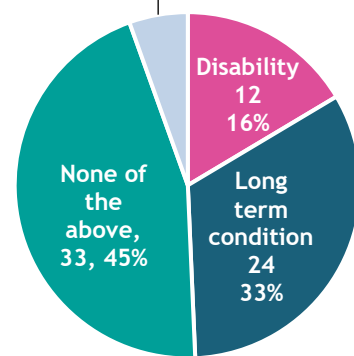
### Disability of long-term condition

49% (36 of 73) considered themselves to have a disability and/or a long-term condition.



**Disability or long term condition**

Prefer not to say, 4, 6%



## 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](http://www.healthwatchnorthamptonshire.co.uk)

**healthwatch**  
Northamptonshire





## 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](http://www.northamptonshire-carers.org)





## 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 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](http://www.connectedtogether.co.uk)





## Appendix 1 - Survey questions

### Main survey (for adults) (further information and links to support were included)

1. Are you currently caring for someone or have cared for someone between March 2020 and now?
 

Yes	No (this survey is only covering the period of the pandemic so you do not need to complete it)
-----	--
  
2. Please tell us your age:
  - 13 - 17 years
  - 18 - 24 years
  - 25 - 34 years
  - 35 - 44 years
  - 45 - 54 years
  - 55 - 64 years
  - 65 - 74 years
  - 75+ years
  
3. Who do you care for? (Please tick all that apply)
  - A child I live with (age under 18)
  - A young adult I live with (age under 25)
  - An adult I live with (age 25-74)
  - An older adult I live with (age 75 or over)
  - A child I do not live with (age under 18)
  - A young adult I do not live with (age under 25)
  - An adult I do not live with (age 25-74)
  - An older adult I do not live with (age 75 or over)
  - Other (please tell us):
  
4. Approximately how many hours per week do you provide carer for this person/people?
  
5. Has the amount of care you provide changed as a result of the coronavirus (COVID-19) pandemic?
 

Yes	No	Don't know
-----	----	------------
  
6. If you are providing more care due to the impact of the coronavirus (COVID-19) pandemic, please tell us why that is: (Please tick all that apply)
  - Because local services have been reduced/closed (e.g. day care or specialist school)
  - Local services have opened but I am worried about services being COVID-secure so am not using them
  - I am worried about paid (by the NHS/council or privately) health and social care staff having contact with the person I care for
  - Paid health and social care staff have reduced personal care
  - My employment hours/status has changed so I have more time
  - People that normally help me so I can have a break are not available or are unable to help
  - The needs of the person/people I care for have become more complex
  - I am providing more care for another reason (please tell us below)
  
7. If you are providing less care due to the impact of the coronavirus (COVID-19) pandemic, please tell us why that is: (Please tick all that apply)
  - Because local services or volunteers are providing more care (e.g. food shopping or parcels)



- Paid (by the NHS/council or privately) health and social care staff have increased personal care
- My employment hours/status has changed so I have less time
- I have had less time as my children have not been in school
- The place where the person I care for lives is not allowing visitors
- I am reducing face to face contact with the person I care for
- Virtual or remote services (e.g. GP appointments) have made it quicker or easier for me to support the person I care for
- I am providing less care for another reason (please tell us below)

8. Please tell us more about what has changed and the impact it has had on you as a carer:

**Guidance, information and advice**

9. How easy/difficult is it to find information about coronavirus/COVID-19 that you need as a carer? (Please tick one)

- |           |                |                              |
|-----------|----------------|------------------------------|
| Very easy | Easy           | Neither easy nor difficult   |
| Difficult | Very difficult | Did not need any information |

10. If you have found it difficult to get the information you need, can you tell us why and what information?

11. The inability to meet face to face during the coronavirus/COVID-19 pandemic has led to an increase in the use and reliance on digital technologies, such as video calls using computers and smart phones (e.g. Zoom and WhatsApp), website and social media. Have you experienced any challenges using digital technology? (Please tick all that apply):

- I do not have the necessary equipment/Wi-Fi/data, etc.
- I struggle to afford things like equipment/Wi-Fi/data
- I do not know how to use digital technology
- I struggle with broadband and/or phone signal in my house
- I have found it challenging to find a private space and this has made it harder for me to connect with others and use services digitally
- I have experienced other challenges (please tell us below)

