



# Newcastle Carers' survey 2022

## Understanding carers' experiences during the pandemic

## About Healthwatch Newcastle

Healthwatch Newcastle is an independent not-for-profit organisation. We help children, young people and adults to have a say about social care and health services in Newcastle upon Tyne. This includes every part of the community, including people who sometimes struggle to be heard. We work to make sure that those who plan and run social care and health services listen to the people using their services and use this information to make services better.

Healthwatch Newcastle is part of Tell Us North CIC (company no. 10394966).

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# 1. Introduction

Newcastle City Council is currently reviewing all support for carers across the city. Focus groups with Newcastle Carers' service users and staff have recently been completed. To provide further evidence for Newcastle City Council, Newcastle Carers reached out to Healthwatch Newcastle to help survey carers' experiences. This was based on a recent piece of work carried out by Healthwatch North Tyneside.

The purpose of this work was to gain a greater understanding of people's experiences of caring during the COVID-19 pandemic and in accessing information and support. We included a short evaluation for people who had used Newcastle Carers' services.

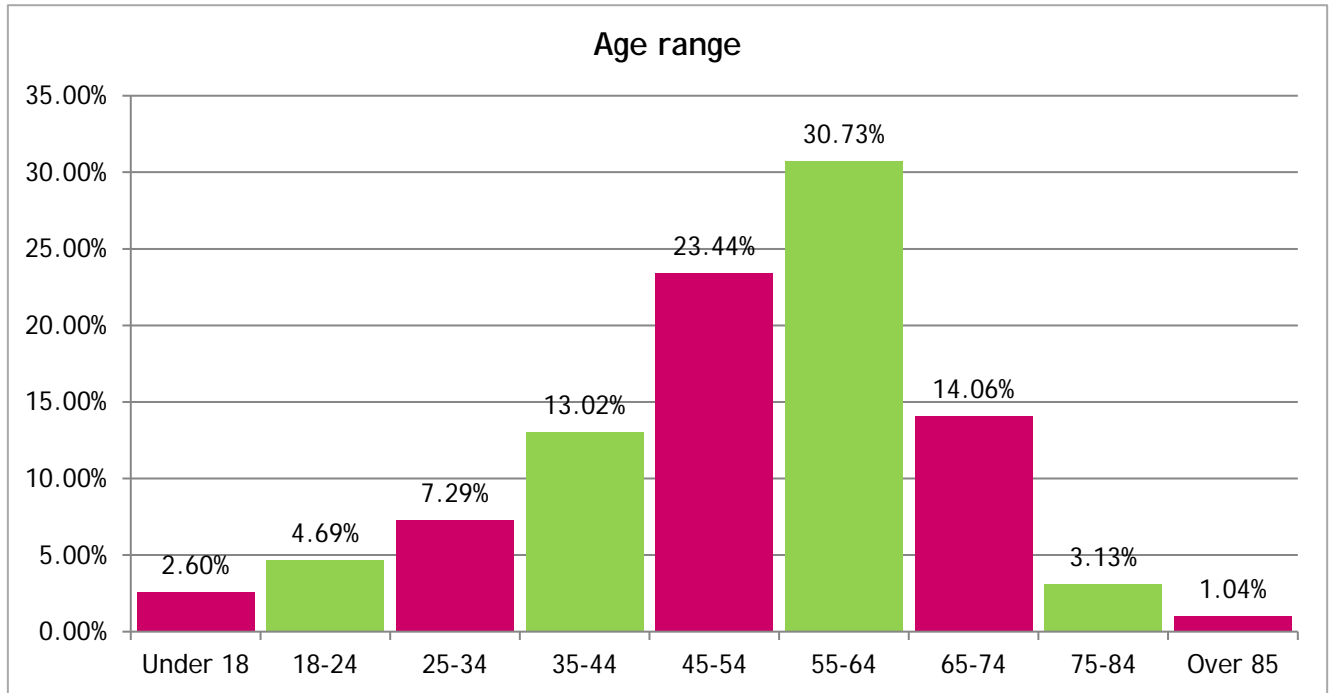
# 2. Methodology

Healthwatch Newcastle worked with Newcastle Carers to adapt Healthwatch North Tyneside's survey. A questionnaire was created using an online survey tool (SurveyMonkey) and promoted between 22 November 2021 and 23 January 2022. It was publicised to carers in Newcastle, through social media platforms and via the networks of Healthwatch Newcastle and Newcastle Carers. Paper copies were also available at the Newcastle Carers' centre and phone calls were offered to people who needed help completing the survey.

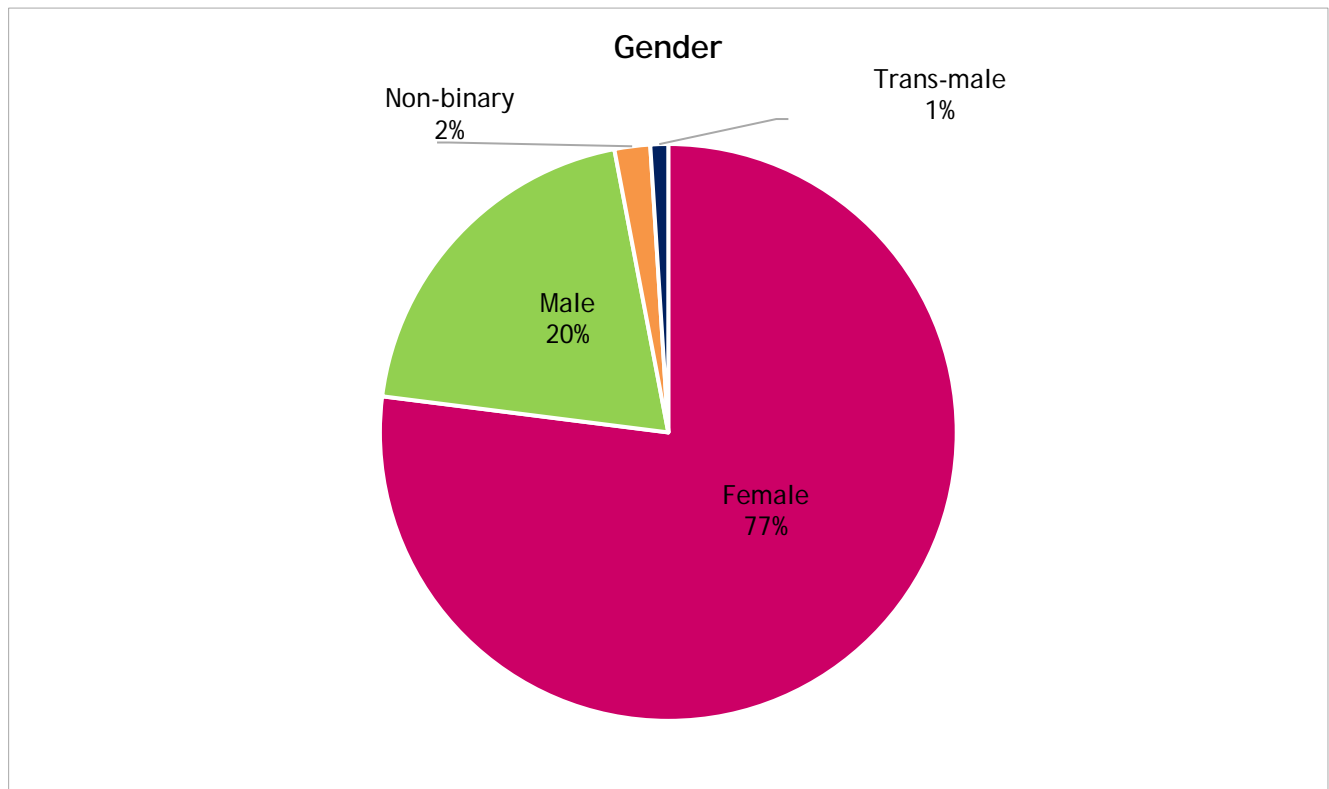
Despite another lockdown and the survey running over the Christmas period, we gathered the views of 192 Newcastle residents who are unpaid carers. People did not answer every question, so the total responses don't always add up to 192. The results were analysed and sent to Newcastle City Council and other key stakeholders to provide evidence of the needs of carers in Newcastle and support the Newcastle Carers' contract review.

