# Caring for Care Givers in Gateshead

## Autumn 2022

# About Healthwatch Gateshead

Healthwatch Gateshead is one of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act, 2012.

Healthwatch Gateshead is an independent not-for-profit organisation. We are the local champion for everyone using health and social care services in the borough. We

- help people find out about local health and social care services
- listen to what people think of services and feed that back to those planning and running services, and the government, to help them understand what people want

We help children, young people and adults to have a say about social care and health services in Gateshead. 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 Gateshead is part of Tell Us North CIC (company no. 10394966)

Healthwatch Gateshead would like to thank everyone who generously gave their time and expertise to assist with this report.

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# Executive Summary – Gateshead Carers Survey

## Summary

This survey was developed by Healthwatch Gateshead to help Gateshead Council understand the experiences of care givers (unpaid carers) as we come out of the Covid 19 pandemic.

The survey was based on a questionnaire which was available as both an online and paper-based versions. It was widely publicised across the Borough at local sites, via organisations (charities and voluntary sector) which might have contact with care givers, and over local radio.

## About the care givers

A total of 77 responses were received, including 63 women and 10 men (four people did not specify gender). The majority (68% of respondents were aged between 55 and 64 years, and a quarter were over 75 years old.

A quarter of the respondents said they themselves had care needs and described a wide range of health and care problems, mostly focussed around musculoskeletal and mobility issues, and mental health problems including depression and anxiety. For some care givers, their own needs were impacting their ability to care for their dependant.

Less than a quarter of care givers had had a carers assessment; including just 5 of the 22 care givers who also had their own care needs. Several respondents said they did not know about the assessments and one comment suggested that carers assessments were not available.

## Impact of Covid 19

The impact of the pandemic had been negative for most respondents, especially in terms of emotional, social and physical impact. Financial impact usually related to change of employment.

For example, 15 respondents had given up work because of their caring responsibilities and dealing with their own ill health and its impact on their ability to provide care.

A third of respondents had suffered a bereavement during the pandemic. Some had sought support, but mostly from family and friends or primary care services.

## Coping with caring responsibilities

Respondents were fairly evenly split between those who felt they were managing/coping and those who felt they were struggling to cope or at breaking point. None of those struggling to cope had had a carers assessment.

It was clear that some the households involved here had some social care support, but we did not enquire about details of this. Comments focused on lack of care staff, their poor quality and their attitude. These were recurrent themes throughout the comments provided.

Isolation was also a recurrent theme, reported by nearly half of all respondents. However, of these, more of the care givers were coping than having problems.

## About the people they care for

Altogether, the 77 respondents looked after 94 service users. Most were caring for one person, but one was caring for 5 people.

Over half of the people being cared for were over 70 years old, and a third of all those being cared were aged 81-90. Some of the care givers for this group were themselves elderly. For example, three care givers aged over 85 were caring for dependants over 90.

Sixteen children and young people were being cared for by respondents and had 50 diagnoses between them, most commonly autism and learning disabilities, . One child had 6 separate diagnoses.

The adults being cared for had 189 diagnoses altogether, and many were age-related such as physical impairment and dementia.  Few of this group had a diagnosis of autism or learning disability.

Over half of the respondents who completed the survey shielded during the pandemic, mostly at the request of the government.  Support accessed came from friends and family rather than statutory services, and some seemed not to know support had been on offer.

## Main concerns for care givers

The biggest single worry for respondents now was their ability to cope with the stresses of caring and access to support.  This was exacerbated by the care givers' own increasing care needs and declining health.

Access to and shortage of (paid) care support were constant themes, with comments about poor practice amongst some of the carers such as unreliability, not following a care plan, not turning up, and making errors.

Concern for the future centred around the potential impact of another major outbreak of Covid on their loved ones and on services.  Some emergency practices like automatic DNR applied to some patients was also scaring respondents.

## Caring now

Most respondents felt the level of care they had to provide post Covid had increased, mostly due to the deterioration of the health/condition of the person they cared for, and in some cases impacted by their own care needs.

The support services accessed varied, but were mostly seen as positive with the exception of social workers, mental health team care co-ordinator and talking therapies each which received more negative feedback.

Extra carer support was high on the list of what was helpful – for relief, for respite, for capacity and for the simple pleasure of there being someone else there.

We were asked to look at communication with the hospitals as a possible concern, but most of the comments from those who had been involved with the hospitals were positive about both care and attitude.

## What was most difficult

For men this was balancing work and caring and loss of social freedoms; for women it was dealing with deterioration of the person they cared for and their own health, and the emotional impact of that, including feelings of isolation and having to cope alone. For some this included a lack of family support and a widespread lack of understanding that caring is 24/7.

The lack of services, many of with closed during the pandemic and have not reopened in full, has been difficult too. People felt 'left to get on with it'.

Poor access to information was cited repeatedly. Most information was online, but not all carers can access this effectively, or did not find it effective for signposting to services.

## Positives now

Respondents identified several positive outcomes from their Covid experience including practical things like working from home/hybrid working, closeness to family, and even the value of phone consultations.

Respondents also mentioned a variety of things that had helped them through the worst times including shared activities (online) with friends and family as well as activities outside the home. Use of technology was mentioned several times for different purposes as well and was seen as a boon by those who could use it.

## Access to information

Men preferred to get information from formal sites, and these might be expected to provide accurate and valid information. Women were more likely to also use informal sites like social media, and such sites may be less reliable or accurate and create new problems.

# Executive Summary Continued – Main concerns highlighted.

## Carers assessments

The lack of carers assessments reported by respondents should be addressed. They are not compulsory, but at least all care givers known to the Council should be offered an assessment through a social worker or direct from Gateshead Carers who provide the service.

Care givers could also be encouraged to register as a care giver at their GP practice to make sure their specific needs are recognised. They should also been signposted to Carers Allowance if not already claiming.

## Level of support

The biggest single issue raised by respondents was around capacity and support – carers, financial support and services. At the moment there is a general shortage of care workers across the country that is unlikely to be resolved any time soon. It may be helpful if the Council was explicit in acknowledging this and making public what it has in place to manage the situation locally. This should be updated or refreshed on a regular basis so it is seen as current by care givers and families.

Alternative support approaches may also be helpful. An example for some people could be opportunities to develop online groups for care givers to provide mutual support to each other and even cross cover to provide respite space in some instances. These services are already in place via some national charities, but a local version could be advantageous.

## Poor performance

Issues with poor performance from some paid carers should be a concern and needs to be addressed by the Council which commissions the services. Some of the comments received, suggest there could be safeguarding issues if care plans are not being followed, errors made, or care workers do not have the knowledge and skills to deliver their role.

## Holistic approach to needs

There were requests for a co-ordinated approach meeting caring needs, including a more holistic approach from clinical practitioners (rather than one issue at a time) and social services. Care givers wanted to be listened to and heard by service providers. They know the person they care for and the complexity of their needs best, and sometimes felt dismissed and side lined. Being more involved in decisions being made across health and care services would give care givers some reassurance and ultimately result in better care outcomes for the service users.

Some respondents suggested that access to clinical care was also proving very difficult and this is likely due to the same sort of staffing issues as social care support. These issues are widely reported on national media and is again not something within local influence and is being addressed at a national level. Where there is positive information, local updates may be helpful.

## Access to information

Care givers and service users are disadvantaged if they cannot access the information and details of services that could help them. There are a lot of local and national sources of information, both formal (NHS/local authority) and informal (social media). Whilst most respondents got information from a variety of sources, it was clear that some of the potential information sources, such as the Council website, Our Gateshead or social prescribing services, were not used at all.

This suggests there needs to be a rethink about how information can be disseminated. Information that is only available online is automatically exclusive for a range people who do not or can not routinely use online services. Other issues such as searching skills may also be inhibiting. A website is easy to keep up to date whilst paper-based resources can go out of date quite fast, but if the web-based information is not being accessed, other strategies need to be considered, and sources of information, even if online, may need to be better publicised to direct people to good quality and up to date information.

# Introduction

Gateshead Council wanted to understand peoples' experiences of being a care giver (unpaid carer) during the height of the Covid 19 pandemic (2020 – 2021) and as we move out of the worst of it and are learning to live with the disease.

They commissioned Healthwatch Gateshead as an independent voice to explore the issues with local care givers to help inform future decisions about meeting the needs of care givers in the Borough.

# Methodology

Healthwatch Gateshead designed a questionnaire to encourage Gateshead residents providing unpaid care to vulnerable people to look back at the Covid 19 pandemic period and explore how their caring responsibilities had changed over the last couple of years.

The questionnaire was available both on-line and in paper copy. It was publicised on the Healthwatch Gateshead and Newcastle websites, through our social media feeds (Facebook, Twitter, Instagram) and via personal contacts both before the survey opened and during the time it was available. Radio Tyneside broadcast both an interview and a short 'advert' about the project.

We shared the questionnaire with charitable organisations in Gateshead that work with care givers and asked them to promote it to their clients using the online tool, and we offered them paper copies if they would be more suitable for their clients.
The Council advertised the survey via their own internal contacts. Paper copies and flyers were also sent to all community centres and libraries in Gateshead with the request that they also publicise the survey on our behalf. Reminders were sent halfway through the survey period.

The online and paper versions of the questionnaire were available (using Smart Survey) from mid July to mid August 2022.
A second round of data collection for paper returns was reopened at the end of August with one of the participating organisations. This phase of data collection was closed in mid October.

A total of 77 responses were received from all sources. We presume that all respondents were care givers and not paid carers.