12. Have you been able to use digital technology (such as Zoom, WhatsApp, websites and apps) more during the coronavirus/COVID-19 pandemic? (Please tick all that apply):

- I have started using new technology and digital services since the start of the pandemic
- I use video conferencing calling services such as Zoom or WhatsApp more to access local support services for myself or the person I care for
- I use video conferencing and calling services such as Zoom or WhatsApp more to keep in touch with friends and family and/or connect with other carers
- I use online support groups and forums more to connect with other carers
- I have online video consultations for appointments with my GP and for other health and social care services
- I use online mental health support services
- I have found it beneficial and have been able to connect with more people using digital technology
- I have experienced other benefits of using digital technology (please tell us below)

13. If you or the person you care for has needed a COVID-19 test, have you experienced any difficulties getting tested? (Please tick all the apply)

	For yourself	For the person/ people you care for
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I/they have not needed a COVID-19 test		
I/they needed a COVID-19 test but could not get an appointment or home testing kit		
I/they needed a COVID-19 test but could not get to a testing site		
I/they needed a COVID-19 test but could not use the testing kit or had difficulty with it		
I was unsure about whether I/they needed a COVID-19 test		
I/they had a COVID-19 test without difficulty		

14. If you or the person/people you care for have previously tested positive for COVID-19, were you given sufficient information and advice about self-isolation?  
 Not applicable                      Yes                      No

15. If you or the person/people you care for tested positive for COVID-19, or had symptoms of COVID-19, was it more difficult for you to care for them as normal?  
 Not applicable                      Yes                      No  
 Please tell us more:

**Experiences of GP and hospital (appointments, discharge, medication, support, etc.)**

16. Have you had any difficulty accessing the following health services for yourself during the coronavirus/COVID-19 pandemic?

	Not applicable (haven't tried)	Yes	No	Yes and no (different experience at different times)
GP appointments (face to face, online or by phone)				
District or community nurse				
Obtaining medication/prescriptions				
Routine or regular hospital appointments (e.g. outpatient appointment)				
Scheduled hospital treatment (e.g. delayed surgery)				
Emergency healthcare (e.g. A&E or emergency ambulance)				
NHS 111 (phone or online)				
Dental care				
Mental health care or support				
Other (please tell us what):				

17. Have you had any difficulty accessing the following health services for the person/people you care for during the coronavirus/COVID-19 pandemic?

	Not applicable (haven't tried)	Yes	No	Yes and no (different experience at different times)
GP appointments (face to face, online or by phone)				
District or community nurse				
Obtaining medication/prescriptions				
Routine or regular hospital appointments (e.g. outpatient appointment)				
Scheduled hospital treatment (e.g. delayed surgery)				
Emergency health care (e.g. A&E or emergency ambulance)				



NHS 111 (phone or online)				
Dental care				
Mental health care or support				
Other (please tell us what):				

18. Please tell us more about any difficulties you experienced, or things that worked well, accessing health services for yourself or the person/people you care for and the impact this had on you as a carer.

### Personal Protective Equipment (PPE), e.g. face masks, aprons or gloves

19. Please tell us your experiences of using or needing PPE during the coronavirus/COVID-19 pandemic

	Not applicable	Yes	No	Yes and no (different experience at different times)
Do you need PPE to carry out your caring duties?				
Were you asked by any service if you needed PPE?				
Have you had trouble getting PPE to help you care?				
Have you had to buy PPE yourself specifically for use when caring?				
Were you given advice on the most effective way to use PPE as part of your caring role?				
If you have been using PPE equipment, were you given advice on safe disposal of it?				

20. If you were provided with PPE, who provided you with it?  
 A health or care service                      A charity  
 Other (please tell us who)

### Other support services

21. We would like to know about your experience of different support services for you and the person/people you care for - if these services have resumed, if you are receiving the same level of support as before, or if you have started using new services. Please tick as applicable and leave blank for services not used.