### 3. Findings

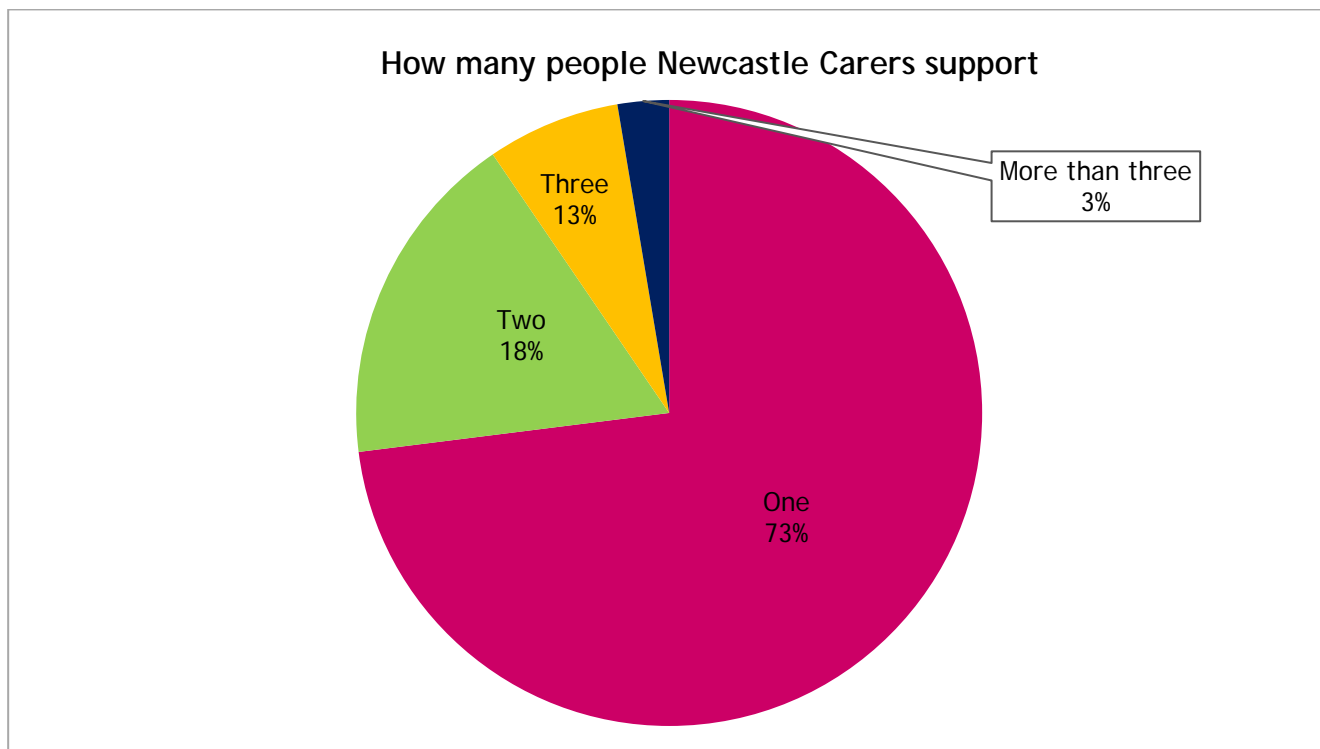
#### 3.1 About carers in Newcastle



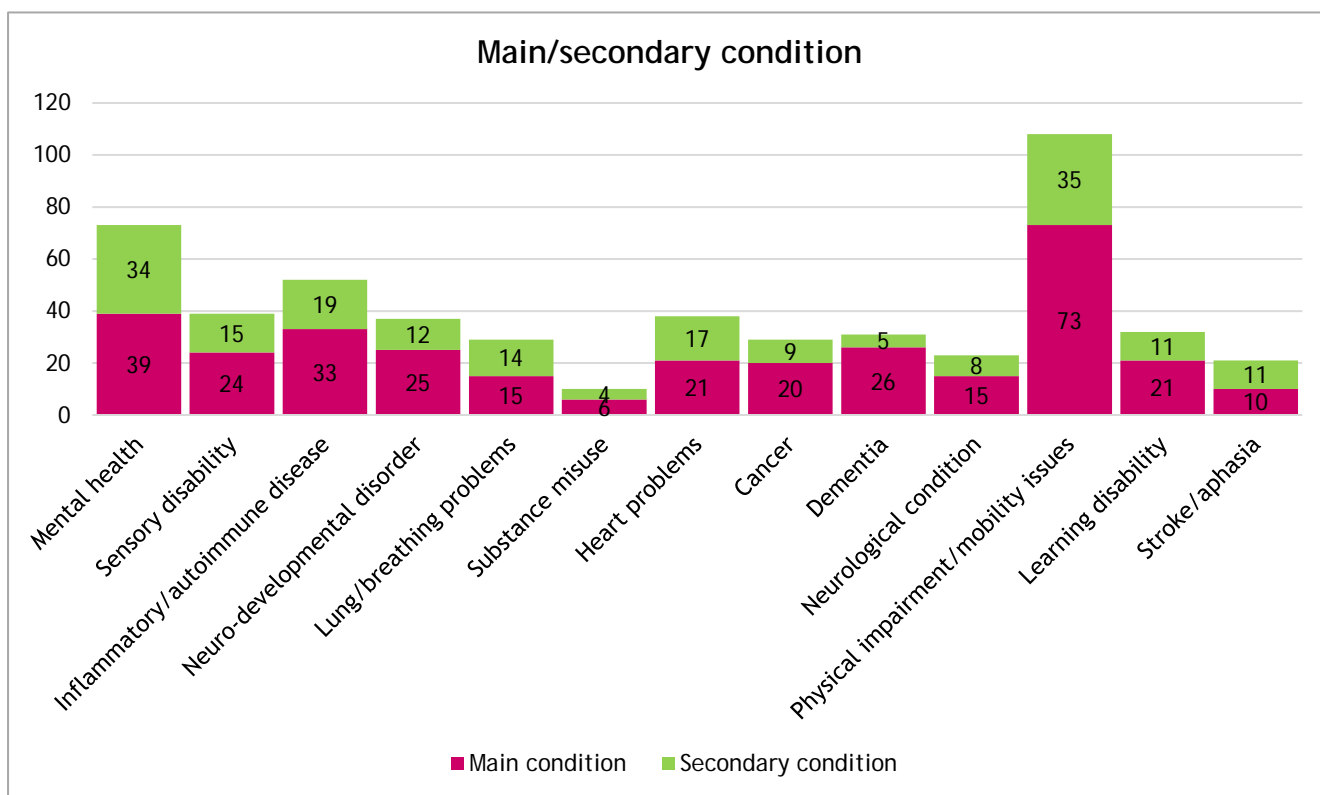
Out of 192 people, 190 chose to disclose their age and gender. Newcastle Carers' demographic data reports that 69% of the people it supports are aged 26–64 and 75% are female, which correlates to the percentage of the survey respondents.



Most respondents reported they care for one person (73%), followed by two (18%) and then three people (13%).



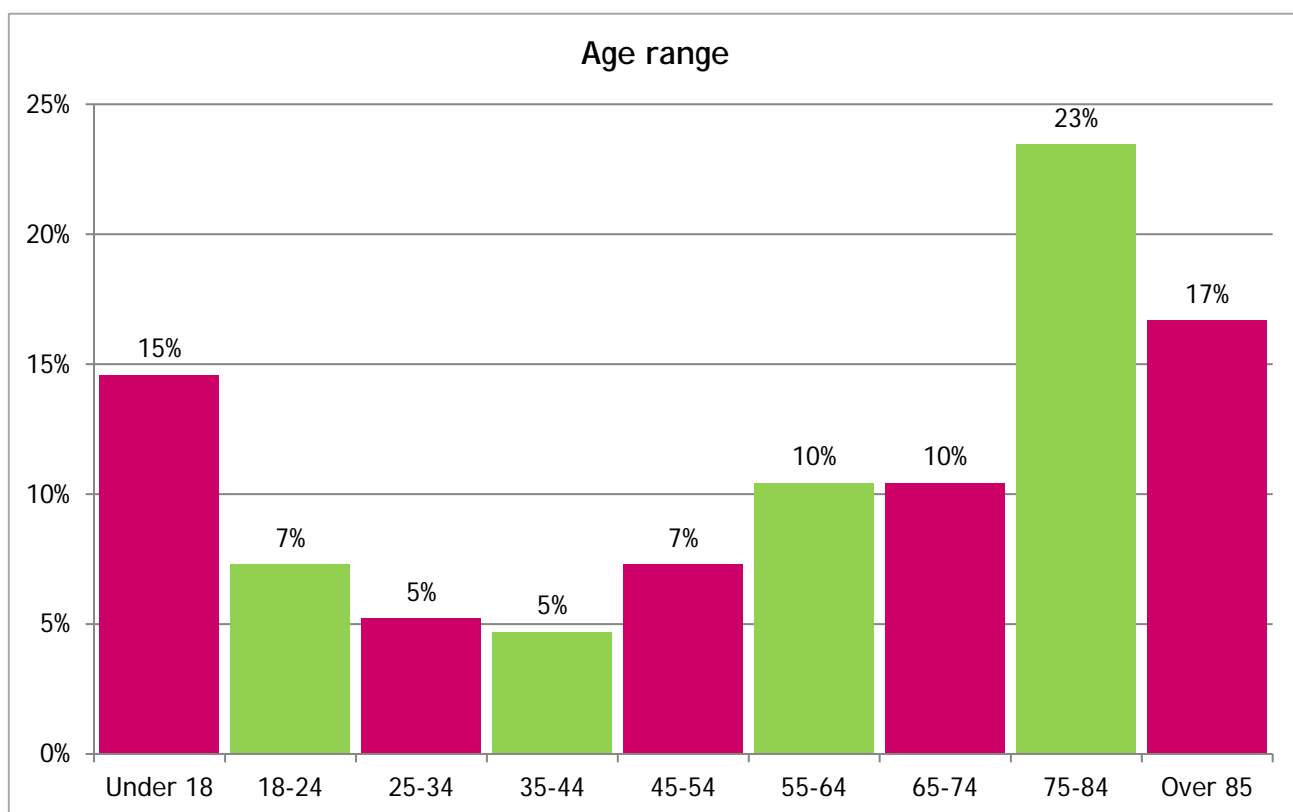
### Who is being cared for?



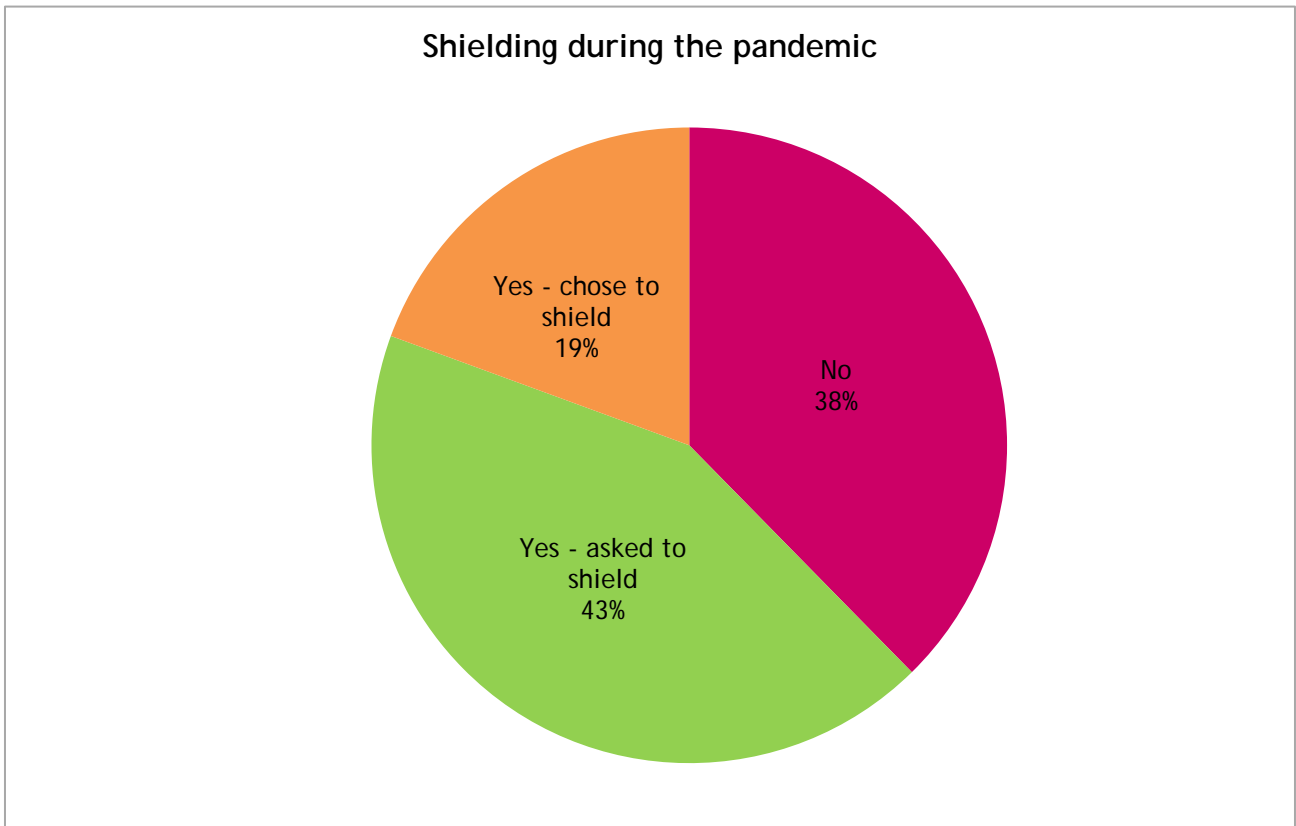
Out of the 190 carers who responded to this question, 57% were caring for someone with physical impairments or mobility issues, which equates to the second most cared for condition presented within Newcastle Carers' monitoring data. We also received a high response from those caring for people with mental health conditions (38%), which is the third most cared-for condition reported.