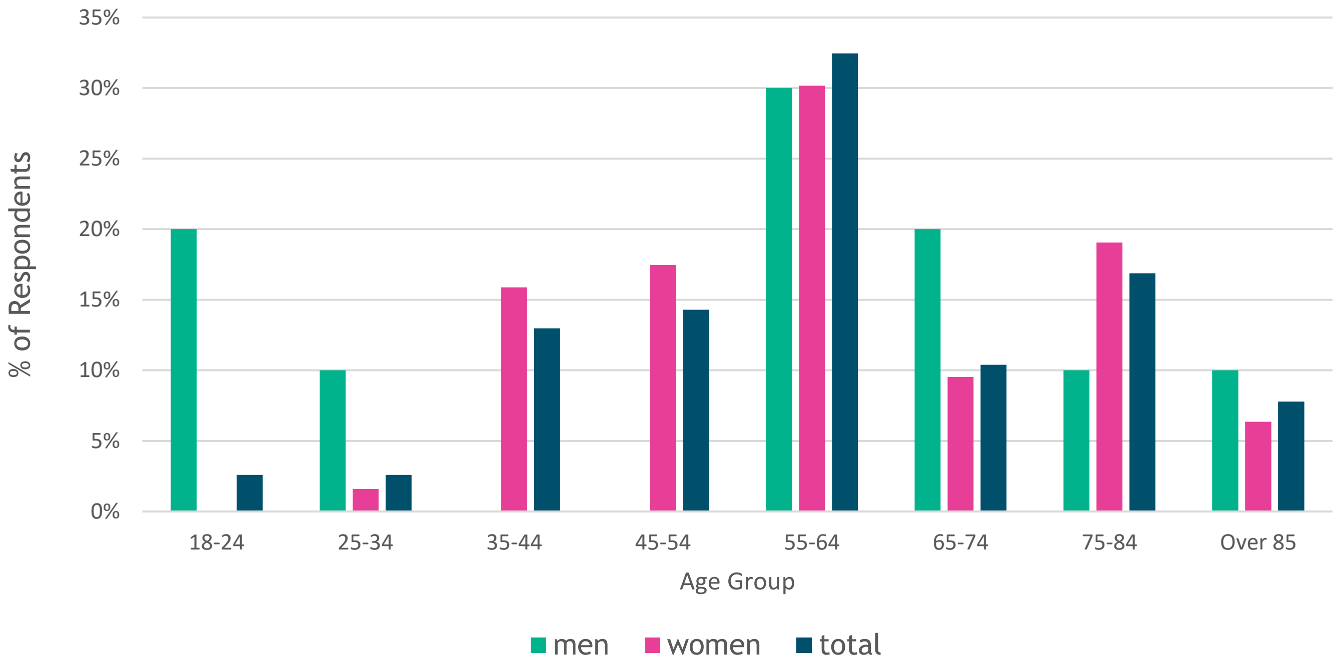
These results have been analysed and are reported here. A final report has been given to Gateshead Council and is available on the Healthwatch Gateshead website. Paper copies are available upon request from Healthwatch Gateshead.

# Findings

## 1. About the Care Givers

Care givers who responded to the survey were invited to tell us about themselves and their personal situations.

**Figure 1 Age of Respondents**



*NB The data is presented here in percentage terms to indicate the pattern of age groups amongst men and women caregivers, and overall. Please note that these are proportional and the actual percentage can be misleading where there are small numbers involved.*

The majority of our respondents were women (63 respondents, 81%). Ten men responded and four respondents did not indicate their gender.

The majority of all respondents were in the 55–64 age band (68% of caregivers), representing a third of both men and women in the sample.

The two youngest care givers who responded, aged 18-24, were both were men. Nineteen care givers were over 75 years old (two men, 16 women, one gender not specified - 25% of respondents).

Only one respondent between the ages of 24 and 55 was a man.

## 1.1 Care Givers Care Needs

We asked the care givers if they had a disability or care needs of their own which could impact on their ability to provide care, over and above the needs of the person/people they cared for.

We also asked if they had had a carers’ assessment about those needs and possible support.

Twenty one respondents (16 women and 4 men, one gender not specified) who answered this question (28% of all respondents) said they did have their own caring needs. These respondents were all aged between 35 and 74.

Respondents cited a wide range of issues they were dealing with themselves. In some cases they had multiple needs. These are summarised below.

**Table 1 Care givers own health needs**

| **Health issues/care givers needs** | **No. mentions** |
|---|---|
| Mental health, inc. anxiety and depression | 7 |
| Arthritis | 5 |
| Diabetes | 1 |
| Heart problems | 3 |
| Mobility/musculoskeletal | 9 |
| Eye (sight loss, cataracts, glaucoma, macular degeneration, retinal tears, blepharitis, Fuchs endothelial dystrophy) | 2 |
| Personal care | 3 |
| Hearing loss | 1 |
| Addison's disease | 1 |
| **Total** | **32** |

The most common issues reported were musculoskeletal and mobility problems, and mental health issues including depression and anxiety.

Overall, the 21 respondents to this question cited 32 issues they were facing, and two others listed off multiple diverse problems.

> *"I have fibromyalgia, various tendonitis, carpel tunnel, back problems, interstitial cystitis, and anxiety and depression. Other issues still being explored."*

This respondent said that her health issues were affecting her ability to provide care for another, and she had had to give up both a part time job and voluntary work due to problems with fatigue.

Another respondent cited major problems due to multiple injuries sustained in a hit and run accident, which has left him in constant pain and with limited mobility.

> *"Suffering with depression, [illegible] spondylosis, arthritis in knees and both feet, left shoulder in constant pain, as is spine due to injuries sustained in hit and run whereby surgeries performed to place pins, plates in left shoulder. Bolts in left feet also."*

We did not ask the respondents if they felt their own medical and care needs were being met by the appropriate services, but a couple commented that they were well looked after in terms of their clinical needs.

Two other respondents said they did not have care needs themselves, but went on to list problems with daily living and heart problems.

There was little commonality about the support needs of care givers overall, and they need to be treated as individuals in obtaining support.

## 1.2 Carer's assessments

Under the Care Act (2014), local councils can provide care and support for people who require care, *and* their carers, based on assessed needs. This includes, in particular for this report, unpaid carers who often make big sacrifices to take on their caring role. Carers' assessments are available to adults who look after another adult who is disabled, ill or elderly. The assessments look at the impact caring has on the care giver's life such as physical, mental and emotional needs, and what support services the care giver may need.

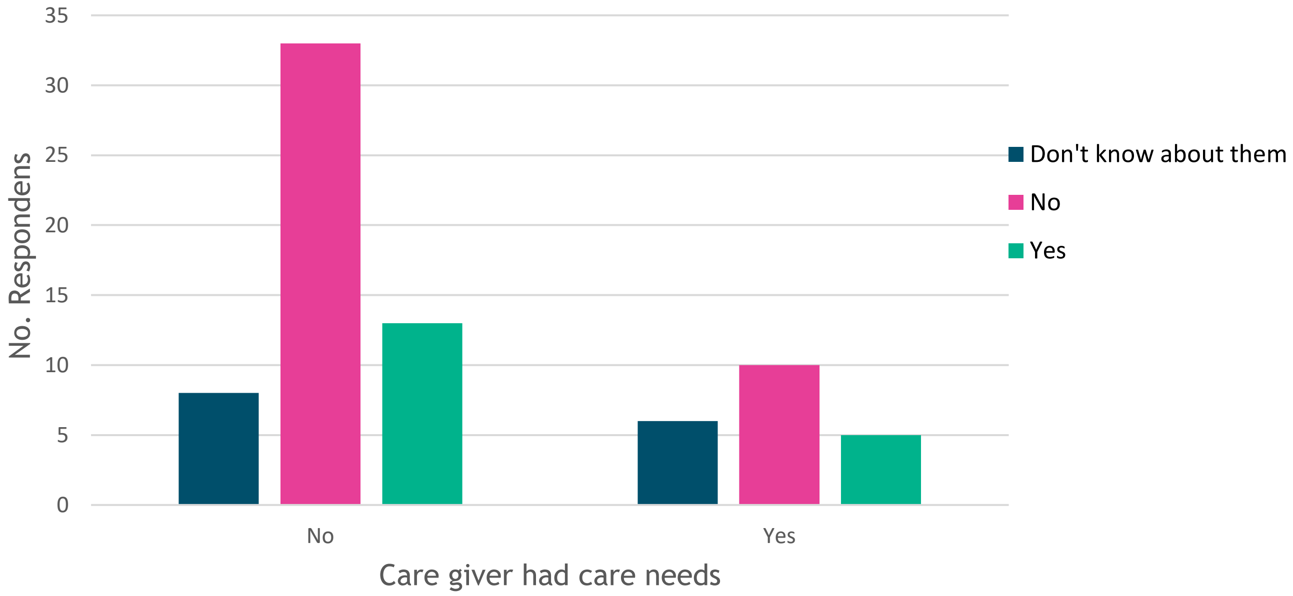
Getting a carer's assessment is the first step to getting help as a carer. It gives care givers the opportunity to discuss their needs as a carer and to see what practical and financial support they may be entitled to from their local council.

A care giver's assessment is unrelated to the type of care they provided, financial means or the level of support needed. Where the assessment shows that the care giver has eligible needs, the council has a legal obligation to meet those needs and provide a support plan setting out how the needs will be met.

Care givers' needs assessment are free and anyone can ask for one. In Gateshead, carers' assessments are carried out for the council by Gateshead Carers.[1]

(A Carer's Assessment is unrelated to the clinical needs of either the care giver or the person they care for – these are met by the NHS and remain free at the point of care.) Overall, just 18 of our respondents (23%) had had a care givers assessment, 3 men and 14 women (30% and 22% respectively). We did not ask about the outcomes of these assessment, and no comments were offered by respondents.

**Figure 2 Knowledge of Carers' Assessments**



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[1] https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment https://www.carersuk.org/images/Factsheets/2022-23_factsheets/Assessments_-_England_April_2022-23.pdf

Of the 22 respondents who had said they had their own care needs, only 5 had had a carers assessment (5%), including 1 man and 4 women. Six others said they were not aware of the assessments (27%).

Fifty-four respondents had said they had no care needs of their own. Of these, 13 had had a carers assessment (24%) and eight were not aware of them (15%).
In both cases, the remaining respondents said they not had an assessment, but presumably were aware of them.

It would seem that there is scope to make information on support for care givers more available. Both statutory and non-statutory services have a role in publicising carers' assessments to unpaid care givers and are best placed to promote support for people who provide care and form such a crucial part of care provision overall.

Similarly, service providers should ensure that all staff are fully knowledgeable about support services. Care givers should be encouraged to talk to any support service that helps with the person they care for, and should ensure they are recorded with their doctor as being a care giver so any proactive support can be shared with them.

Local council investment in supporting unpaid care givers is good for the quality of life for the care giver, the quality of life for the person they care for, as well as the overall provision of care in Gateshead.