	I <u>started</u> using this during the pandemic	This <u>continued</u> throughout the pandemic	This has <u>reopened/resumed</u> but I am getting a <u>lower level of support</u> than before	This has <u>reopened/resumed</u> and I am getting the <u>same level of support</u> as before	This has <u>reopened / resumed</u> but I am <u>not using it</u>	This has <u>not reopened / resumed</u>
Day services						
Care home						
Residential care						
Specialist schools						
Before and/or after school provision for my disabled child						
Activities provided by Northamptonshire Carers						



Activities/support provided by a local charity (e.g. meals on wheels)						
Visits from NHS or council-funded care workers						
Visits from self-funded care workers						
Sitting service						
Other breaks services						
Support from local community or NHS volunteers with shopping, prescriptions, etc.						

Please tell us more about the impact on you of the changes in services, including any difficulties or improvements

22. Are there any changes in services that you would like to see continue? Please tell us what.

#### Other impacts of the pandemic on you as a carer

23. Have you been able to take a break/enough breaks from your caring role since the start of the coronavirus (COVID-19) pandemic?

Not applicable                      Yes                      No

Please tell us why you have been unable to take a break/enough breaks and the impact this has had on you:

24. I have been able to take a break because... (Please tick all that apply).

My family or friends provide some care

I formed a support bubble

The person I care for goes to day care or other support services

The person I care for goes to overnight care services outside the home (e.g. care homes)

The person I care for received home care support

I have accessed online activities, e.g. online coffee mornings

Another reason (please tell us what)

25. How are you feeling at the moment? Please indicate how you feel about the following statements on a scale from strongly disagree to strongly agree, or leave blank if not applicable.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I feel that I have a network of people around me to support me					
I am worried about how I would cope if lockdowns or local restrictions continued					
I feel able to manage my caring role at the moment					
I am worried about being able to care safely due to a lack of knowledge, information or equipment					
I feel exhausted and worn out as a result of caring during the coronavirus (COVID-19) pandemic					



I am reaching breaking point					
I felt left behind when lockdown eased					
I feel I am able to keep in contact with neighbours, family members or local community					
I feel lonely and cut off from people					
I am worried about the person/people I care for going into hospital					
I am worried about what happens in case of emergency as I do not have a contingency plan in place					
I feel that my ability and willingness to provide care is respected by health and social care professionals					
I am worried about how I will manage this winter					

Please tell us more

26. We would like to know whether caring during the coronavirus (COVID-19) pandemic has affected your health and wellbeing. Please indicate on a scale of strongly disagree to strongly agree how you feel about the following statements, or leave blank if not applicable.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I have been able to maintain my health and wellbeing					
I have reduced the amount of physical activity I am taking part in/doing					
I have been able to maintain a healthy diet					
I have had more time to take action to support my own health					
I have put off going to the doctor or another health professional about my own health due to the coronavirus (COVID-19) pandemic					
My mental health has worsened as a result of the coronavirus (COVID-19) pandemic					
My physical health has worsened as a result of the coronavirus (COVID-19) pandemic					
My NHS treatment has been delayed as a result of the coronavirus (COVID-19) pandemic <u>and this has affected my wellbeing</u>					
NHS treatment for the people/person I care for has been delayed as a result of the coronavirus (COVID-19) pandemic <u>and this has affected their wellbeing</u>					

Please tell us more about how the pandemic has affected your health and wellbeing, and the impact this has had on you, whether positive or negative

27. Which of the following support would help you most in the near future? Please tick all that apply.



- Increased financial support
- Access to breaks and replacement/respite care
- Better personal protective equipment (PPE) for unpaid carers
- More support in the community e.g. from local volunteers
- Better personal protective equipment (PPE) for social care workforce
- More support from the local authority and local services
- Clearer/more specific guidance for unpaid carers
- Someone to talk to
- More support from community pharmacies
- More support from your GP
- More support from district/community nurses
- Prioritised access to vaccinations for carers and people they care for
- Better recognition of carers in the community
- Something else (please tell us below)

28. Is there anything you would like us to know about the impact of difficulties of caring since the start of COVID-19 that you haven't already told us?