Whilst Newcastle Carers' monitoring presents neurodevelopmental disorders as the most cared-for condition, only 18% of carers who participated in our survey were caring for people with those disorders. We did however get a representation of those caring for people with inflammatory/autoimmune disease (27% of carers) and sensory disabilities (22%), which are within the top 12 conditions of who Newcastle Carer service users care for.

It must be noted that the survey was open to all carers in Newcastle, not just the ones accessing Newcastle Carer services.



Survey respondents cared for people across a wide age range, with the highest number of respondents caring for 75–84-year-olds (23%), followed by those over the age of 85 (17%) and then people under 18 (15%).



Respondents to the survey varied in shielding requirements during the pandemic. This allowed us to collect a wider range of experiences based on the impact of the pandemic.

### 3.2 Carer experiences

#### Care during the COVID-19 pandemic

It is not surprising to see that out of 171 people who responded to this question, most (78%) provided more or significantly more care during the pandemic and 134 respondents told us more about their increased care. The following themes emerged:

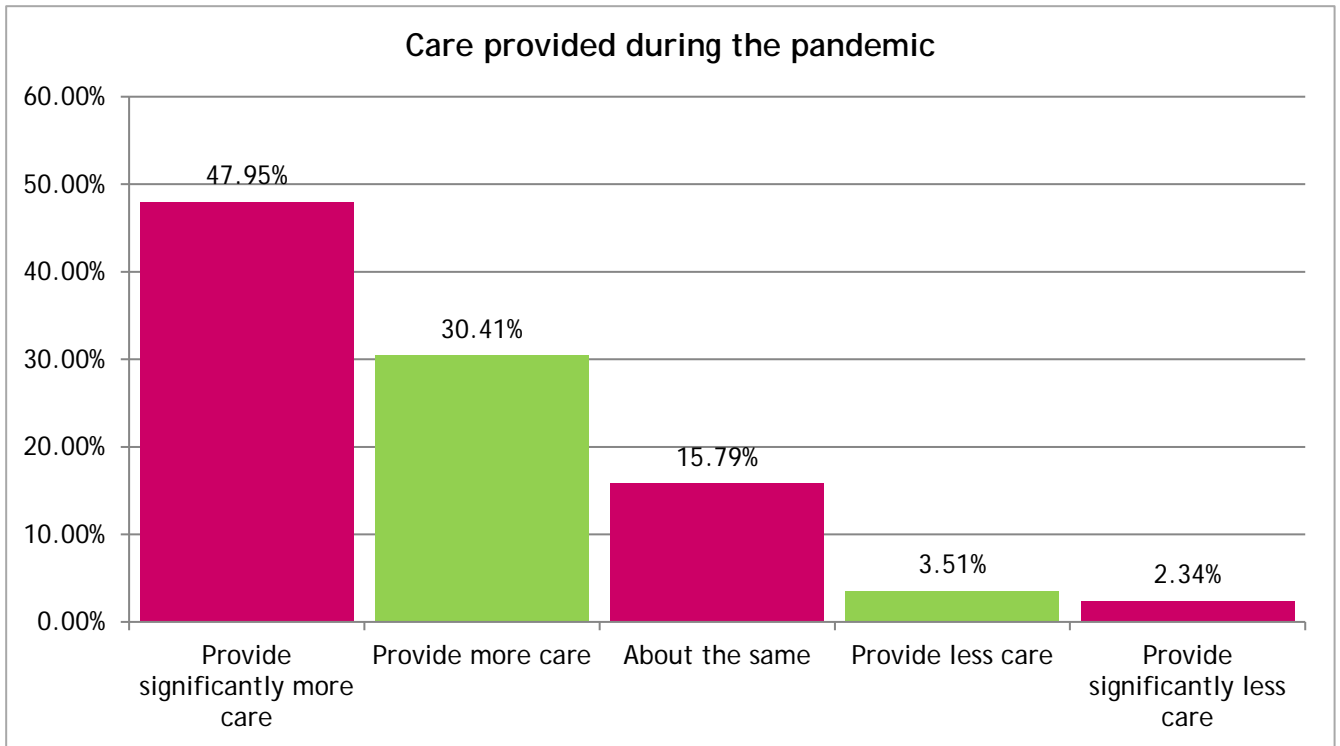
1. Condition deteriorated/got worse (32%)
2. Reduced outside care (28%)
3. Provided more care due to COVID-19 shielding (23%)
4. The carer was available more (11%)
5. Service closure (6%)

Out of the respondents who provided significantly more care, 32% of them said it was mainly because the condition of the person they cared for was deteriorating/getting worse



A reduction in the external care being provided was another reason for increased care. While many had chosen to reduce care to protect their loved ones, 80% were impacted by a reduction in support available from Newcastle City Council social services, support workers or private care agencies.

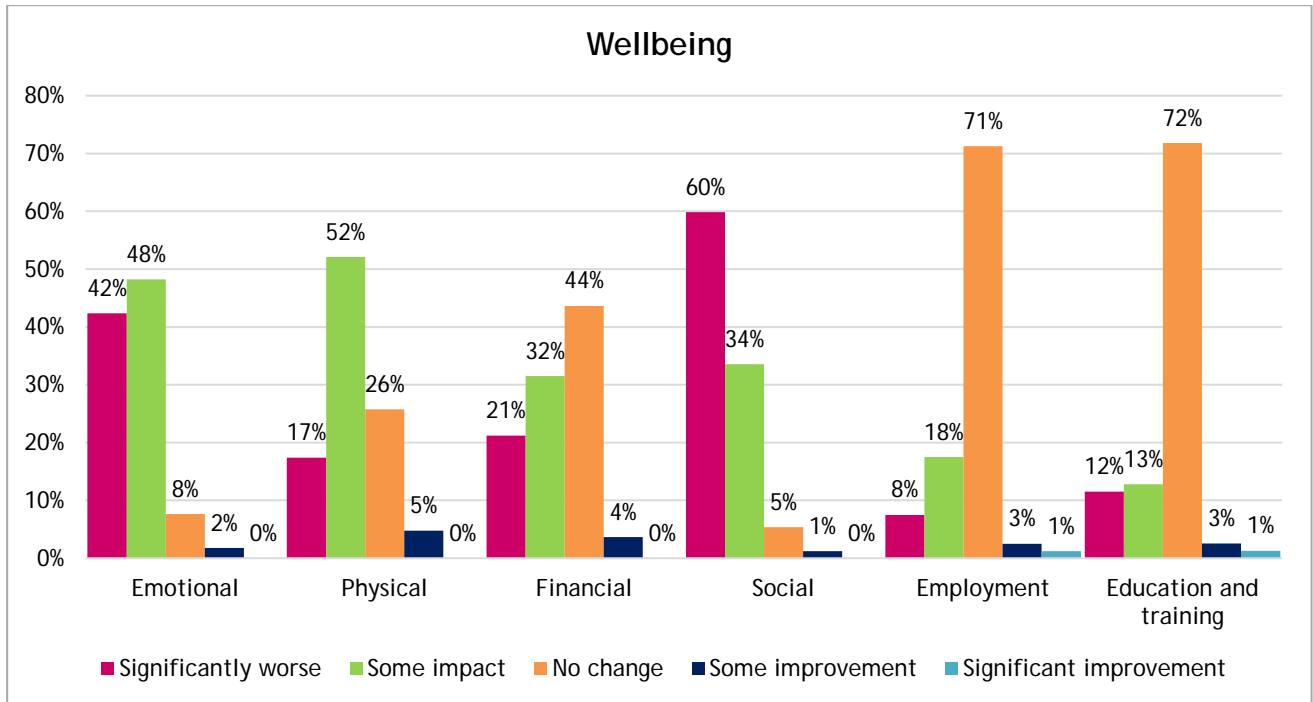
**“The people I care for are getting worse physically. Tried to get social services involved however they only telephoned, and I feel if they had come out and saw how my relatives are not managing at home.”**



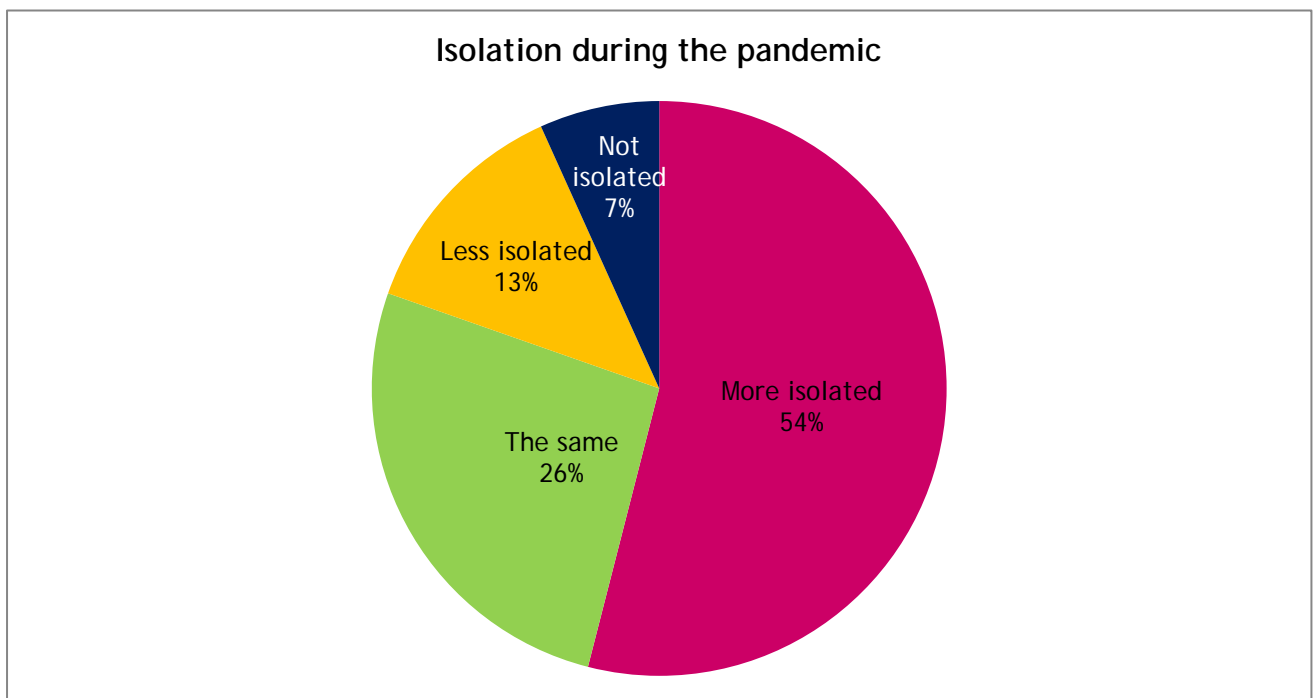
Additionally, more care responsibilities were needed because of covid shielding. This included shopping, collecting prescriptions, technology support for medical appointments and providing more emotional support due to isolation.