## 1.3 Impact of the Covid pandemic on care givers.

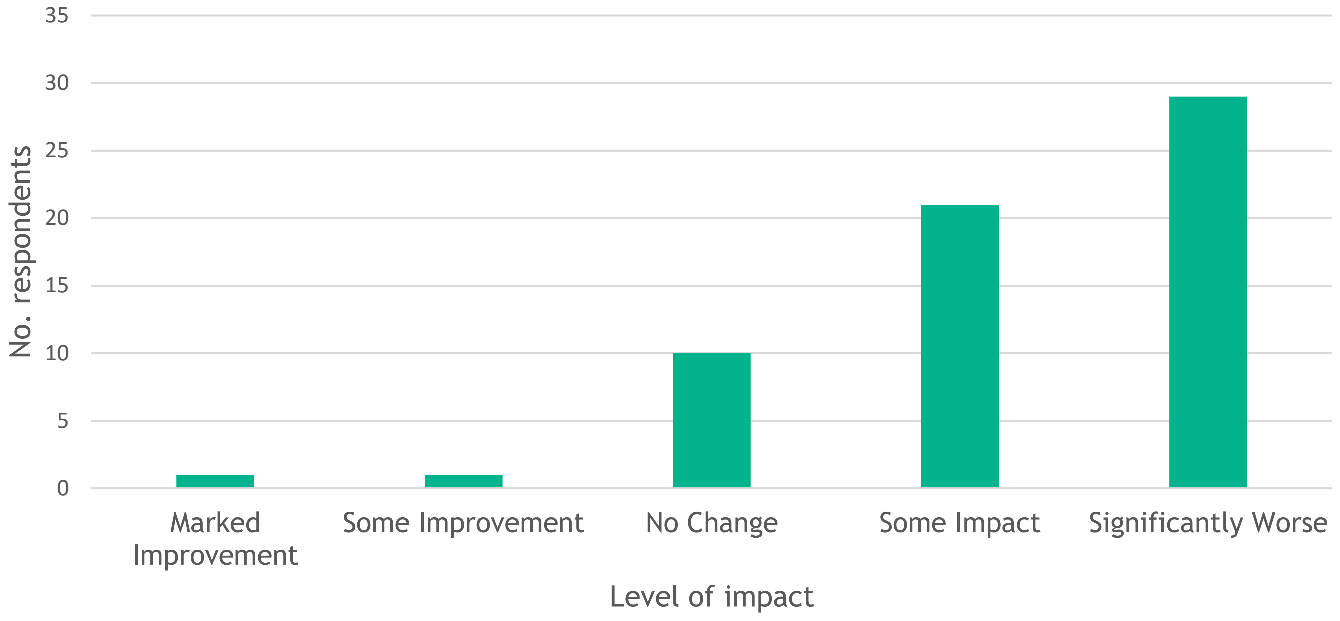
In line with the areas of assessment in the carers' assessment, we asked our respondents what impact they felt the pandemic had had on them in various areas.

### 1.3.1 Emotional Impact

Of the 62 people who answered this question, one woman and one man told us that the emotional impact for them had been positive, although neither offered any comment or explanation.

Eleven women said they did not feel that the pandemic had had an emotional impact on them (no change).

**Figure 3  Emotional impact of Covid**



However, much as expected, for the majority of respondents the emotional impact had been negative.  A third of respondents to this question said that Covid had had ‘some emotional impact’ and half of the group said things were now ‘significantly worse’. One woman sadly told us

> *“Since I was carer for 3 until end of January until my sister died and I want to be with her, she spent the last year of her life confined to bed due to her illness.”*

Another told us

> *“I cared for my mum for last 6 years after a stroke.  I moved her in with me at start of pandemic and she never went home.  She died 6Nov 21.  I had a terrible time with her doctors as they wouldn’t come out to see her as she was at house.  We tried to get her to the docs but she kept collapsing so not always poss.  I eventually changed her to my docs and they diagnosed her with pancreatic cancer and she died 6weeks after.”*

A man told us

> *“Trying to maintain a job in healthcare as well as provide care for wife who has a long-term disability has nearly put me on the sick.  Too much to deal with in your own.”*

Another respondent told us how difficulty in accessing care support added to an emotional situation.

> *"My mental state has drastically got worse because the care company are stretched by taking on new clients, no staff so I am working harder for friends and family. Doctors are useless so I am having to ring round finding appropriate medical needs."*

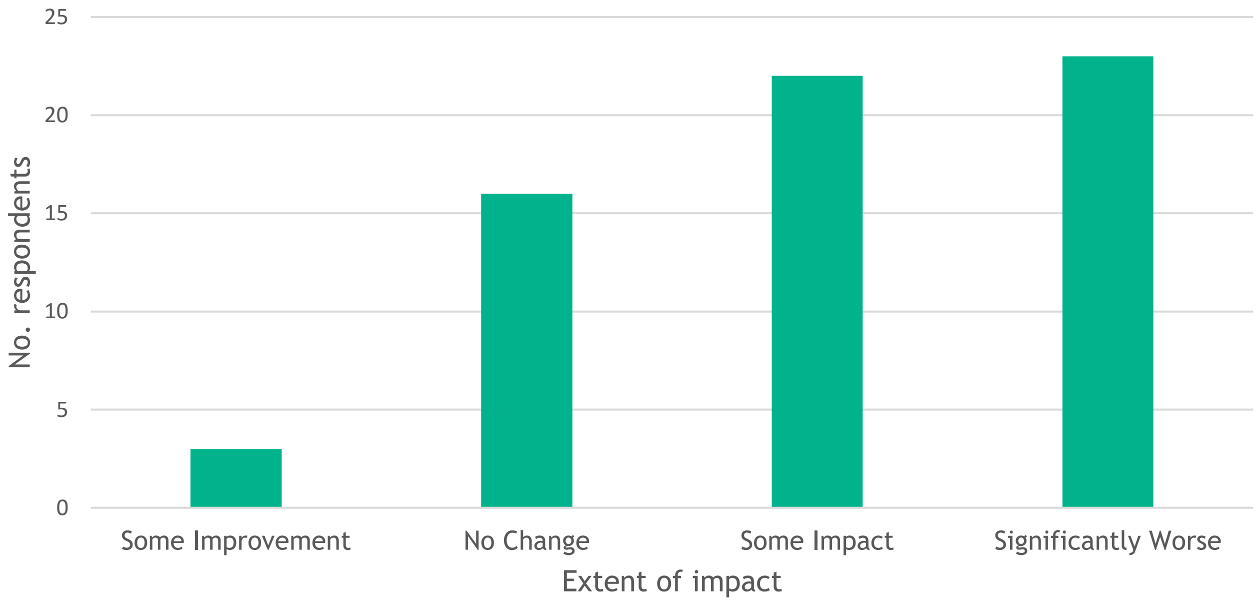
This emotional impact of trying to find support is a recurrent theme through this survey. Similarly, the issue raised here about professionals not attending service users and care givers having to do what they saw as the role of professionals in seeking care support for clinical issues in particular, was mentioned repeatedly in responses to this survey.

## 1.3.2 Physical impact

Of the 62 respondents that answered this question, 46 (88%) felt that caring during Covid had had a negative physical impact on them, and for half of these respondents the impact had been significant.

None of the respondents gave any details of this impact or made any comment.

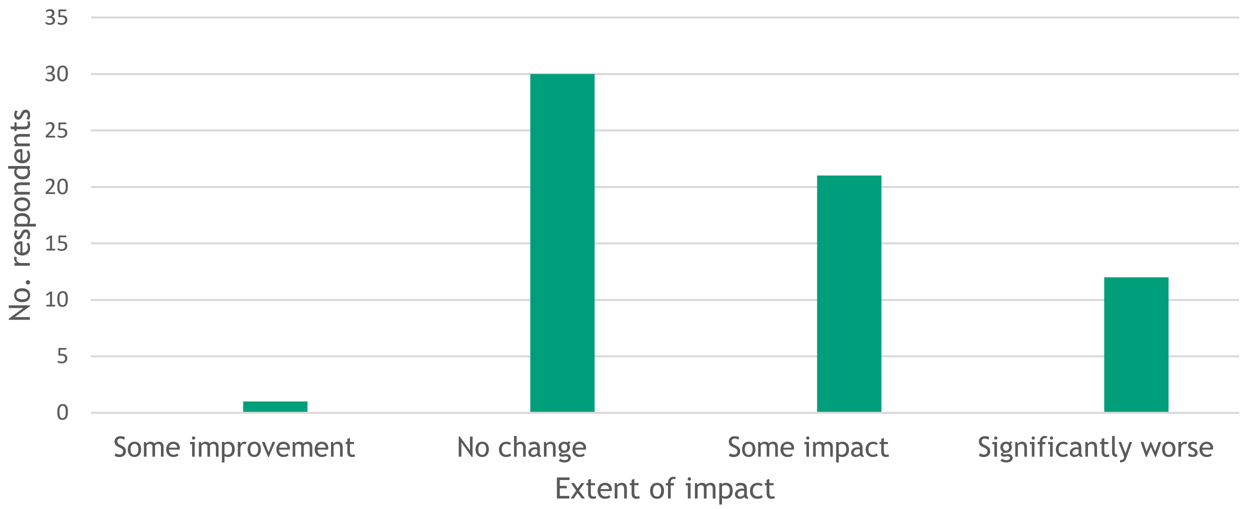
**Figure 4 Physical Impact of Covid**



### 1.3.3 Financial impact

One respondent said that she had seen a positive financial impact due to Covid and 30 respondents (46%) told us that there had been no change to their financial status.

**Figure 5 Financial impact of Covid**



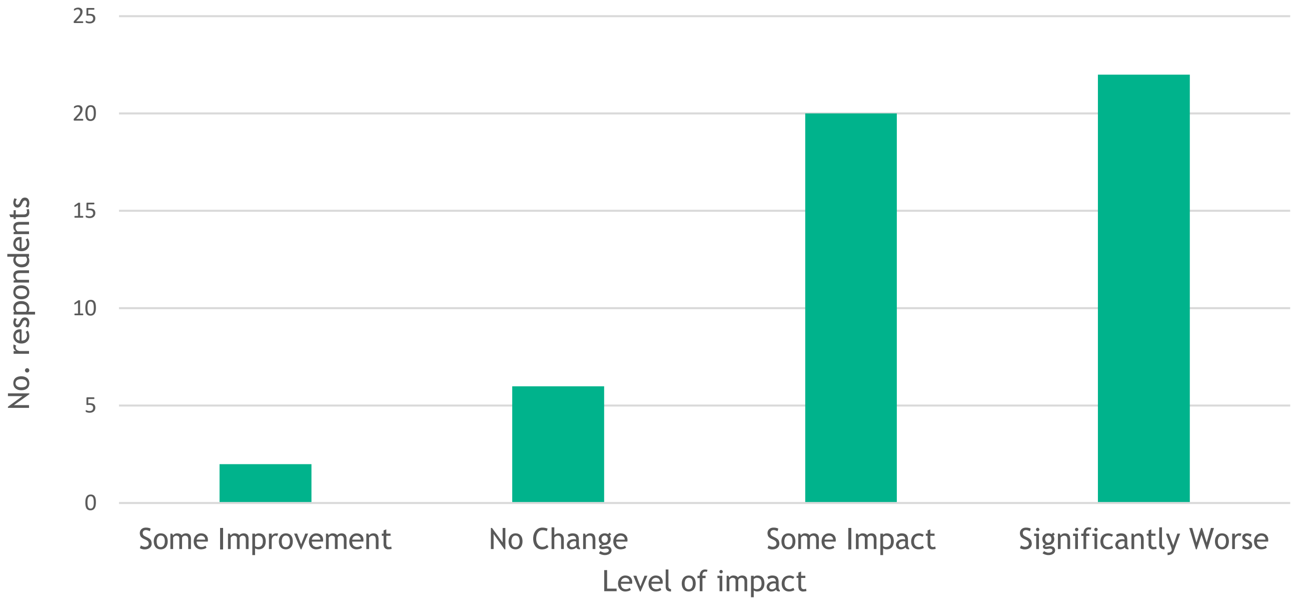
Of the remaining 33 respondents, 21 said there had been some impact and 12 said the impact had been significant. For all of these respondents, the financial impact correlated with the impact the pandemic had had on their employment.