### Tell us about you

By telling us information about yourself, you can help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

29. Which district or borough of Northamptonshire do you live in?

- Corby
- Daventry
- East Northamptonshire
- Kettering
- Northampton
- South Northamptonshire
- Wellingborough
- Prefer not to say
- I do not live in Northamptonshire (please tell us where you live)

30. What is your gender/what gender do you identify as?

- Male
- Female
- I prefer to self-identify (please specify)
- Prefer not to say

31. Please select your ethnic background:

- Arab
- Asian / Asian British: Bangladeshi
- Asian / Asian British: Chinese
- Asian / Asian British: Indian
- Asian / Asian British: Pakistani
- Asian / Asian British: Any other Asian / Asian British background
- Black / Black British: African
- Black / Black British: Caribbean
- Black / Black British: Any other Black / Black British background
- Gypsy, Roma or Traveller
- Mixed / Multiple ethnic groups: Asian and White
- Mixed / Multiple ethnic groups: Black African and White



- Mixed / Multiple ethnic groups: Black Caribbean and White
- Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background
- White: British / English / Northern Irish / Scottish / Welsh
- White: Irish
- White: Any other White background
- Another ethnic background
- Prefer not to say

32. Please tell us about your marital or civil partnership status:

- |                        |  |
|------------------------|--|
| Single                 | Divorced / dissolved civil partnership |
| Married                | Widowed                                |
| In a civil partnership | Prefer not to say                      |
| Separated              |  |

33. Do you consider yourself to have a disability or a long term health condition?

- Yes, I consider myself to have a disability
- Yes, I consider myself to have a long term condition
- None of the above
- Prefer not to say

### Young carers survey (further information and links to support were included)

#### A few questions about you and the person you help to look after.

1. How old are you?

- 11     12     13     14     15     16     17

(If you are 18 or older please complete our other survey at

<https://www.healthwatchnorthamptonshire.co.uk/experiences-caring-during-coronavirus-pandemic> if you are online)

2. What is your gender?

- Male                       Female                       Non-binary or gender neutral  
 Prefer not to say                       I prefer to self-identify

3. What area of Northamptonshire do you live in?

- Wellingborough                       Kettering                       Corby  
 East Northants                       Northampton                       South Northants  
 Daventry                       Other (please tell us where you live)

4. What is the main disability or health condition of the person you care for?

- Drug or alcohol dependency                       Learning disability  
 Physical disability                       Sensory impairment, e.g. blind or deaf  
 Mental ill health                       Prefer not to say  
 Other illness or health concern (please tell us about it)

5. Who do you help to look after or care for?

- Mum or Dad     Brother or Sister                       Grandparent  
 Someone else - please tell us who that is:

#### How do you help to look after people?

6. Has how much you do to support your family changed since COVID-19 started?

- I am doing more to support them  
 I am doing less to support them  
 The amount I do hasn't changed  
 Not sure

Can you tell us more about what you do and how it has changed since the COVID-19 pandemic?



7. Has it been easier or harder to help your family since Covid-19 started
- It's got harder
  - It's got easier
  - It's been easier in some ways and harder in others
  - It hasn't changed
- Can you tell us more about how it has got easier or harder - for example, maybe it was easier because you didn't have to go to school or college, or it's been harder because other help has stopped or there's less money.
8. Have you found it difficult to get the information and help you needed?
- Yes
  - No
  - Not sure
- Can you tell us about more about finding the information you needed? And whether this information was difficult to find? Has anyone been helpful to you?
9. Has anyone, such as a teacher, doctor or anyone else checked in to see how you have been doing during COVID-19? If yes, please tick who has spoken to you.
- Teacher
  - Doctor
  - No, no one has checked up on me
  - Support worker
  - Social worker
  - Family or Friend
  - Other, please tell us who
10. Have you used any of these support services (or any others) for your emotional wellbeing or mental health during COVID-19, e.g. Young carers, The lowdown, Service Six, time2talk
- The lowdown
  - Young Carers (Northamptonshire Carers)
  - Service Six
  - School nurse or Chat Health text line
  - Time2talk
  - CAMHS live
  - CHAT
  - SHOUT
  - No, I have not used a support service
  - Something else - please tell us what
11. If you have used a support service, what would you score the support as out of 5, with 5 being very good. Please tell us your score for each service, e.g. Name of service 1: 4/5, Name of service 2: 2/5
12. Did you come across any challenges when trying to access the support service you needed?
- The service I wanted wasn't available
  - I wanted to see someone to talk and couldn't
  - I had to wait a long time to talk to anyone
  - I could only talk to someone online and do not have access to the internet
  - I had other problems or challenges - please tell us about them:
13. What would have been helpful for your emotional wellbeing or mental health during COVID?
- Being able to talk to someone face to face
  - More chance to talk on the phone or on video
  - Being able to talk to someone in my situation
  - Being able to have some time to myself
  - Something else - please tell us what would have been helpful
14. Did you find coping with caring during COVID-19 easier when school was open or closed?
- Easier when I'm at school or college
  - Easier when school or college is closed
  - No difference for me
  - Not relevant, I was at school all the time
- Can you tell us more about it?
15. Is there anything else you would like to tell us about the impact on your life of COVID-19 and helping look after someone?