## Impact of the pandemic



Out of 171 respondents who answered this question, over 60% of respondents had been socially impacted by the pandemic. This coincides with respondents reporting their emotional health as having some impact (48%) or made significantly worse (42%). As well as the pandemic, this could be due to a deterioration in the person they care for and the detrimental impact this has on emotions. Given an increase in unemployment and furlough schemes throughout the pandemic, it's good to see that the impact of the pandemic on employment, education and training and finance has had minimal impact on carers in Newcastle.







### Medical help (6%)

- Occupational therapists
- Counsellors
- Early intervention psychosis team
- District nurses

### Garden (4%)

- Sitting in the garden
- Gardening

"We had district nurses coming initially and Newcastle Carers advised me about the covid vaccination and even where to go on my GP's website to make them aware I'm a carer also.

They helped again by giving advice and referring me to someone to request attendance allowance."

### Biggest fear coming out of lockdown

We asked carers in Newcastle what their biggest fear was coming out of lockdown. Out of 132 carers who responded to this question, the following top themes emerged.

#### Covid spreading (16%)

- Passing the virus to vulnerable people
- Cared for person catching covid
- People not following rules/guidelines

#### Another lockdown (15%)

- Ever coming out of pandemic
- Living in fear of lockdowns

#### Support available (13%)

- Limited support for carers
- Difficult to access services
- Reduced NHS service provision

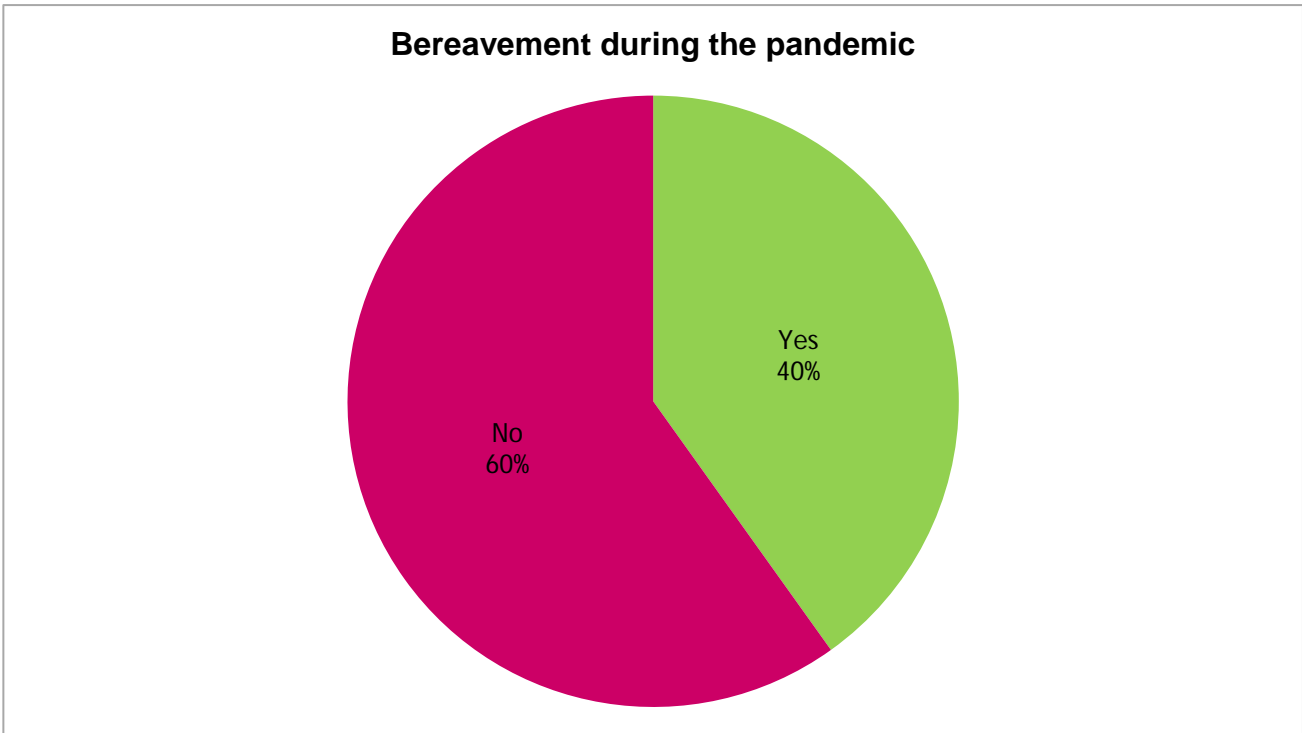
#### Normality (10%)

- Getting used to the new 'normal'
- Return of normality too quickly



"For most people the risk is less, and society has opened up with no rules. That's great for most people but don't forget the impact this has on vulnerable people."

## Bereavement during the pandemic



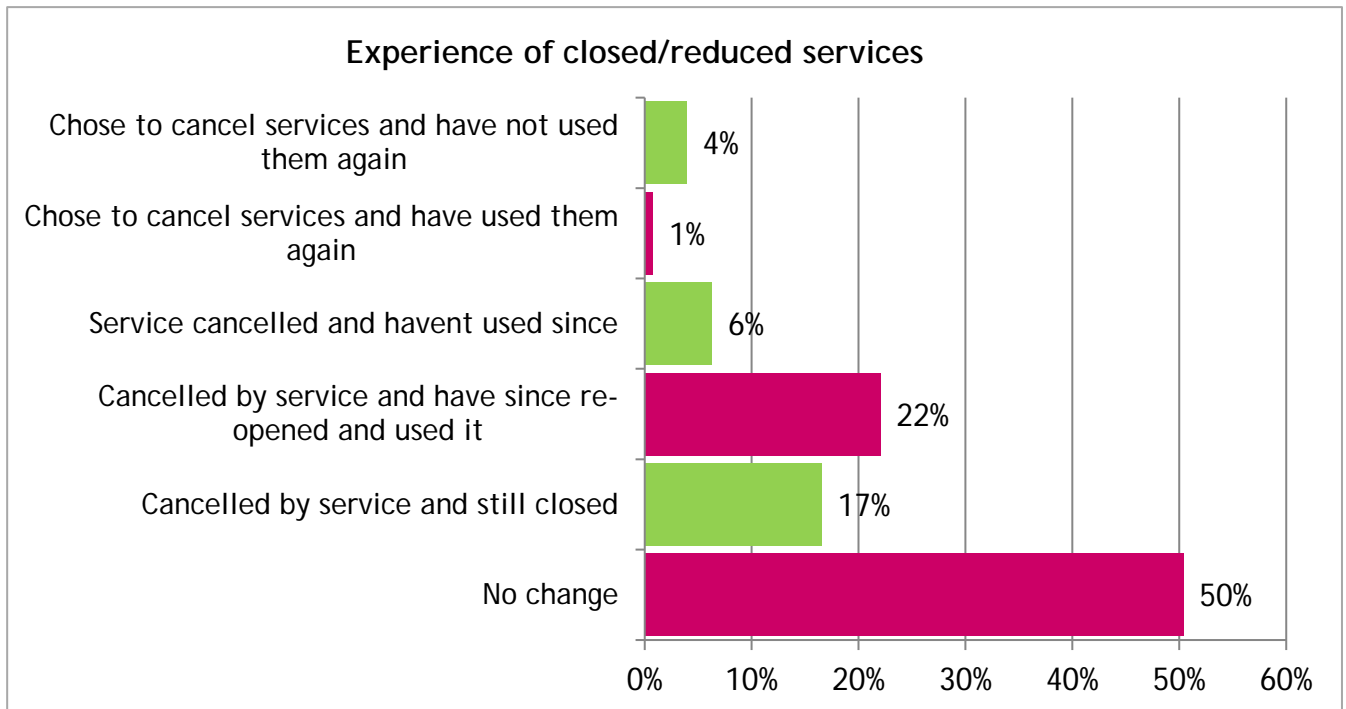
Out of 162 carers, 60% had not experienced bereavement during the pandemic. We asked respondents who had experienced a bereavement what support they received. Out of 49 carers who answered, 30 carers (61%) did not receive any support with their bereavement. Only two carers took up support offered by Cruse and Newcastle Carers.

**“There was no support. After dad died the hospital experience was awful. Hospital were great in the last days but after was shocking.”**

Although the majority of respondents had not used professional bereavement support services, 31% did receive support from friends and family. It must be noted that two carers were offered support but chose not to take it up due to caring responsibilities and just wanted to 'get on with it'.

### 3.3 Experiences of the person with care needs

#### Reduced/closed services



Out of 127 carers who responded, it is good to see that 50% of them experienced no change in services during the pandemic. This was described as positive, especially regarding Special Educational Needs schools remaining open.

However, many carers commented that this answer was due to not using or being able to access services before the pandemic. Services reported to be cancelled and still closed included face-to-face social groups, cafes, sporting activities and overnight respite care.

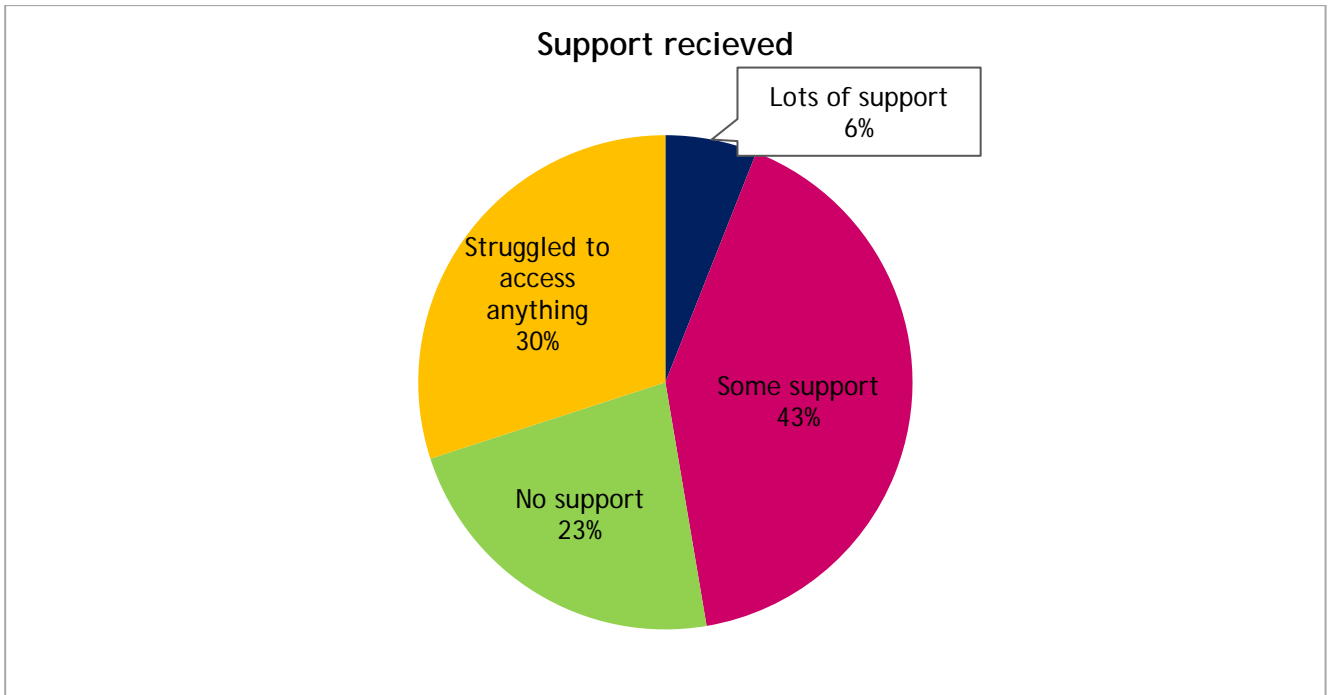
*“Some social groups have opened to some extent, and we are using them. Those still only online has meant that we no longer can use them, as my cared-for person cannot engage with that.”*

Numerous comments were also made about accessing services as a new service user being near impossible or worse because of the pandemic. Examples included housing service and care support.