> *"I had just managed to find a PA for my son when all kinds of things went wrong due to covid, (lack of PPE, isolating) my son also had scoliosis correction surgery after the first lock down but meant I was the only person able to stay with him."*
>
> *"I handed in my notice at Newcastle uni where I worked because my autistic son was at home, due to his enterprise being closed. It was very difficult trying to hold down a job working from home, while trying to keep him occupied, otherwise he would just end up watching TV which would make me feel guilty."*

## 1.3.4Social impact

Only 50 respondents gave a response to this question.  Of those, two women felt the impact on their social activity had been positive, but offered no comment to say how or why.

**Figure 6  Social impact of Covid**



Seven people felt that Covid had had no social impact (one man and six women). Five men and 21 women across the age ranges felt Covid had had some impact, and one man and 25 women felt the negative impact had been significant.
Only one respondent gave any detail

> *"My social contacts have reduced substantially.  There are fewer volunteering outlets for me now.  Local transport has also reduced and I am also less confident driving."*

## 1.3.5 Education and training

Just 49 people responded to this question, 8 men and 34 women.  Only 7 of them reported any impact on their education and training.  They were all women, but gave no details.

In six cases the impact had been negative and some improvement in the other case.

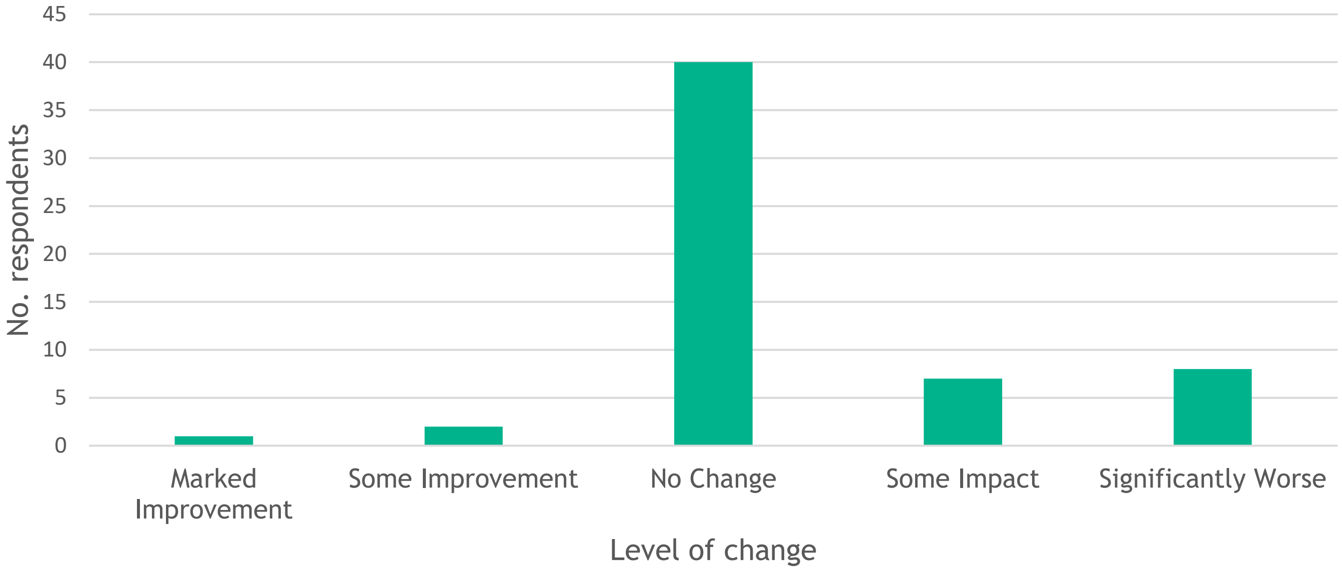
### 1.3.6 Employment

We asked care givers if they felt Covid had had any impact on their employment and how they would describe their work situation now.

A total of 58 people commented on the impact of Covid on employment. For one man and one woman things had got better, but for one man and seven women things had got significantly worse. A further seven women had experienced some impact. However, for the majority of respondents, (40 people, 69% of respondents) there had been no real impact on employment.

One respondent did comment on the benefits of home working during the lockdown, and others mentioned that they had worked throughout the pandemic.
Where things had got worse, comments suggested that this was related to increasing caring needs allied with reduced services. These comments were general and not specific to this question.

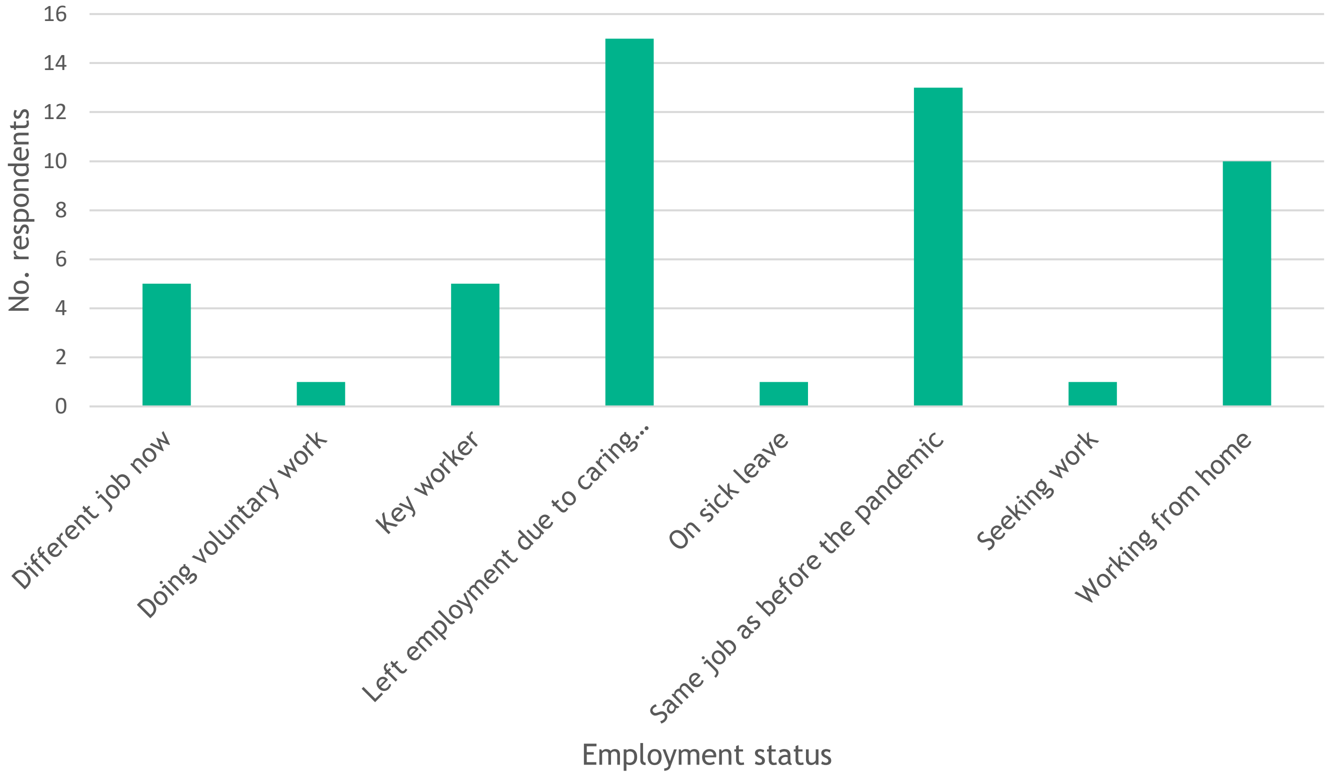
**Figure 7 Impact of Covid on employment**



### 1.3.7 Current employment

We also asked care givers if the nature of their employment had changed since the pandemic. Fifty-one people explained their current employment status.

**Figure 8 Current employment status**



The biggest single group of respondents (15 people, 29%) was people who had given up paid employment due to caring responsibilities. For five people this was a 'significantly worse' impact, but one person said it had only had 'some impact' and for 7 this was no change.

> *"I've always struggled to maintain a job due to my caring responsibilities, but since my health is getting worse I find I can't manage other things in addition to my caring role, even keeping on top of house work and washing etc is a huge challenge."*
>
> *"I was a self-employed cleaner, I now care, run errands, clerical work for family and friend because care company don't do it."*
>
> *"Had to leave work due to the impact of my own health condition and my caring responsibilities. Unable to get a balance between work & caring that did not put my own health & mental health at risk."*
>
> *"I left my job in Dec 2020 because I was finding it increasingly difficult to work from home, while having to provide care + support for my son who would normally be accessing council services."*

A further 13 (25%) were still in the same job as before and offered no comment. Five respondents were key workers, and this had not changed.

Ten people were working from home, but how impactful this was varied. For 4 people this was no change, for one it was a marked improvement and for one other it was some improvement.

One respondent however, saw this as a significant negative impact, but did not explain. Another respondent said

> *"Working from home more commonplace which is helpful in terms of balancing caring for my disabled daughter. Terrible emotional strain during pandemic, but better now we can be out & about & schools are up and running again."*

Five people had changed jobs, but opinions on impact were mixed. For 2 there was no change, and for one this was a marked improvement. The other two respondents felt this was a negative impact.

> *"Gave up work before pandemic to care for my Gran and Grandad, due to finances now I have had to take up part time employment to make ends meet"*

> *"Moved job for more money due to cost of living crisis"*

Comments from those reporting some impact included

> *"I am currently working from home, but will be going to hybrid working and luckily my employer is sympathetic to my circumstances."*

And for the respondent who reported some improvement

> *"Blend of working in the office and working from home. Can only work part-time given that I might have to drop everything for my disabled daughter at a moment's notice."*

## 1.4 Bereavement

Sadly, 27 respondents (35%) had suffered a bereavement during the Covid 19 pandemic. This included 6 men and 19 women. We did not ask the respondents' relationship with the person they had lost, although some mentioned it in comments. For some, this was the person they cared for, for others it was a more remote connection.

Ten of these respondents said they had received support to help them cope, including four men and just five women. Others said they had not sought support as they felt they could cope without it, or they had not felt support was available to access.

> *"What support is there? If there even was any I would not have time to take off work + caring"*

Another commented simply

> *"Rules Rules Rules!!!!!"*

A couple of people who did not access support, explained that their loss was not someone with whom they were close

> *"It was a friend not a close relative, lots of people were losing someone they knew or were close to, didn't really think I needed any support."*

We asked those who suffered bereavement who they had received support from. Those respondents who answered said it was mostly from family and friends, and some from counselling or primary care/GP services.

No comments were offered by respondents who had not suffered a bereavement. Locally, there is a range of services offering support in event of a bereavement (for care givers and non care givers) and these could be more widely promoted so that those seeking support could find it easily. This could include information from statutory and charitable care providers or care support organisations.