## Appendix 2 - Consultation event notes

Following Northamptonshire Carers' AGM, Healthwatch Northamptonshire, Carers Voice and Northamptonshire Carers held a joint consultation event for unpaid carers, young adult carers and professionals via Zoom. 56 people attended.

Three questions were asked with attendees split into breakout rooms before group facilitators fed back to the main group.

1. What challenges have been faced by Carers during the coronavirus pandemic?
2. Despite the challenges, have there been any positives this past year for Carers?
3. Looking forward, what support will Carers need post-coronavirus?

The feedback sessions were recorded and uploaded to YouTube (<https://youtu.be/oNWG4RPxcKA>) and key comments added to an interactive Padlet board (see below).

### What challenges have been faced by Carers during the coronavirus pandemic?

#### Social isolation

- Not being able to visit loved ones in residential care, more should have been done sooner
- Not being able to visit in hospital and little facility to communicate with loved ones, dropping your cared for person off at casualty sometimes not knowing if you would see them again.
- “The telephone befriending has been great, really a life saver”.
- Isolation particularly relevant to those who have mental health issues - What before was normal, has now completely changed. This ‘new normal’ is now terrifying and causing major anxiety. When carers do get the opportunity to speak it is usually in front of the person they care for especially when caring full time.
- Isolation.

#### Impact on services

- Lack of access to health care for both the carer and the cared for person.
- “I had just plucked up the courage to go to a carers group in Towcester and then it switched to online, my daughter makes me log on and it has been wonderful, hope it continues online”.
- “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.”
- Lack of respite - even for short periods. Carers are tired and some have their own health conditions to manage.
- Mental health and the lack of access to support.
- Amount of services unavailable - Some day centres act as short periods of respite for carers since respite services are unavailable it not only impacts the person being cared for but also the carer.
- Access to primary health care - calls are not always welcomed and because of the pandemic a lot of people are struggling to get appointments, being turned away when they need to speak to someone and cannot always get past the receptionist.
- GPs have been the hardest to get hold of - for support line and carers. GPs not speaking to many people and GPs not willing to speak to carers who are not living in the same place - unapproachable. Shortage of GPs doesn't help...





- Issues around visiting in hospitals including lack of communication, change in their loved ones being unexpected.
- not being able to visit in residential care.
- Issues in accessing services.
- Lack of respite.
- Getting hold of basic provisions especially in rural areas.
- Self-funders not getting any support, just sent the care directory - feeling dismissed and isolated (from support line calls).

### Digital exclusion/issues

- Zoom is not easy for everyone, those with mental health needs prefer to speak to someone on the phone or face to face. It is difficult to understand gestures on virtual platforms and people do not always like being within a group. People should be offered a choice.
- Online provision of services can be helpful but need to find the right balance. e.g., care assessments over phone haven't picked up on all the issues and problems not identified leading to later crisis.

### Bereavement

- Funerals were difficult, difficult to arrange, very, very low numbers could attend and no wake or acknowledgement afterwards, meant the normal process of grief was hampered and no visits from family, neighbours or friends to offer support.
- "A friend was left with the ashes but unable to carry out the persons wishes as could not travel to scatter them."
- Lack of normal routines around death.
- Having to manage alone, making arrangements for loved ones and dealing with deaths - alone and isolated.