*“We did not use services beforehand, but the pandemic has made it difficult/impossible to access services as a new user.”*



## Support received

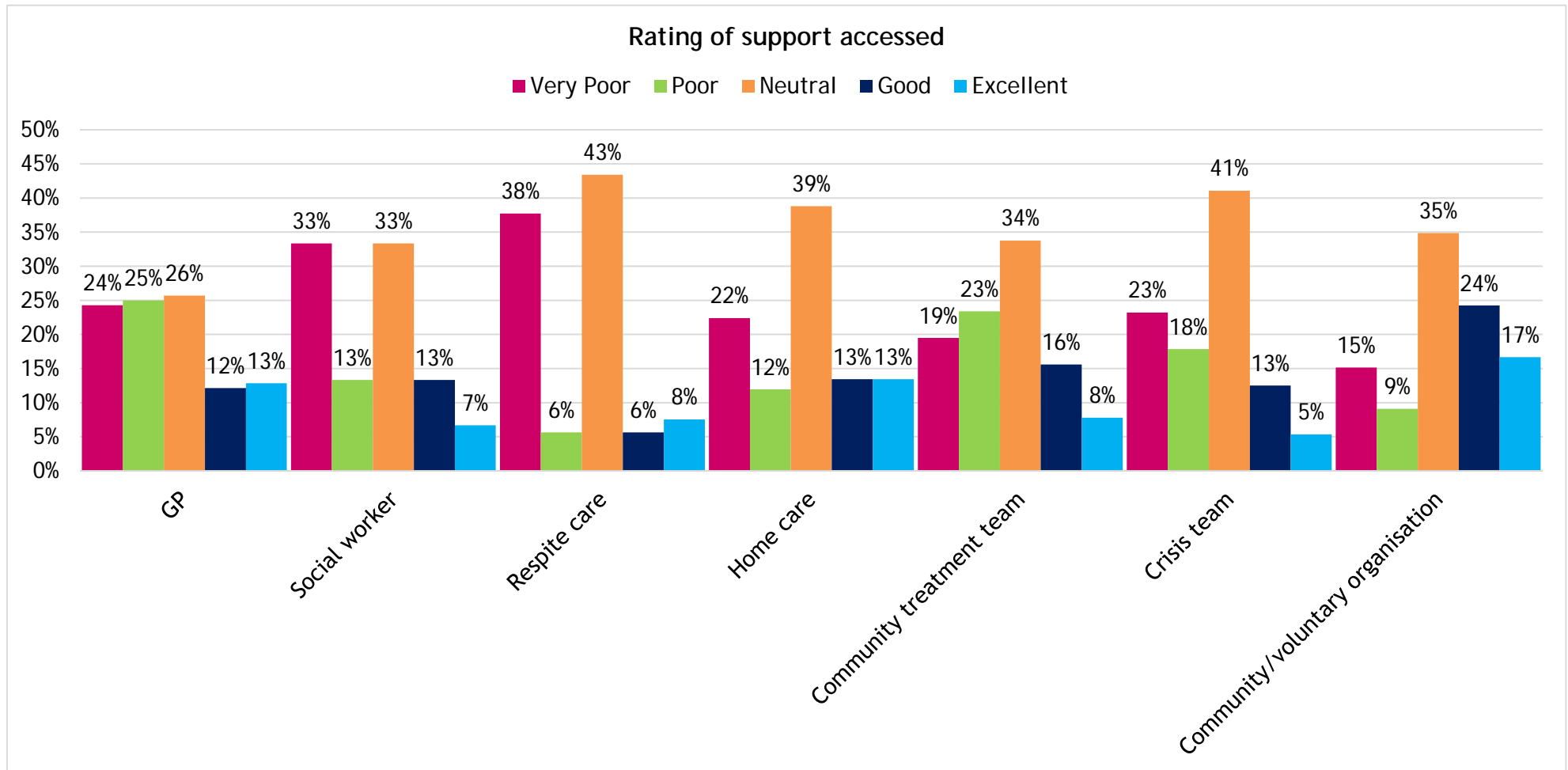


We asked carers in Newcastle if the person they cared for received the support they needed during the pandemic. Out of 150 responses, 43% reported receiving some support.

However, it is concerning to see that overall 53% struggled to access or receive support from services. It is important to note from previous comments that many respondents did not choose to use services or struggled to access them before the pandemic.

We also asked respondents to rate the support their cared-for person received during the pandemic. It is excellent to note that 41% of carers gave community and voluntary organisations the two highest support ratings.

*“The various charities that support my son all moved their services online so he could remain connected.”*



GPs were understandably the most accessed service, with 140 out of 151 respondents receiving support. On average, GPs received the lowest support rating out of all services (49% of respondents said they had received very poor or poor support.) with 49% of respondents. When asked to tell us more, carers told us about difficulties in getting a face-to-face appointment and a lack of communication, and this resulted in some hospital admissions. However, some respondents said that treatment and care, once accessed, was excellent and this is similar to feedback that Healthwatch Newcastle has been receiving from all Newcastle residents.

Looking at ratings individually, respite care support was rated as very poor by 38% of respondents, closely followed by social workers (33%). Respite care was reported as being closed and yet to reopen. We also received numerous comments regarding social workers not returning calls or disappearing and not getting replaced, as well as assessments taking up to 50 or 60 days. However, it must be acknowledged how overworked and under pressure social workers were and still are.

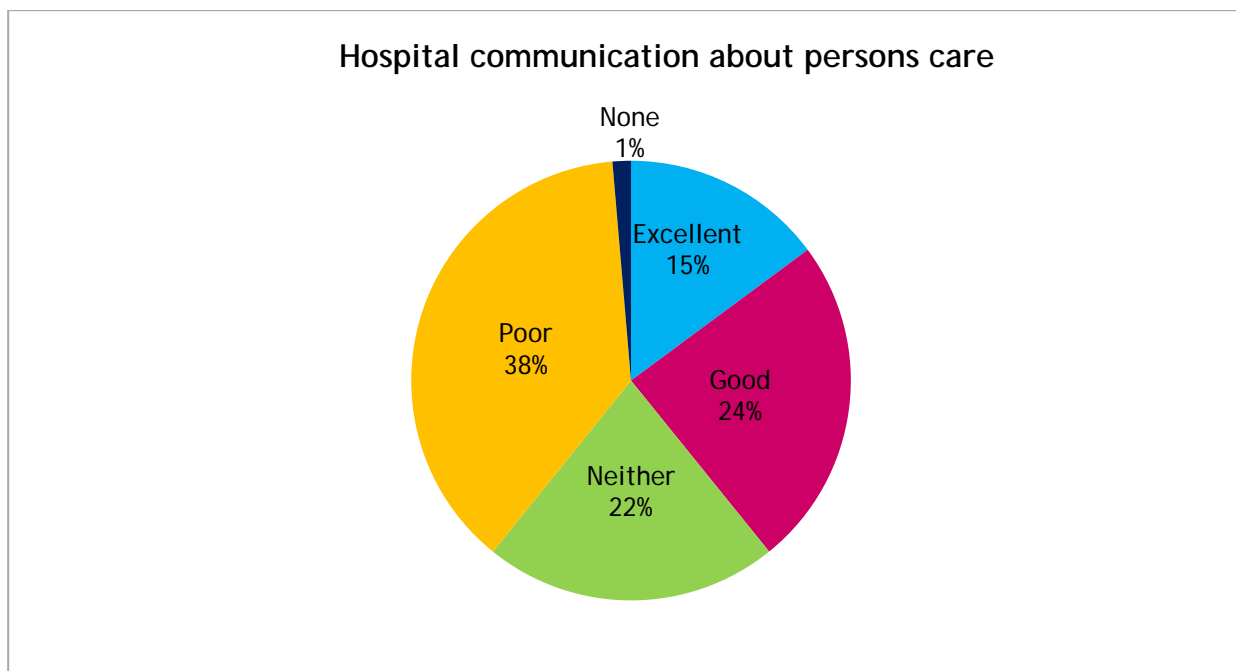
**“The carers’ centre helped me through a difficult time when my mother was extremely unwell with multiple hospital admissions. We felt let down by social services as they would not come out to the home and only rang up. My mother was confused following a delirium and I felt it was unfair that social services just rang her up and she said everything was fine and they accepted that despite me contacting them several times with concerns.”**

Respite care (43%), crisis team (41%) and home care (39%) were all rated neutral for their support. As previously mentioned, many reported that respite care had stopped, which explains the neutral rating as they wouldn’t have received support. Similarly to GP support, the crisis team was reported as difficult to access, but treatment was excellent. Respondents expressed views that agency carers helped, but many were more concerned by fear of COVID-19 and a lack of PPE in earlier days of the pandemic.

It should also be noted that many respondents stated they didn’t receive any support because they managed and relied on themselves to provide support to the person they cared for.

**“We don’t really access stuff, we’ve always managed. We wouldn’t register on anyone’s radar. How many people are there like us?”**

## Hospital communication



Out of 74 carers who answered this question, collectively 39% of carers received excellent and good communication from the hospital. When asked for further details about their experiences, they reported that the hospital staff tried their hardest with video calls and keeping them up to date under difficult circumstances.