## 1.5 Coping with caring

Coping as a care giver can be hard. During especially difficult times such as the pandemic, it all becomes harder.

To explore how well they had been coping during this period, we asked care givers how much they agreed with the statements below

‘I feel I am coping well’ and ‘I feel I am managing’.

‘I struggle to cope most days’ and ‘I feel at breaking point’.

We also asked respondents if they felt isolated. Feeling isolated can be a problem for those who are coping as much as for those who are not.

Care givers gave us feedback under each of these headings, but the number of responses varied for each one.

Overall, we had responses from 7 men and 51 women. One man gave strongly negative responses to all four of the statements, both positive and negative.
For this analysis, we are concentrating on positive (strongly agree and agree) and negative (disagree and strongly disagree) responses. Taken together there was an almost equal (50:50) split between positive and negative responses.

Respondents also made 24 comments.

As expected, respondents who replied positively to the first two statements (coping and managing), generally responded negatively to the second two (struggling and at breaking point) and vice versa.

### 1.5.1 I feel I am coping well

Twenty two people (36%) gave a positive response to this statement (two responded ‘strongly agree) and 23 (38%) were negative. There was no real difference between the age groups of those who agreed or disagreed.

Of those who were positive, 4 were men and included one man aged 85 or above, but no comments were made.

There were a few comments from women.

> *"It's a very careful balance and we as a family can go from almost thriving to barely surviving depending on the day as there is always a background pressure being a carer and small things can tip the balance quickly in the wrong direction."*
>
> *"There are ups and downs but coped well so far."*
>
> *"With the support I have in place (Grove House & Carers Trust) we are coping OK."*

Just over a quarter of respondents were neutral in their response.
The 23 negative responses included 17 who disagreed with the statement and six who strongly disagreed.

One woman who strongly disagreed with this statement said

> *"There is no support out there as I feel I am meddling, District nurse, doctors and care company are not listening to me or patients."*
>
> *"They are making life really hard and frustrating for them."*

Others told us of their own stresses

> *"I care for 5 members of my family. I am Power of Attorney for three of them and I am the main point of contact for another. I provide emotional support to four of them and help all five with paperwork and financial dealings as well as taking them to their doctors and hospital appointments."*
>
> *"We need re housing and the stress and pressures of living in an unsuitable home is awful. It's having a mental and physical affect on me."*
>
> *"I'm struggling meeting 2 people's needs!"*

### 1.5.2 I feel I am managing

Sixty seven people responded to this statement. Thirty one (46%) agreed with it and 24 (36%) disagreed. Twelve people (18%) gave a neutral response.

Those who agreed they were managing, had mostly responded that they were coping well too, or had given a neutral response.

Respondents who said they were not managing had also said they were not coping. Four respondents (two men and two women) strongly agreed with this statement, two of whom had also strongly agreed that they were coping well.

The remainder of the group did not offer any insights to how or why they felt this way.

### 1.5.3 I struggle to cope most days

Sixty five people responded to this statement.

Just under a third of the respondents (20 people, 31%) agreed that they were indeed struggling to cope and six of them strongly agreed with this statement.

Of these respondents, all had their own care needs, but only one had had a carer assessment.

> *"Lack of care staff available to employ to help out with moving and handling, the one we did have for a short time didn't really do much and tried to gear my son's activities towards things he wanted to do rather than what he was employed to do."*

### 1.5.4 I feel at breaking point

Eighteen respondents agreed with this statement. One was a man and one did not disclose their gender. The respondents were distributed across the age ranges.
Three people who agreed with this statement had also said they agreed that they were coping/managing well.

> *"It varies but at the moment I feel at breaking point"*

Eight of the respondents who said they felt at breaking point (six women, one man, one gender not specified) had care needs themselves, but none had had a carers assessment and one said they did not know about them.

### 1.5.5 I feel isolated

In this survey, 28 people across the age groups agreed that they felt isolated (48% of respondents to this question). This included one man, but no comments were offered. Eight of the respondents who felt isolated had reported that they were coping well/managing and 3 had said that they were struggling/at breaking point.
Their comments have been included above.

It is clear that some care givers are coping better than others; those struggling need to be identified and extra support offered. For example, for those with care needs themselves, a carer assessment may identify extra support that they are entitled to, which may ease their burden.

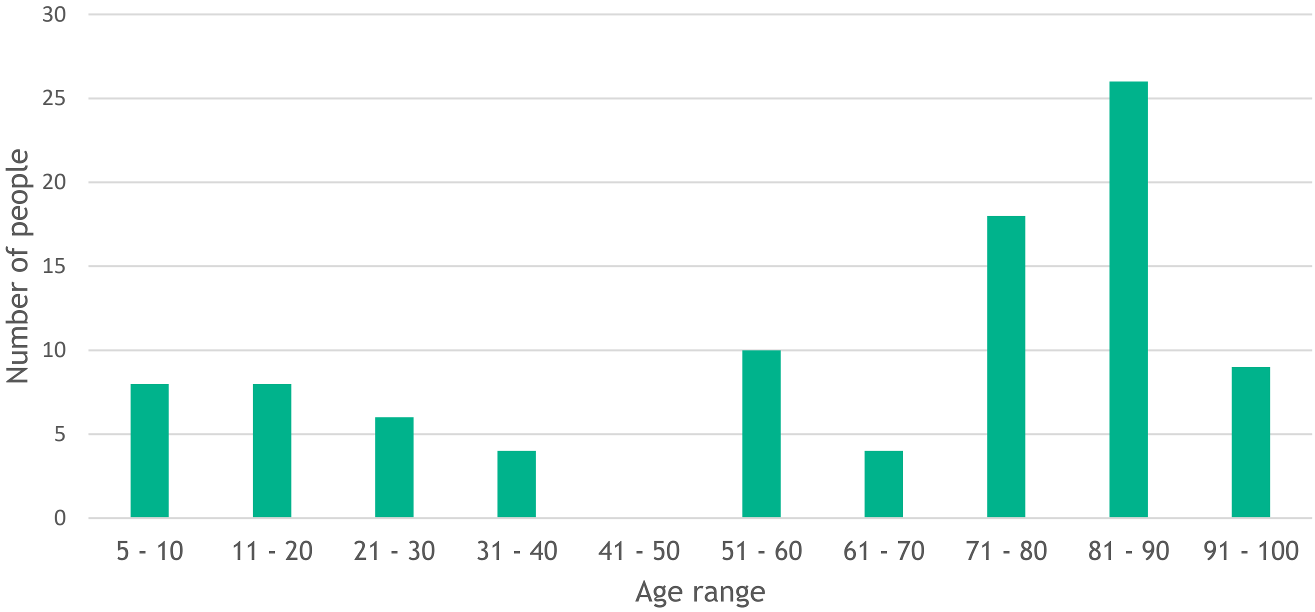
# 2. Those receiving care

We asked the care givers to give us a snapshot of the people they cared for. We did not ask for any personal details for the people cared for beyond their age and diagnoses. We did not ask what the relationship was between the care giver and the person they cared for. Some told us, but most did not.

## 2.1 Age of people cared for

We asked the care givers about the ages of the people they cared for.

**Figure 9 Age of people being cared for**



Of the people being cared for

- 16 (17%) were children or young people, all cared for by women
- just 10 people (11%) were aged 21-50, all cared for by women. Oddly there were no people aged 41 – 50 in the sample.
- 14 people (18%) were aged 51-70, 4 of whom were cared for by men.

It is clear that the people who were being cared for were mostly elderly (53 people, 57% were over the age of 70,) and the biggest single group were aged 81-90.

It was also clear when we looked at this older age group of people receiving care to see who cared for them, that the care givers themselves were elderly.

For care givers aged 75-84

- one care giver was looking after someone aged 26
- 3 were looking after people in their 50s
- 4 were looking after people in their late 70s
- 4 were looking after people in their 80s

Three care givers aged over 85 were looking after people in their 90s and one was caring for someone aged 60.

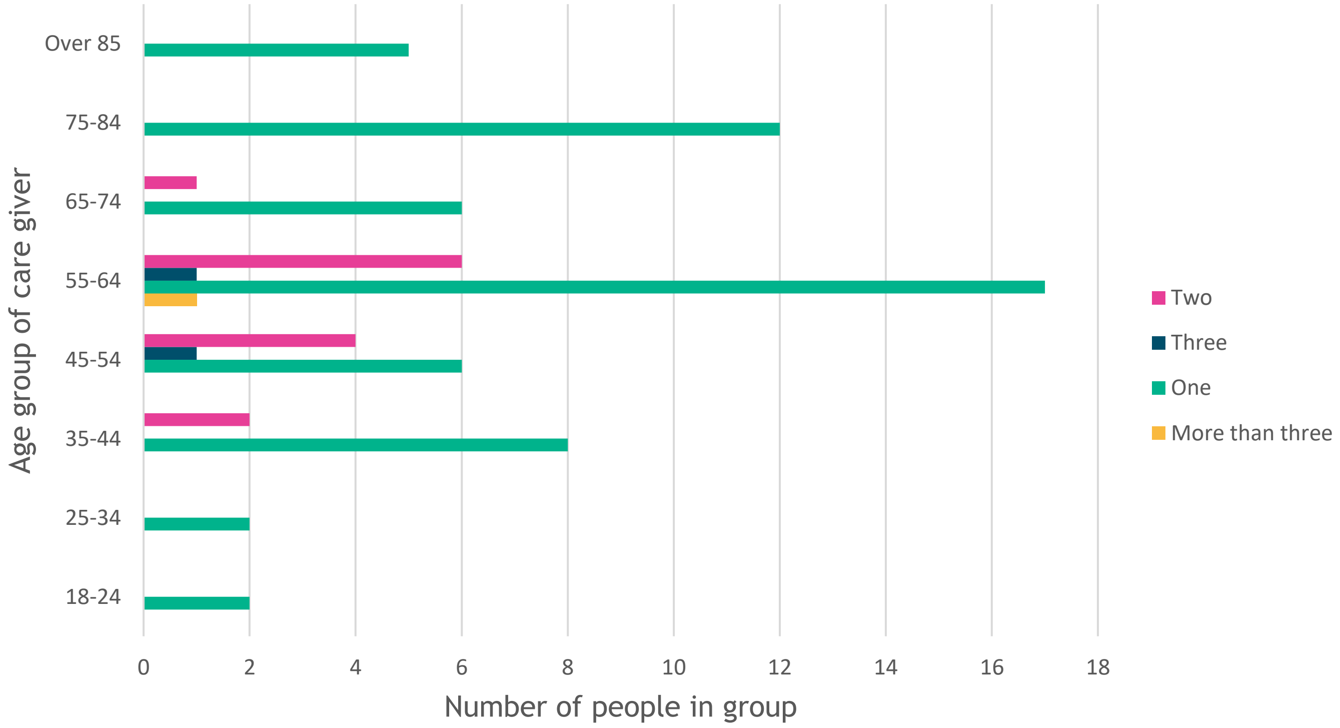
This is a potential concern especially because of the care needs of the care givers themselves. Of the care givers in these age groups, only six had had a carers assessment.