### Wellbeing

- Carers wellbeing, poor mental health but kept in silence.
- I think people are fearful of coming out of lockdown now "an elderly person said she was pleased it snowed so she didn't have to go out with her grandson and dog to the park as she was scared".
- "Propaganda on the news has added to peoples anxiety, every day."
- A friend with MS has lost skills that she will never re-gain as services are closed and has left her with reduced independence.
- Exhaustion - Caring is more increased because of services being unavailable. This is physically and mentally draining; the pandemic heightens this with the worry of contracting COVID.
- Loneliness - see less people. Zoom meetings and choirs and been important support. Hard not seeing wider family. Some are so desperate to see people they would rather risk getting Covid than 'die of isolation'.
- People who have become more unwell during the pandemic and managing this anxiety: Managing the increased needs of the person they care for and complexity of their condition as well as the anxiety of contracting COVID especially when conditions are worse.
- Difficult to see the light at the end of the tunnel, we have been in this for a year and many are too afraid to go out, etc.
- Winter and lockdown has been really hard on peoples wellbeing.
- One carer reported having long covid and now having to manage that.
- The ability to stay well mentally and physically.
- Lack of routine/exercise and poor diet.



## Confusion

- Understanding what is right and wrong. Worrying about what to do and what not to do. Better advice as the contradicting information worries people even more. Carers have also been offered vaccines before the person they care for.
- Do you break the rules in order to provide care? - who do you choose to care for? Those who care for multiple people/family members. Working out who to care for within the rules and how to keep yourself and those you care for safe.
- Conspiracies - getting lost within the conspiracies, becoming more anxious. Contradicting information does not help.
- Concern for the future including increased pressure on carers.
- When someone has dementia they are scared as to why you can't go out, keep your distance, wear a mask.
- IT has been challenging for some carers for fear of scams.
- A whole new group of people that may need care are those with long Covid who are not returning to work and normal life.
- Carers UK said 2 million or 4 million more carers following this pandemic.
- Working carers - some working carers have been forced back into work against their wishes but don't want to lose their job, some have been becoming more confident to say they are a carer but not so confident for fear of job losses.
- Some carers will have lost physical health, when their health is not always attended to prior to pandemic it is now worse which impacts on their ability to face the future caring role.
- Seeing older people now who's frailty has worsened simply because of lockdown.

## Financial hardship

- Where carers have been caring more and doing everything from home it is costing them more money. Supplying their own PPE or indoor activities, taking on shopping deliveries paid for with their (the carers) own money, etc.

## Other comments

- Increase in domestic violence and difficult family situations.
- Caring remotely - Difficult if you are caring for people from a distance.
- Practical caring support and emotional support from NC vital, including respite care, help to have a holiday and job seeking support.

## Despite the challenges, have there been any positives this past year for Carers?

“Something awful gave birth to something nice”

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### Carers digital services

- “Access to online music, art has been great, I don't drive and felt very, very isolated.”
- Mindfulness, art, supportive emails, book club have been great.
- ‘As a former carer and now carer champion I can't believe how quickly Northamptonshire Carers responded to moving online and Zoom support.
- New skills I have learnt is resilience and depth of stamina to see through the difficult times.
- Peer support - the WhatsApp group is wonderful, as a staff member I come in after a weekend and see 40 messages of support, laughter, photos, encouragement, offer of phone calls between all the carers.
- I think there is no one size fits all and it has been great to have the choice.



- Befriending calls started in March 2020 always something that was thought about but it was launched quickly and now supports so many isolated carers.
- The IT equipment that has been given out has meant people could have instant access.
- Save time.
- Embracing this new age of technology and learning new things, the willingness of people and surprising levels of participation.
- Broadened our horizons - choices and flexibility
- Information much more accessible/speed and more personal.
- Tech confidence.
- Befriending services benefitting Carer and cared for.
- New skills/hobbies.
- More diverse offering of activities.
- Action for happiness - approachable and accessible.
- Other organisations diversifying their support.
- The idea that carers need choice of support, some online, some with befriending calls, some doorstep calls.
- Befriending calls were something that we always wanted to do but it just started and is really appreciated by carers.
- The WhatsApp group has wonderful and supportive.
- Northamptonshire carers were so quick to move online, art, music has been a life saver
- Online support activities - carer's choir, etc. Plus online groups for cared-for, and digital ways of 'visiting' places around the country/world (e.g. Max in the Lake District).
- Serve has done online support for older people. But technological difficulties - not all have the tech/broadband or can use it, or want to. And some worried about doing things online. Face to face activities in parks in the summer were better, especially exercise. Also benefits and cost savings being outside.
- NC has been able to support carers with tech but still a need for training. Have also been able to diversify activities to include online/armchair options - more options in the future?
- Online provision of services can be helpful but need to find the right balance.