**“I felt the communication from the wards with myself worked really well and I felt lucky that I was allowed to visit her daily when she was transferred to the Freeman Hospital.”**

However, it is unfortunate to see that 38% received poor communication from the hospital. When asked for further detail of their experiences this included a lack of communication between hospital and multi-agency professionals from GP practices and care homes, which created confusion. It was also reported that although some received phone calls, they were either late in the day or difficult to understand. Another comment stated safe discharge communication would have prevented re-admissions. There were also reports of people with Alzheimer’s and hospitals not understanding this, with the carers not being present. Once hospital visits were allowed, many reported they received sufficient communication. It must be noted that hospitals were the service hit most hard by the pandemic, with pressure remaining high throughout.

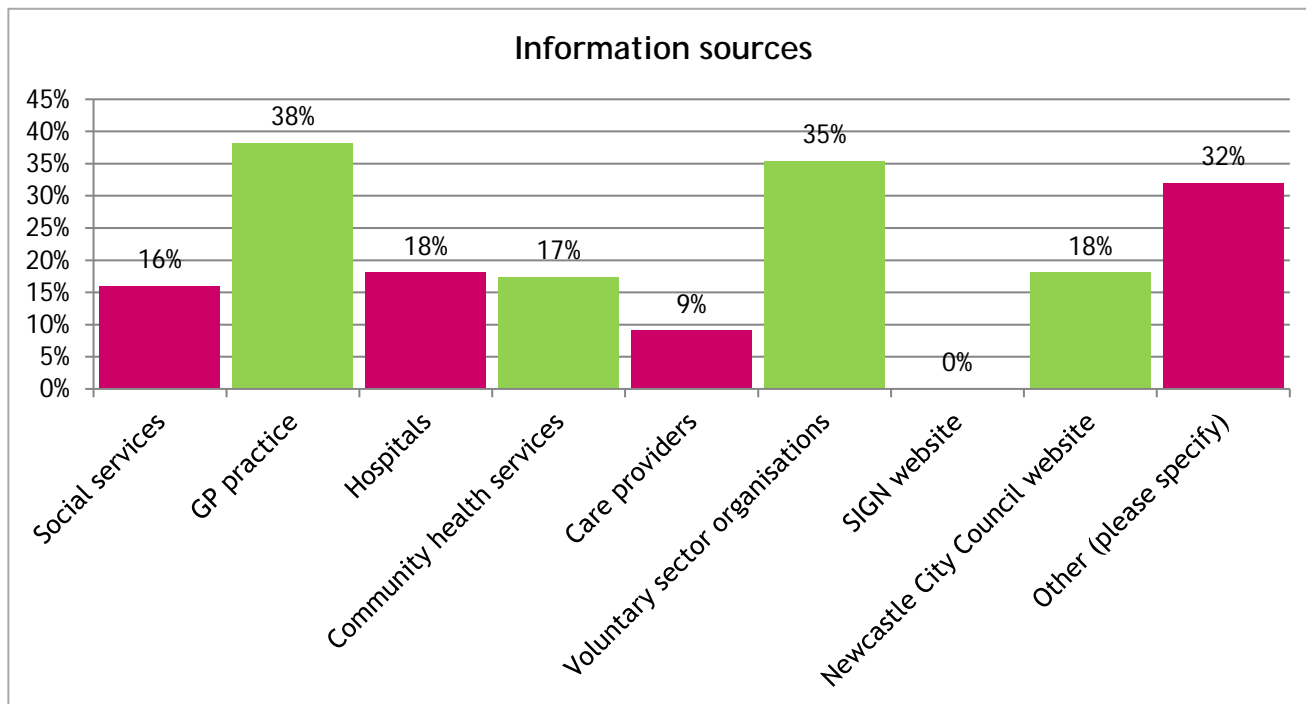
**“Mostly good care but some communication which wasn't so good which is difficult when I don't live nearby. I'm very aware though that hospitals and other health care has been desperately stretched and doing their best in these very difficult times and I'm full of admiration for the healthcare sector.”**

Despite the lack of communication provided by the hospital about the person they cared for, many expressed that they did receive good care from the hospital staff.

“Dad went into the Freeman with sepsis, and although I couldn't visit the staff were really good at taking things in for him and cared for him well.”

### 3.4 Information and support

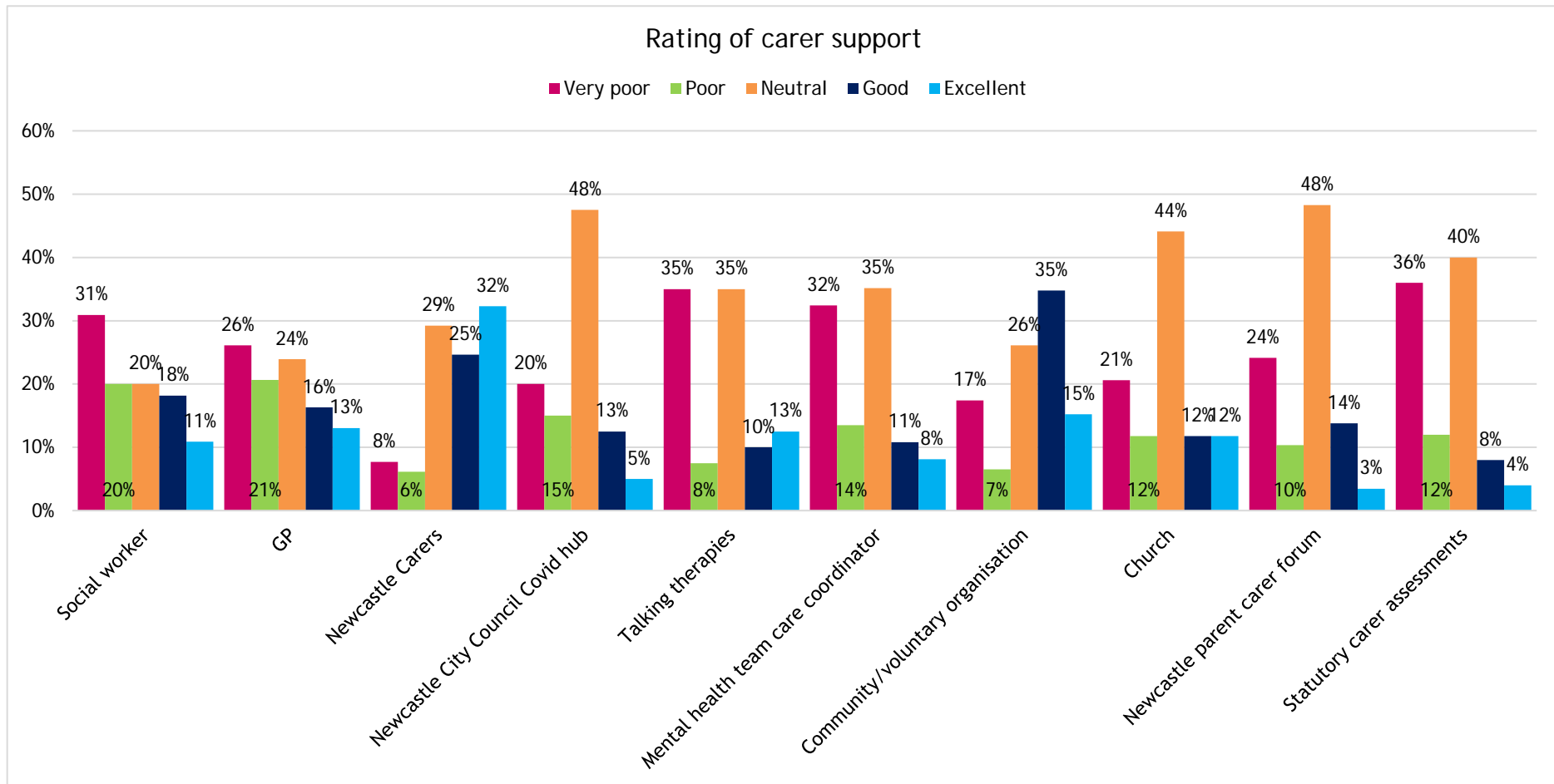
#### Information for carers



This question asked respondents where they get health and care service information from. Out of 144 carers who answered, 38% used GP practices and 35% used voluntary sector organisations as their main sources of information. It could be said these are the services that carers access and trust the most. 'Other' sources came next, with many using internet search engines, Information Now (an information website for people living and working in Newcastle), Facebook and contacts such as family and colleagues.

It is interesting to see that none of the carers who answered this question had used the SIGN website for evidence-based clinical guidelines, which suggests many are not aware of this valuable resource of information.

## Support for carers



We asked carers in Newcastle to rate the support they received for themselves during the pandemic. It is excellent to see that Newcastle Carers had the highest rating of support for carers in Newcastle at 32%. When asked to tell us more, support was reported as regular, consistent and tailored to them.

*“Newcastle Carers have been my only support, have done what they said they would when they said they would, and I would not have managed without their support. It is invaluable.”*

Community/voluntary organisations followed with 15%, with reports of them being responsive and providing good advice and signposting. These ratings coincide with the support for those cared for as Community/voluntary organisations were rated the highest.

Statutory carer assessments were reported as the poorest support out of all services (36%), for reasons which included lack of communication and delays experienced.

This was closely followed by Talking Therapies, with 35% of carers rating them as very poor. Despite this, some rated the support received as excellent (13%) which may be again due to difficulty of access, but once accessed great support is provided. Additionally, a few reported using Newcastle Carers' counselling service.

**“My son is still on talking therapies waiting list (over two years now). Luckily his college was able to provide support. Support and grant from Newcastle Carers made a massive difference.”**

As was the case of the person with care needs, GPs were the most accessed support service for carers and received the most varied ratings out of all services.

The Newcastle City Council coronavirus website hub (48%), Newcastle Parent Carer Forum (48%) and Church (44%) all received neutral ratings which could be explained by the specific support these services offer. Some of which may not be suitable/relevant to some carers, therefore they could not be rated.

It should also be noted that many carers stated they did not receive any support because they had not accessed it.

## **Improving carer support**

Seventy-five carers suggested improvements for support available in the future. The following themes emerged from their suggestions.

### **More accessible (27%)**

- Easier to contact and get responses
- Face-to-face appointments
- Remain open
- GPs and dentists
- Single point of contact
- More support groups and services in the west of Newcastle

## Awareness (13%)

- More advertising of available services
- Main providers who work with carers make them aware of the support available during initial conversations

“Maybe communication with the public, carers, knowing what services are available. People are often left out as they don't know what is available in the way of services/back up in time of crisis.”