## 2.2 Number or people cared for by each care giver

We asked the care givers how many people they cared for.

Altogether, the 74 care givers who answered this question looked after 94 dependents. The majority (58 respondents, 78%) cared for one person, 13 respondents (18%) looked after 2 people and 2 respondents looked after 3 people. None of the men were caring for more than one person.

**Figure 10 Number of people being cared for by one care giver**



One respondent said she was looking after 5 members of her family, 3 of whom were in their 80s, and one in their 50s.

## 2.3 Conditions the care recipients suffered from

We asked care givers to share with us the conditions the people they cared for were suffering from. These diagnoses were the same as those used for similar surveys in both North Tyneside and Newcastle.

The full list of suggested diagnoses we asked about was:

**Table 2 Conditions care recipients suffered from**

| |
|---|
| Autism |
| Cancer |
| Dementia |
| Heart problems |
| Inflammatory/Autoimmune disease (e.g. rheumatoid arthritis) |
| Learning disability |
| Long Covid |
| Lung/breathing problems (e.g. COPD, emphysema) |
| Mental health condition (e.g. depression, schizophrenia, anxiety) |
| Neurodevelopmental disorder (e.g. ASD, ADHD, dyspraxia, dyslexia) |
| Neurological condition (e.g. MS, MND, epilepsy) |
| Physical impairment (movement or mobility problems |
| Sensory disability (sight, hearing loss) |
| Stroke/aphasia |
| Substance/alcohol abuse |

No details were provided by respondents for specifics within a diagnostic category. Our feedback is described below separately for children and adults.

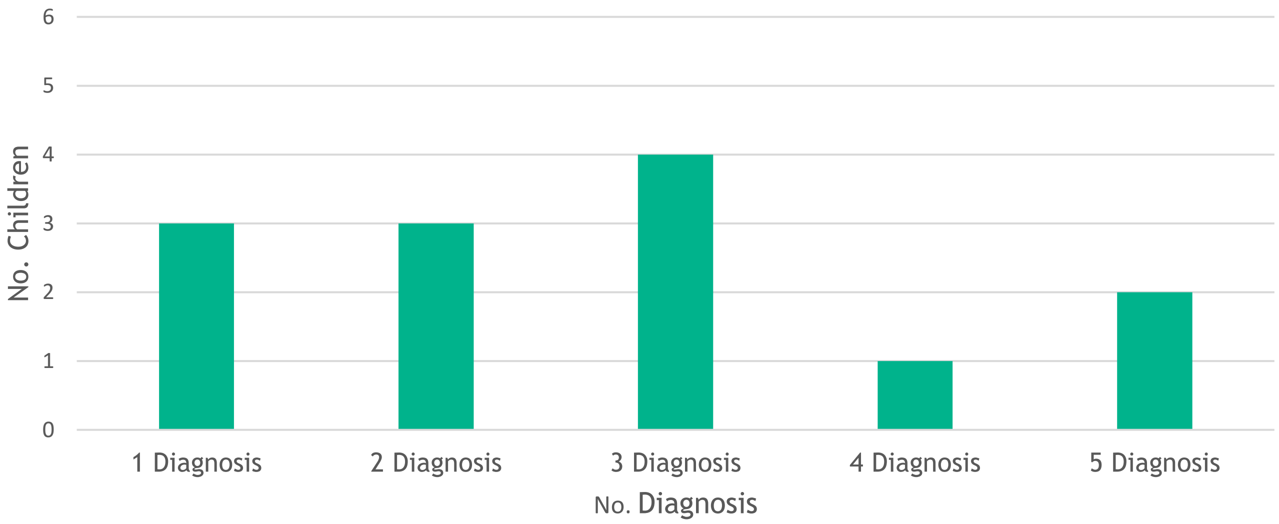
## 2.4 Children receiving care

There were 16 children and young people up to the age of 20 in this survey who were receiving care for a variety of conditions. They were being cared for by 14 care givers (two carers were caring for two children), and three care givers also looked after an elderly person ('sandwich carers'). All the care givers were women.

None of the children were recorded as suffering from stroke/aphasia or substance/alcohol abuse. One child was listed as having dementia, but this seems unlikely`.

Most of the children suffered from more than one diagnosis and 50 separate health issues were recorded for these 16 children.

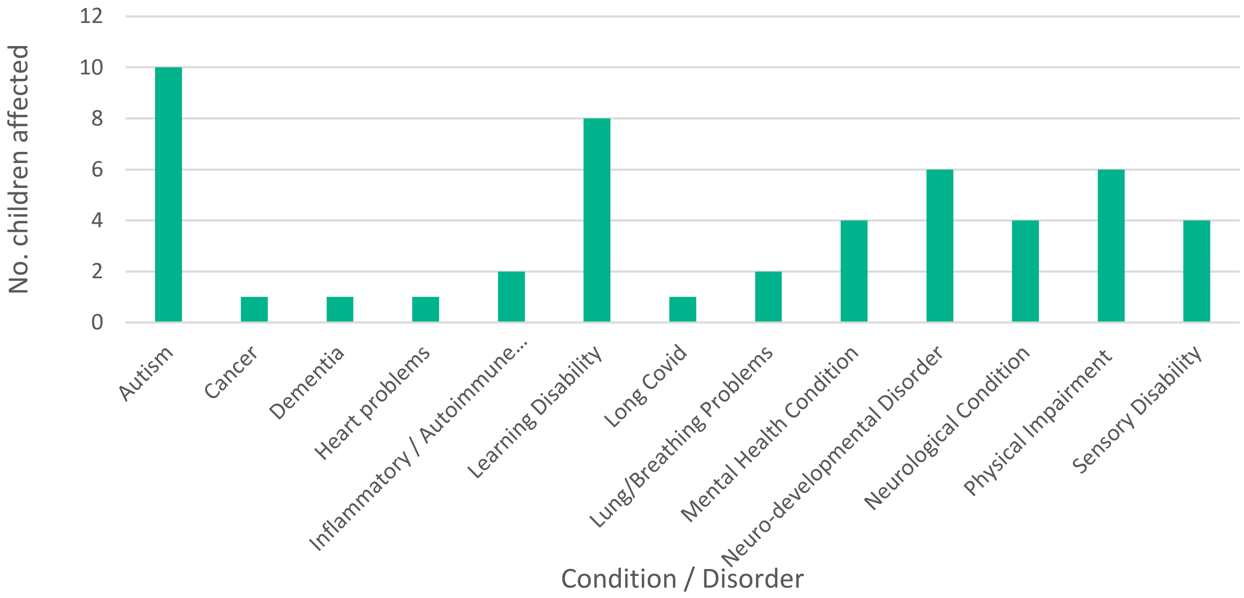
**Figure 11 Children with multiple diagnoses**



Just 3 children had just one diagnosis, and most had 2-4 diagnoses.
Looking at these diagnoses in a little more detail,

- the most frequent diagnoses were autism (63%), learning disability (50%), a neurodevelopmental disorder and a physical impairment (no details were given).
- four children with a diagnosis of autism also had a diagnosis of a neurodevelopmental disorder and autism is sometimes included in this spectrum.
- four children with autism also had a diagnosis for learning disability or mental health problems and two children were diagnosed with all three.

**Figure 12 Frequency of diagnosis for children**



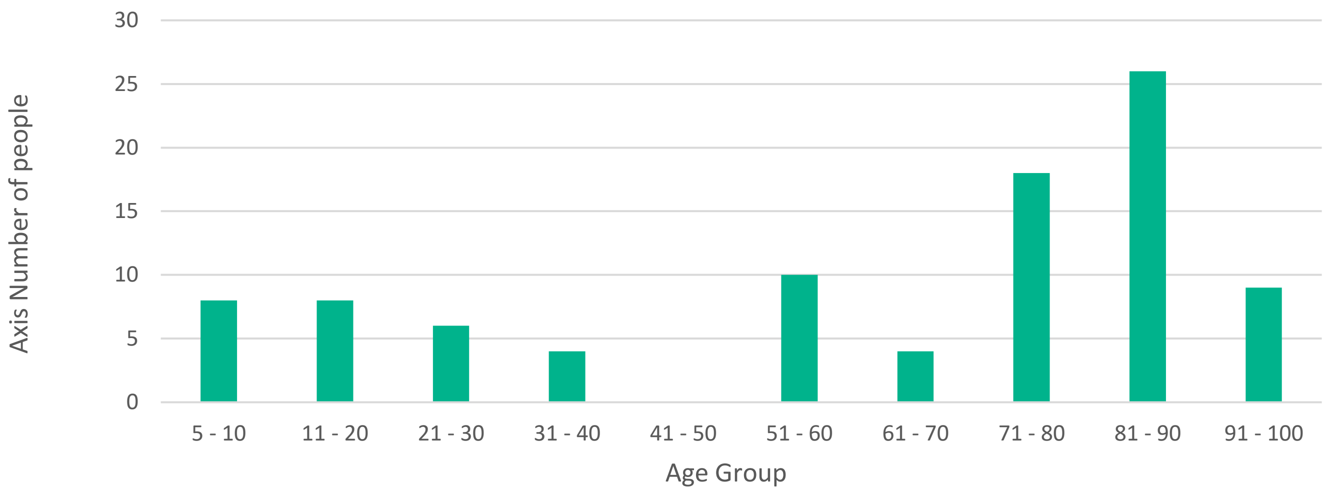
Two children each had six diagnoses. They both suffered from learning disabilities, physical and sensory disabilities, neurological problems and lung/breathing problems. One also had a neurodevelopmental issue and the other also had heart problems.

## 2.5 Adults receiving care

In this survey 63 care givers gave us information about the 70 adults they cared for. Forty seven care givers cared for one person, ten care givers looked after two people each and one care givers looked after three people.

Looking at the ages of the people being cared for, the increase in care with age is stark.