### Other digital services

- Video call from GPs to elderly person made a great difference and much easier than travel to surgery.
- Video call with the vet, much easier as a carer.
- New initiatives such as delivery robots.

### Wellbeing packs (boxes delivered to carers including activities, chocolate, toiletries etc)

- Wellbeing packs were dropped off on doorsteps and caused a tearful but happy response from carers.

### Resilience of carers

- The pandemic has highlighted how resilient carers are and how they are able to take on so much.

### Increased awareness of the needs of carers and those with disabilities

- It has increased the awareness of carers and isolation.
- People thinking about their community, their street and their neighbours.



- Reaching out to carers - finding those who need support. N/Carers have been able to reach people that they never did before. People have therefore been able to receive support that they never had before. (Also reaching those who did not consider themselves to be carers before).
- Community spirit - looking out for each other. Great sense of community spirit and offers to help each other. Church steps becoming libraries, jigsaw exchange.
- Generosity from people and businesses - people have been offering food parcels, money, delivering items etc more than ever before.

### Working carers

- Some people have been able to save money - where people were spending money on going out or taking the person they cared for out, the pandemic has forced them to stay in ultimately saving money.
- Awareness of transmission - since people are now more aware of how diseases can be passed on it may encourage people to stay at home when they are sick.
- Employers/employees are more confident to work from home.

### Other comments

- Appreciation of the NHS.
- Family relationships - members of the family being home who were not before. Family relationships have grown stronger in some cases as most people are at home.
- Experiencing the outdoors more - people are venturing outside more even if it is just to get out. Taking up exercise where they would not have considered it before.
- More time to stop, think, and reflect; The pandemic has made people realise what is important.
- Cooking properly - healthier meals; the pandemic has forced us to think about food and what to cook.
- Pandemic has highlighted serious issues - Where things have gone wrong although awful, it has highlighted the issue and forced people to implement change.
- Value of friendships and seeing more caring side of people.
- We appreciate the smaller things now.

## Looking forward, what support will Carers need post-coronavirus?

### Digital services and/or a blend of digital and face-to-face

- Choice, virtual or physical groups.
- Continuing telephone services - Doing things over the phone can be reassuring to carers especially those worried about going online/using the internet, e.g. registering a death was much easier over the phone than going down to the County Hall.
- Doing all the things we have done before but utilising newfound skills - Going back to how we were doing things before to support carers but now utilising/implementing the new ways of working. For example, giving people a choice of an online meeting, a meeting at home or over the phone.
- Need to fill the digital gap/divide.
- Blended approach of online and face to face would be great, I was fearful that the online might end.

### Increase of current services for carers

- More carers assessments.
- More befrienders - keep the telephone befriending going.



- Support for carers to look after themselves - carers need to be encouraged not to put things off when it comes their own health and care. Some carers have delayed resolving their own health issues because their focus has been on the person they are caring for.
- Wellbeing support for carers is going to be critical.
- Support for carers to look after themselves- don't put things off!

### New services for carers

- Confidence building programme for carers, like a package of support and guidance, people's lives will be changing, jobs lost, housing lost, maybe life coaching will be needed.
- Bereavement support.
- Long covid support for Carers and cared for.
- Risk of people representing in crisis following telephone/online assessments, need to gear up for this.
- Need to start making plans rather than just dealing with minute to minute, to help us look ahead - some carers have given up on planning since plans have had to change so much over the last year.

### Services for cared-for people

- “Packages of support/care have been reduced during this time, without the carer agreeing to the reductions, need more advocacy to represent the cared for person and the carer”.
- carers rights have been eroded during this time, packages reduced without regard for the carer.
- Long covid support for Carers and cared for.
- Continuing telephone services, e.g. to register a death.