## Accessible information (9%)

- Easy to access information
- Less online
- More signposting for mental health support
- Clearer guidance

## Check-ins (7%)

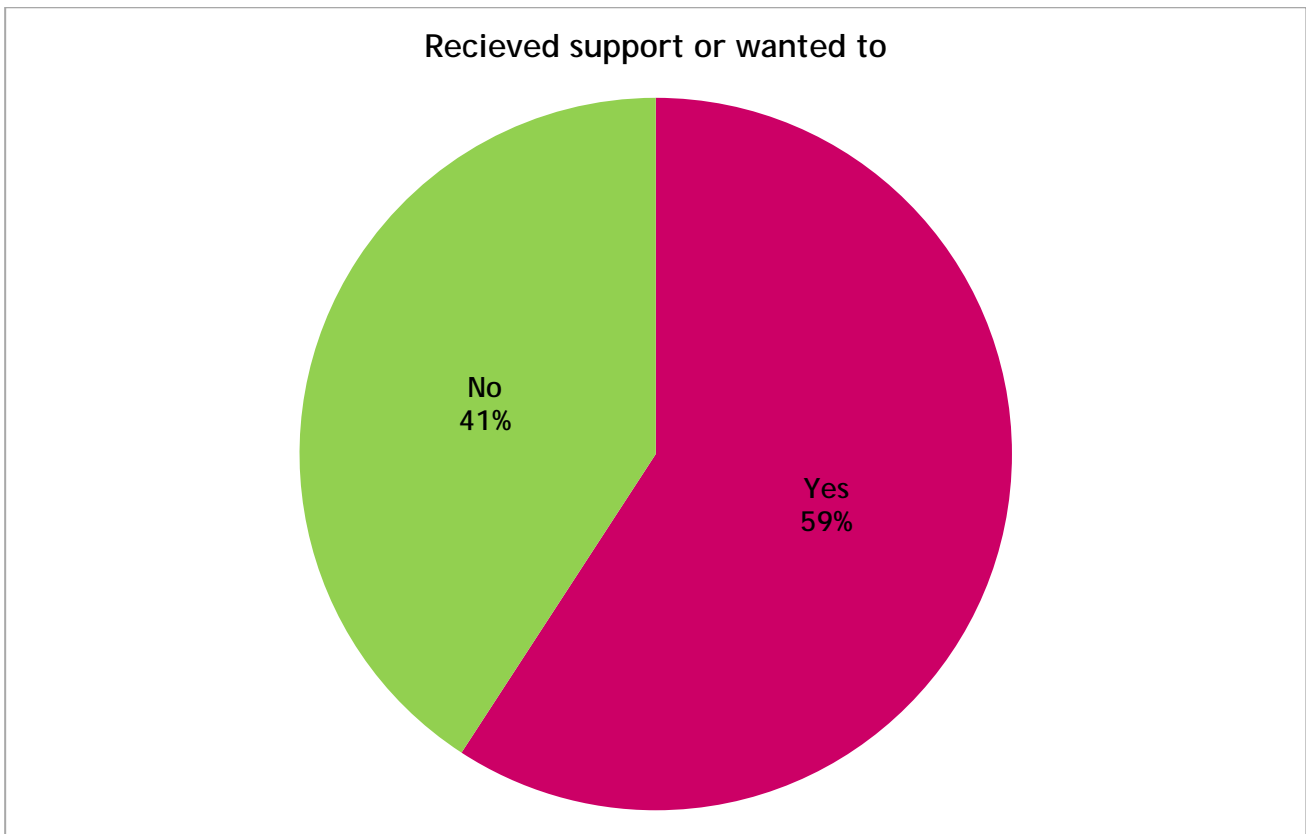
- More communication to check carers are OK
- Update on how things are
- Not relying on carers to reach out

“Just more communication it really doesn't take up a lot of time to pick up a phone and let carers know how things are going and that the person they care for hasn't been forgotten”



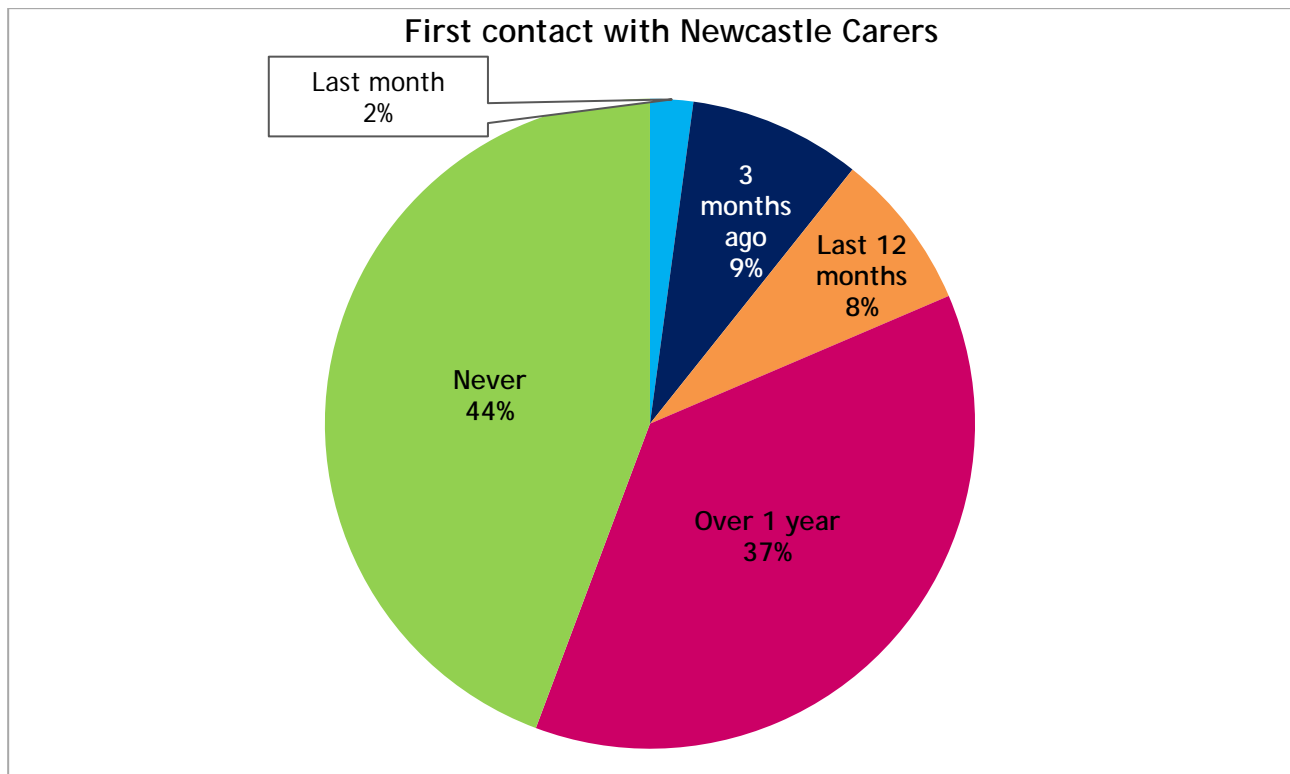
## 4. Newcastle Carers' evaluation

Received support from Newcastle Carers or wanted to



For this question, we asked whether respondents had received support from Newcastle Carers or would like to in the future. Out of 147 carers who answered this question, 87 carers (59%) have received support or would like to. Whilst over 40% of carers answered no, this may reflect their reluctance to access support as previously mentioned in previous questions.

## Contact with Newcastle Carers

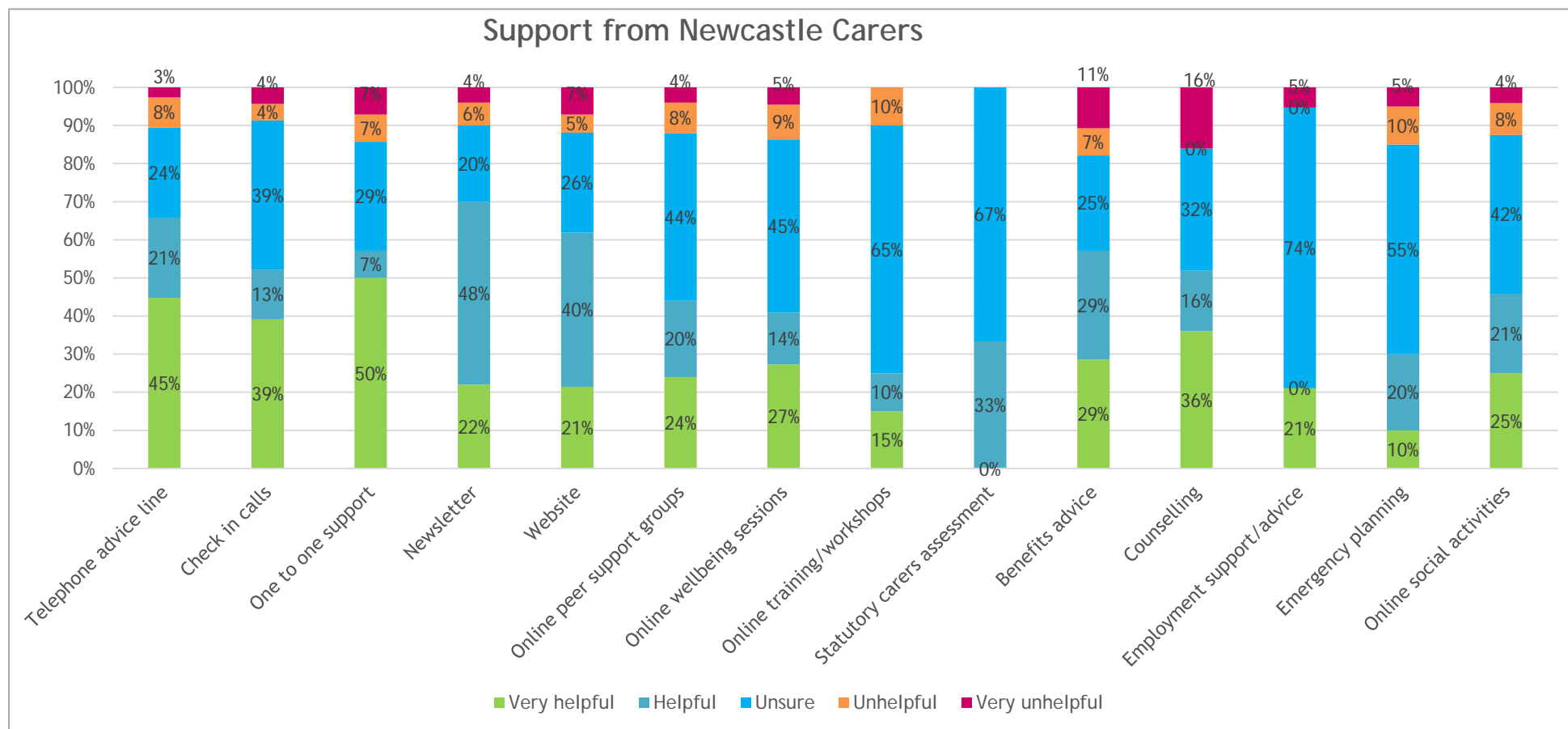


Out of 140 carers who answered this question, 44% had never contacted Newcastle Carers. This is reflective of previous comments about improving support by advertising what services are out there.