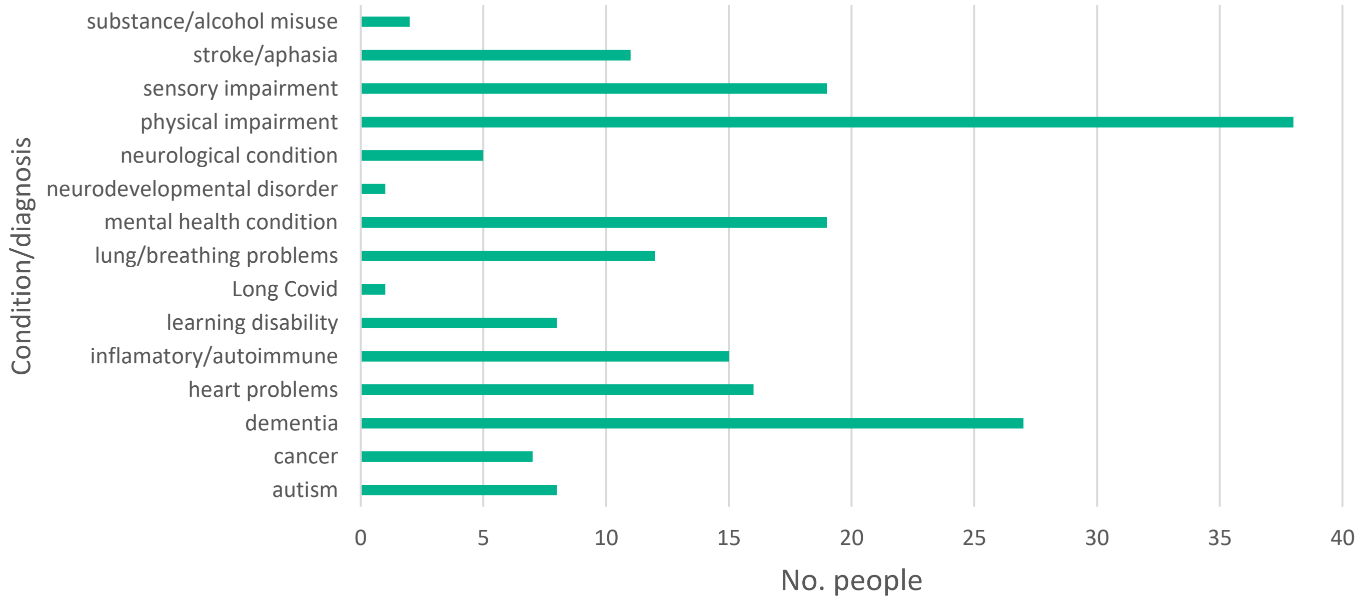
## Figure 13  Age group of person cared for



The people cared for had 189 diagnoses between them.  The most common diagnoses were physical and sensory impairment and dementia, along with mental health problems.  These can mostly be seen as age related deterioration.

The conditions and health problems suffered by the adults cared for in this survey were very different to the children.  Some care givers are looking after both adult and child dependants and anything up to five people at the same time.

## Figure 14   Frequency of diagnosis for adults

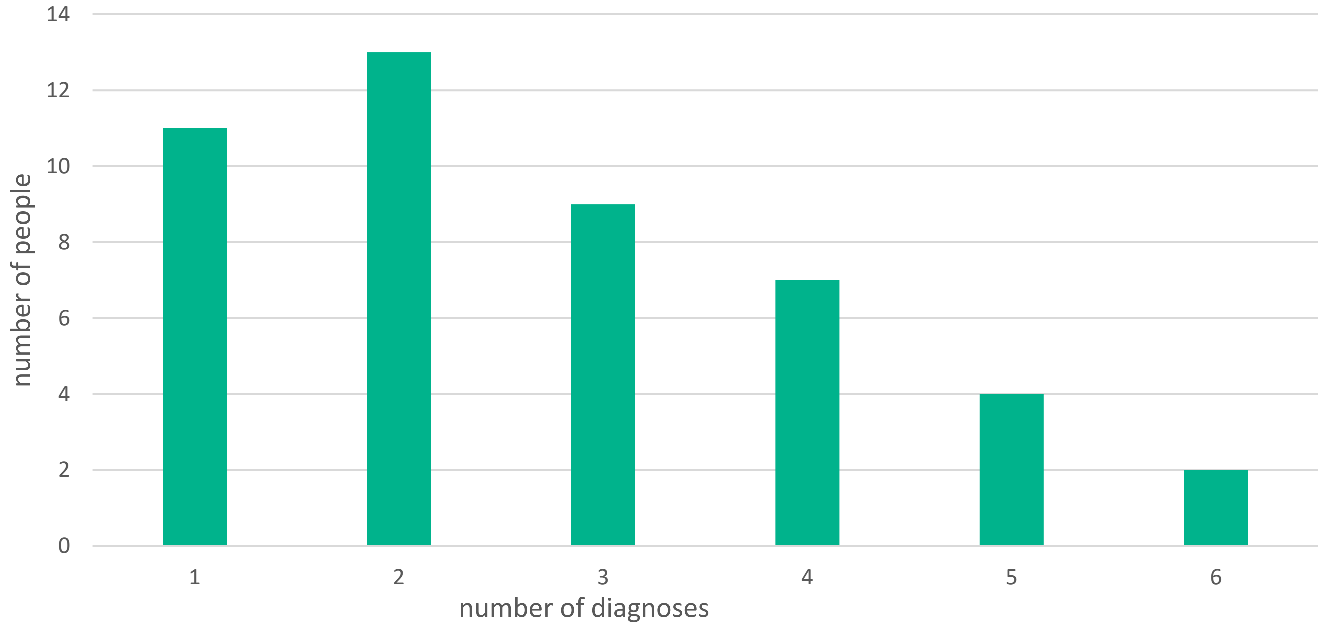


Neither autism nor learning disabilities featured much amongst the adults being cared for as they had with the children (each were listed for 11% of adults being cared for), but there were more cases of long-term conditions such as heart and breathing problems as might be expected with advancing age.

The two men diagnosed with substance/alcohol misuse were both over 75, and both had 4 other diagnoses as well.  One was also suffering from physical and sensory impairments, dementia and inflammatory/autoimmune problems.  The other man had physical and sensory impairments, mental health problems and lung/breathing problems.

Of those care givers who look after one dependent, just 11 of them had a single diagnosis.

**Figure 15   Care givers with a single dependent**



This included 5 people with dementia, and two each with physical disabilities, learning disabilities, and inflammatory/autoimmune disease.

Within this group where the people cared for had two conditions, physical infirmity was the biggest issue mentioned (7 of 13 people).  Two people in this group, aged 82 and 94 had cancer; one was a man aged 93 who was also suffering from dementia, heart problems and had had a stroke.  There was no age given for the other person; he also had lung/breathing problems.

Two people had six concurrent diagnoses. They had dementia, heart problems, mental health issues, physical infirmities and sensory disabilities in common. One also had an inflammatory autoimmune problem and the other had a lung/respiratory problem. It was clear from the complex data set that the care givers were coping with multiple problems and often with the multiple and diverse needs of more than one person, quite apart from trying to maintain normal daily life for both themselves and other family members.

To some extent, the problems listed for adults could be viewed as age dependent (the oldest person receiving care in this survey was 100 years old) such as physical impairment (for example, mobility) and sensory disability (for example, failing eyesight and hearing).

## 2.6 Main caring problems faced by respondents

We asked care givers what they felt were the main caring problems they faced. We were told about a lot of different worries relating to ability to cope with the exigencies of caring and access to support, especially as the care givers' own needs increased. Where the person cared for had mental health problems (not understanding or insecurity) health and safety was an issue.

> *"Person I care for has lost confidence and can feel lonely."*
>
> *"Road safety. Her not understanding her problem."*
>
> *"None of the people I care for will accept carers supporting them, which leaves the majority to me and my husband to sort out."*

For some it was their own situation that caused problems with caring

> *"Not able to take husband out without extra support. My arthritis has become worse recently but I still have to do all tasks and help husband. Having enough time to carry out my caring responsibilities."*

For those caring for children, the extra support needed to cope with school holidays or respite care was an issue.

> *"Support during holidays and half term breaks."*

Access to services was mentioned too

> *"No help, takes too long to sort help out."*
>
> *"Doing everything myself."*
>
> *"Lack of help and support."*
>
> *"Needs hoisting / changing places / someone medically trained to look after my child due to health needs."*
>
> *"Hearing loss, cognitive impairment, mobility problems, sight impairment. Struggling to cope on my own as no family and only 4 hours support from Crossroads per week."*

Two comments of concern suggested that the support the care giver received was an issue in itself.

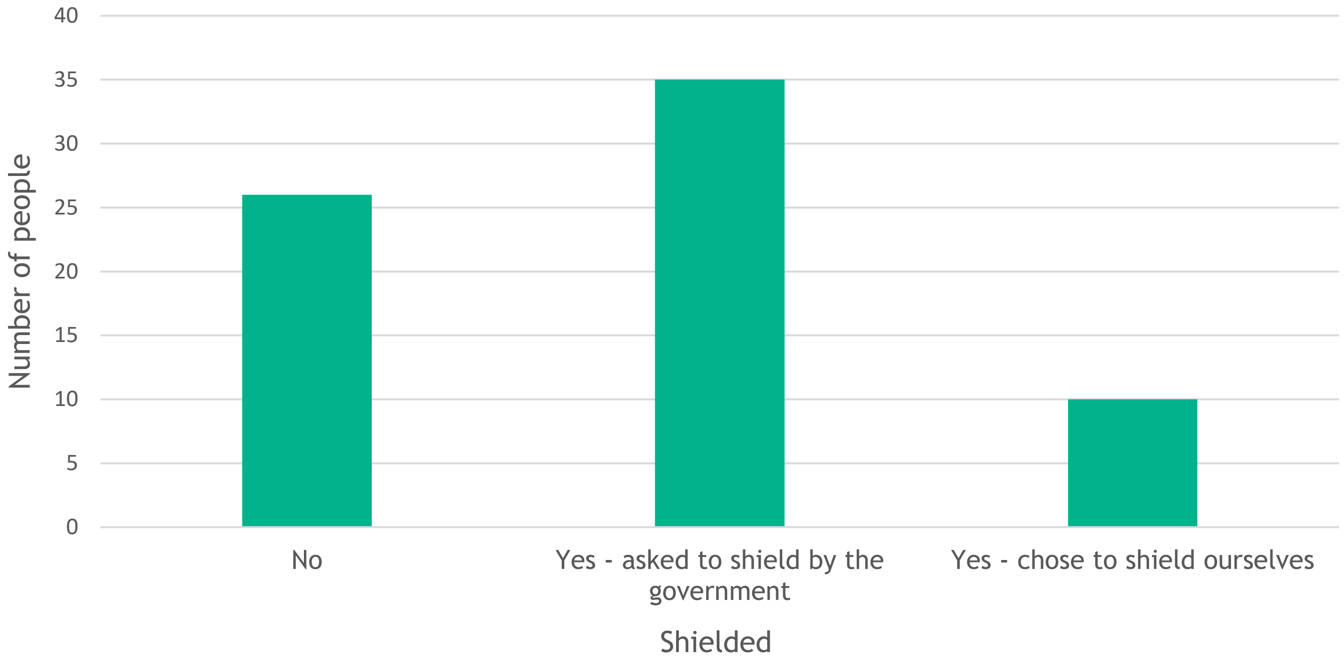
> *"Carers not complying with care plan, medication mistakes, their family getting nowhere with complaints."*
>
> *"Carers not turning up from domiciliary care - different carers - was less stressful not having them but as care needs increased could not cope on own"*

## 2.7 Shielding

During the height of the Covid 19 pandemic, the government asked some people who were deemed to be particularly clinically vulnerable and at risk from the virus to 'shield', meaning they should not leave their homes and should minimise all face-to-face contact with others as their best protection from catching the disease.
We asked our respondents if they had been asked to shield or had made a personal decision to do so.