### Awareness raising

- National campaigns to raise carers views.
- “Carers rights have been eroded, need to get back into campaigning action.”

### Working Carers

- Employers to offer working from home - especially those who have medical conditions themselves, it encourages people to work (who want to work) for example those with Crohn's disease have the option of working from home.
- People are now aware of how diseases are transmitted - people should be encouraged to stay at home if they are unwell.
- Support for employers around long covid for Carers & employees Employers have been flexible during this period - this may have benefited Carers. Will this continue? Have they started to understand the needs of Carers?
- Getting people back into work.

### The 'New Normal'

- Support with the transition back into normality - mental health support for those people who are worried about returning back to 'normal' to help with the anxiety around contracting COVID.
- Mental health support especially around the returning to normal life. This could be very difficult for many.
- Recovery - for those that have lost family members, with grieving process on hold - will need to support people through that- Former Carers Group- see these needs increasing, need to find own routine again, lot of guilt of not been able to be there with them, haven't been able to be with people to support you. Grief has been bottled up.



- Finding ways to reassure those who are worried.
- How do we get people back outdoors - get over the anxiousness, back to normal routines. Need to think about strategies to do this.
- People may have lost jobs, lost confidence and lost loved ones: rebuilding lives by coaching may be needed.

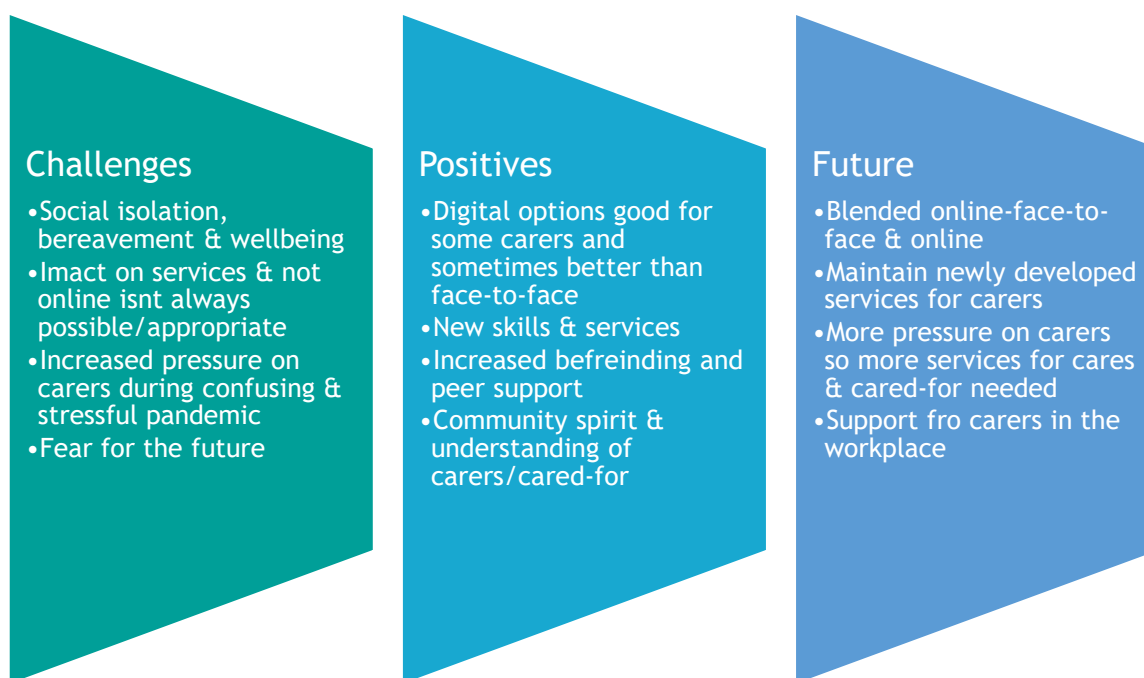
### Other comments

- Need an action plan of what are the challenges and what are the proposed solutions with a budget attached, once the results of the survey and this feedback is reported on in March.
- Looking at things from another perspective - what are we missing? Asking people what they need. Even though we can now offer new things/formats, we still need to ask what it is people need.

### And finally...

- A HUGE party! - people need to celebrate what they have achieved!

## Key Themes





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