*“Although this may be partially done to myself, it would be great to have a little bit more advertisement about the Newcastle Carers support, however, I am not making a detrimental voice about Newcastle care service I’m sure they do a brilliant service.”*

Most carers (37%) who have contacted the centre had their initial contact over one year ago. This emphasises that those accessing Newcastle Carers’ services are established, and they are provided with ongoing long-term support. Only 19% of respondents had their first contact within the last 12 months, this may reflect previous comments around the difficulty of accessing services as a new service user during the pandemic and the overall impact of the pandemic.

## Quality of support received



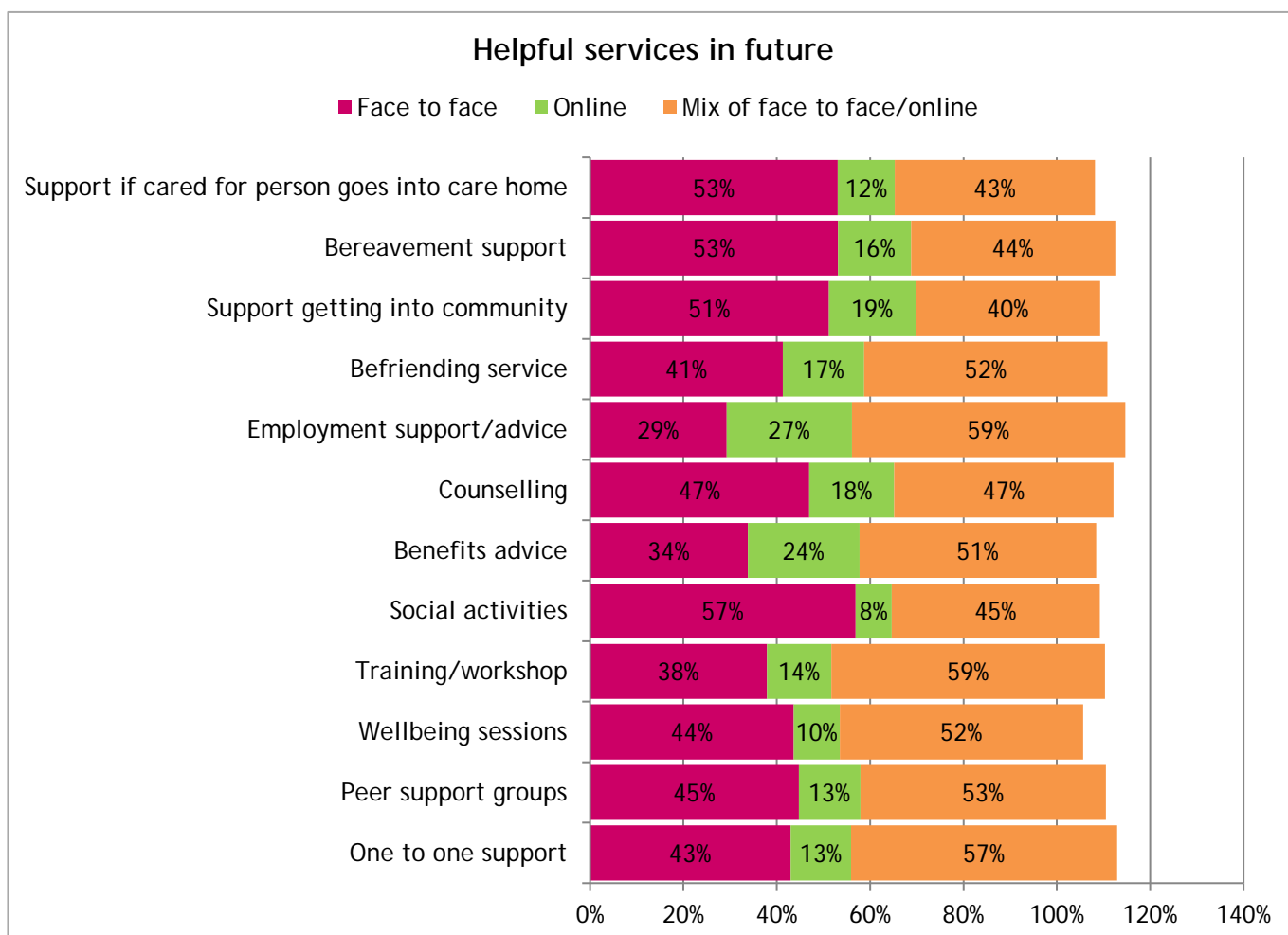
We asked respondents to rate the helpfulness of support from Newcastle Carers. Carers found one-to-one support most helpful (50%), closely followed by the telephone advice line (45%) and check-in calls (39%). The high rating for check-in calls reflects improvements in carer support, which included having regular check-ins. Despite the newsletter rating low on being very helpful, 48% of carers rated its support as helpful. This pattern is also reflected in support through the website. It must be noted that the newsletter was the most accessed support resource, closely followed by the website. Therefore, it could be suggested there needs to be an improvement in support content provided via the website and newsletter.

“During the pandemic I think a call from Newcastle Carers would have been good to check how I am coping and offer any other relevant services that are suited to my needs.”

It is good to see only a small number of carers reported support from Newcastle Carers as being unhelpful or very unhelpful: 16% of carers reported counselling as very unhelpful and 11% found benefits advice very unhelpful. It is worth noting that Newcastle Carers is not funded to provide specialist benefits advice. The local authority has a Welfare Rights Service and carers are one of its priority groups. People receive non-specialist benefit advice from Newcastle Carers and are referred to Newcastle Welfare Rights Service and other specialist advice services where appropriate.

Employment support/advice was rated as neutral by 74% of carers, and 67% rated statutory carer assessments as neutral. It should be noted that Newcastle Carers offer statutory carer assessment support to some young carers only. Carer assessment support is not available for the majority of service users – this is likely why most survey respondents gave a neutral rating.

### Future support services



We asked respondents what services they would find helpful in the future. Out of 115 carers who responded to this question, 93 carers (81%) reported they would find one-to-one support most helpful in the future. The majority preferred this to be a mix of face-to-face and online support (57%) or just face-to-face (43%). This reflects the previous question where carers found one-to-one support from Newcastle Carers to be the most helpful. Peer support groups were also reported as helpful in future for 66% of carers, with 53% preferring a mix of face-to-face/online (53%) or face-to-face (45%).

Notwithstanding the importance of this support, only 28% of carers reported they would like bereavement support in the future, followed by employment support/advice (36%) and support getting back into the community (37%). Once again, this feedback could be due to the specialist nature of these types of support and the relevancy to the carers who completed the survey.

It is interesting to see that for most services, carers would prefer a mixture of face-to-face and online support. This reflects previous comments on the flexibility of support provision around caring needs and work commitments. Further work may be needed to explore preferences once we are beyond the pandemic phase.

### How Newcastle Carers can meet needs in future

When asked how Newcastle Carers can meet carers' needs in the future, of 47 carers who responded, 25% reported only positive feedback about the centre.

**"I am glad to know that Newcastle Carers are there if ever I need their help. Even though I have not used them yet, I feel helped just by knowing they are there for me if circumstances change.**

**"Nothing I can think of now, but it's really good and reassuring to know Newcastle Carers is there."**

**"Please continue to be there, it's such a reassurance. I could not have managed through my mum's end of life years without your support"**

**"Keep doing a fabulous job! This service is worth more than its weight in gold. Thank you."**

For 36 carers who chose to share how their needs could be met in the future, the following themes emerged.

### Advertise (25%)

- What services are offered
- 63% did not know about Newcastle Carers until filling out this survey

**“They need to be more widely promoted on what they offer as I have only just heard about them today”**

### Communication (19%)

- Out-of-hours support for people working full-time
- Reaching out to previous carers who contacted in the past
- More frequent updates

### Access (17%)

- Reopening social groups
- Consider opening a carers’ centre in west Newcastle
- Main office remains open
- Service access outside of Newcastle criteria
- Easier to access information and guidance



## 5. Conclusion

This work has provided insight into the experiences of Newcastle carers during the pandemic.

### Carers' experiences during the pandemic

Carers saw a significant increase in the amount of care they provided during the pandemic. This was due to the condition of the person they cared for deteriorating and/or a reduction in the availability of external care support. Some did not choose to take up outside support, but there was also a reduction in available support from social services, support workers or private care agencies. Because of this, many carers felt they struggled to cope sometimes over the past 19 months and there was an impact on mental health. Social and emotional wellbeing was heavily impacted during the pandemic, with most carers feeling more isolated.

A recurring issue throughout this report is the difficulties carers noted with their mental health and their inability to socialise during the pandemic.

On a positive note, carers had more time to care, be with family and take up new hobbies. Other benefits included flexibility and the reduced costs of working from home. Exercise and online social contact were helpful coping mechanisms during the pandemic. The biggest fears of coming out of lockdown were COVID-19 spreading and another lockdown occurring. It was unfortunate that carers who had been bereaved during the pandemic did not always receive professional support, with many relying on family and friends.

### The cared-for person's experience during the pandemic

It's good to see that people who were cared for experienced no change to their services, or services that were closed have now reopened. However, it must be noted some gave this answer due to not using or being able to access services before the pandemic. This coincides with the majority reporting they struggled to access or receive support from services. It is great to see that carers found the most helpful support from voluntary and community organisations. It is not surprising that GPs received the lowest support rating given the underlying issue of access in the current climate, however, some said that treatment and care, once accessed, was excellent. This is similar to feedback that Healthwatch Newcastle has received from Newcastle residents in general. Hospital communication experience was very mixed for carers, with many reporting that once they were able to visit, they received better communication.

### Information and support

Most carers use GP practices and voluntary and community sector organisations as their main sources of information. These may be the carers most accessed services and who they trust the most. It is excellent to see that Newcastle Carers received the highest rating of support for carers in the city. Carers reported that support services could be improved by being more accessible and more known to the public.

## Newcastle Carers' evaluation

Most carers had received support from Newcastle Carers or wanted to. For those that did not want support or never contacted the centre; this may reflect the reluctance of some carers to access support, as well as a lack of advertisement of Newcastle Carers. Other carers had contacted the carers centre initially over one year ago, which emphasises those accessing Newcastle Carers services are established and receive ongoing long-term support.

One-to-one support was said to be the most helpful service offered, followed by the telephone advice line, and check-in calls. Newcastle Carers' website and newsletter were the most accessed support resource. Despite this, these resources were reported to be the least helpful, support content provided could be improved. However, one-to-one support, peer support groups, wellbeing sessions and benefits advice were said to be the most helpful services provided by Newcastle carers in the future, with the majority preferring these are provided by a mix of face to face and online.

Whilst most carers reported mainly positive things about Newcastle Carers' services, some recommended increasing advertising, increasing communication such as out-of-hours support, reaching out to carers and updating them more.

## Acknowledgements

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- Information Now
- MEA House community
- NAS Tyne and Wear
- Newcastle Carers
- Newcastle City Council
- Newcastle Vision Support
- NHS Newcastle Gateshead Clinical Commissioning Group
- Throckley Primary Care



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