In total, 45 respondents (63% of all respondents) had done so. Most of them (78% of the group) had been asked to do so by the government and the remaining 22% of the group had chosen to do so.

**Figure 16 People who shielded during the pandemic**



We asked those who had been shielding if they had accessed any support during that period and what that support had comprised. Fourteen people shared details with us. Of the 35 respondents who were shielding at the request of the government, 15 had not accessed any outside support services.

Others had got support from friends and family (specifically mentioned by 2, but others were living as a family), and volunteers (Shared Lives) helped 2 people with shopping drops.

One woman who had looked for external support said she had

> *"Cancelled as carers not turning up, or were very late. As working from home could not cope with inconsistencies as scheduled meetings around care visits."*

Eight people commented on having support during shielding at the government's direction. The support included shopping (by Shared Lives volunteers), takeaways from local providers, family support, and two people accessed carer support via the council. Two others continued to have their normal carer support throughout.
For one respondent, medical support was particularly complicated

> *"Yes, but it was difficult because more than 5 departments were involved and some were a lot slower than others, resulting in my sister being hospitalised for 3 weeks before a bed with the correct mattress could issued. My sister contracted Covid while in hospital but luckily she was OK."*

Another respondent had not tried to access support

> *"I did not access support, during Covid didn't think support was possible."*

One respondent told us about providing support rather than receiving it

> *"We did not access any support, I did everything for my Gran while she didn't leave the house in over 2 years due to covid."*

For those who chose to go into shielding (10 people), two said they had not accessed support and three people gave us details.  One had been supported by family with shopping.  Others told us

> *"Yes, we were supported by 'Shared Lives' to take him for walks during the day keeping away from the public."*

> *"Yes and no.  Wife in hospital.  Myself called for ambulance 3 times."*

A range of support was in fact available, if limited in capacity, but there seems to have been an issue with getting information to people who do not use online services.

Befriending calls made by charities and standard local media such as radio, TV and printed brochures could be revitalised to reach the maximum number of those in need.

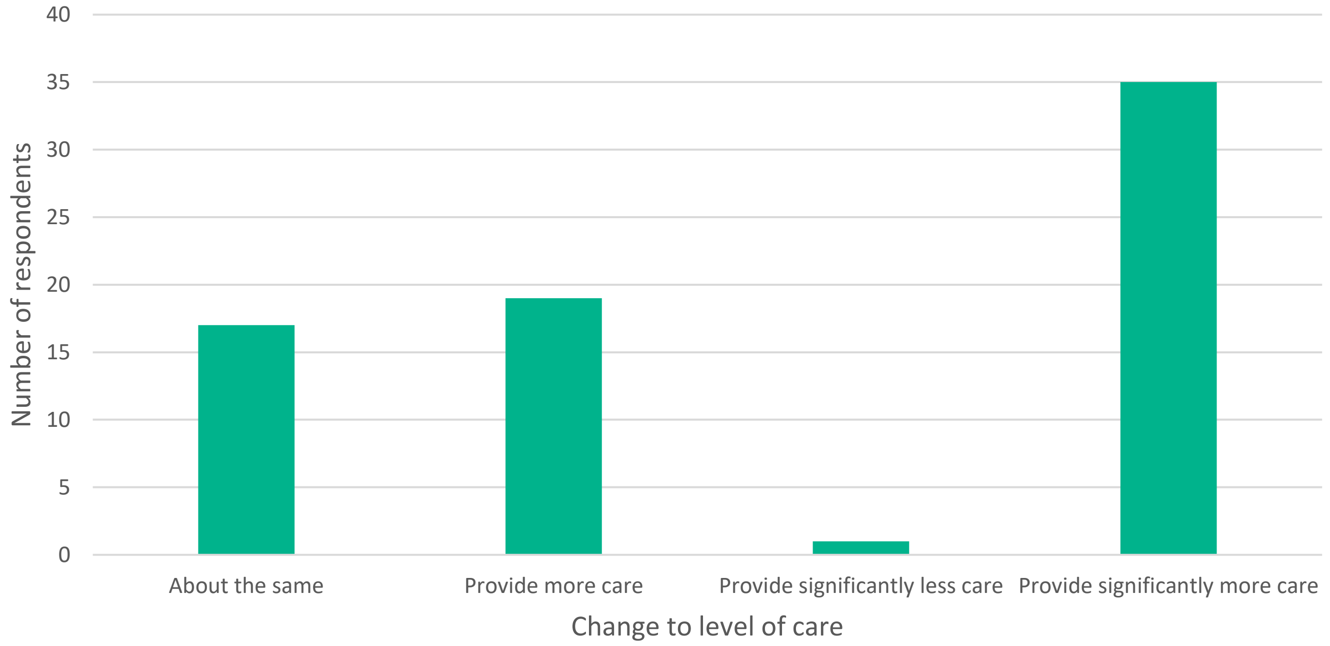
# 3. Experience as a care giver

## 3.1 Level of care

We asked care givers how they felt the level of care they now need to provide had changed.

Overall, the level of care that care givers are delivering now is higher than it used to be.

**Figure 17 Level of care provided**



For 17 care givers (24% of respondents to the question) the level of care they are now delivering was about the same as it had been before and 2 people were providing less care (they gave no details).

However, 19 care givers (26% of respondents) said they now provided more care and 11 explained some details. In general, the need for more care was due to the deterioration in the condition of the people they looked after. Comments included:

> *"My father has a lot more falls and more hospital appointments."*
>
> *"I need to provide more practical and emotional support as the person I care for is largely housebound."*
>
> *"Deterioration in wife's physical ability to do day to day tasks."*

> *"Because of Covid I have had to shield them plus do more tasks as nobody else to help me."*
>
> *"My son is on the road to recovery but my parents illnesses has declined considerably over the last 18 months which means providing more care. husband memory understanding has changed."*

Thirty-five care givers (47% of respondents) said they now had to provide significantly more care. Eighteen of these care givers explained further. Essentially these respondents were also looking after people whose health or condition had deteriorated and is a testament to the level of care some of them provide.

Their comments reflect the care they provide personally, although it is clear from this question and others that some recipients of care also have some social care support in place (as well as clinical care, or course).

> *"Sibling with alcoholism is now chronically ill. Both parents ill health has deteriorated significantly including incurable cancer, heart problems and memory problems. Plus Aunt diagnosed with Alzheimer's."*
>
> *"My mum developed vascular dementia, her mobility decreased and she kept collapsing almost daily. She needed 24 hour supervision and care. I was there all the time. I had to get up 2/3 times in the night."*
>
> *"As condition progressed - mobility issues, medicine, full hoist transfer and assist required - continued deterioration now requires feeding, full personal care."*

In some cases the need for extra care was exacerbated by lack of services or closures during the lockdown.

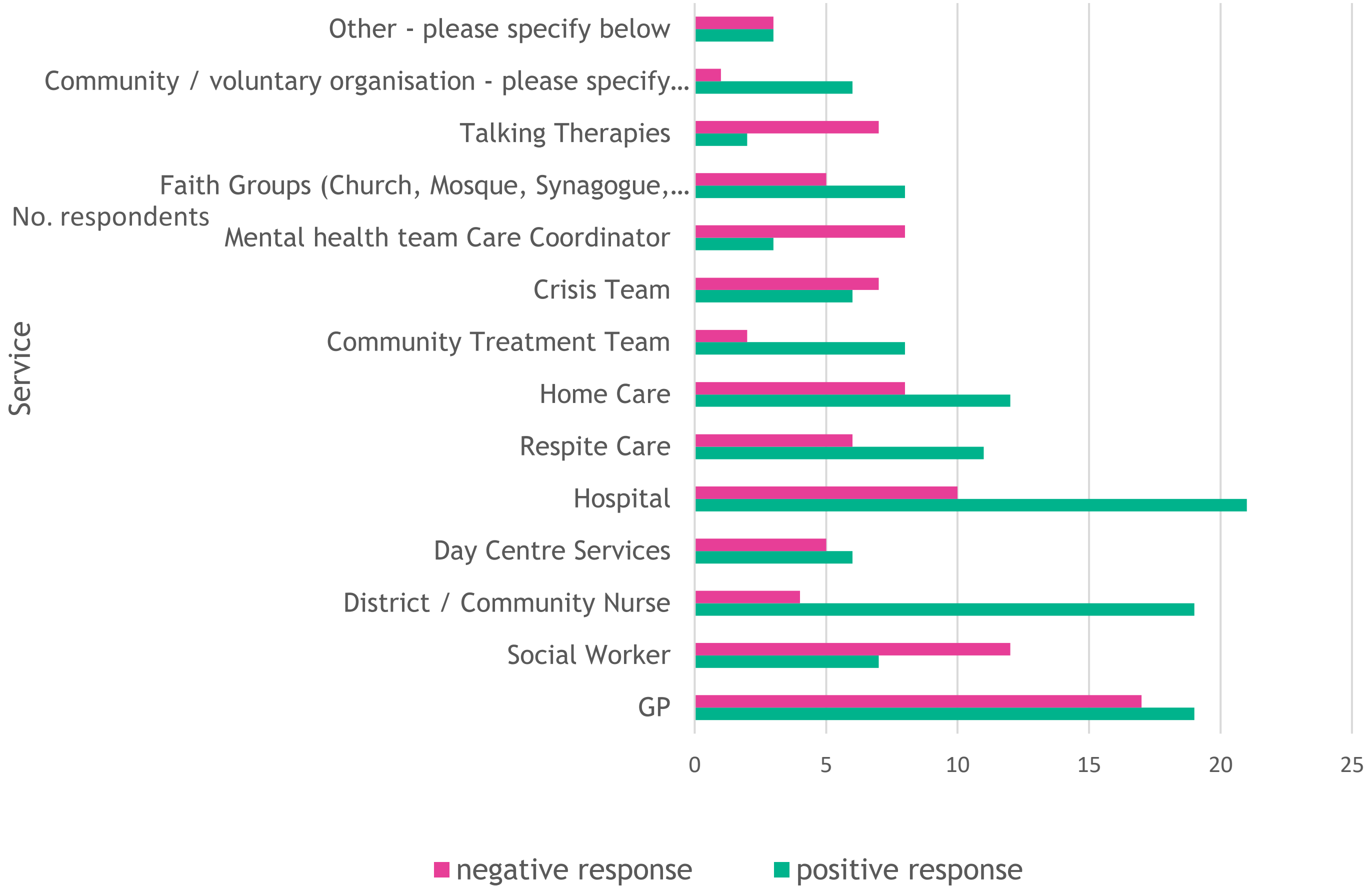
> *"Day support drastically reduced."*
>
> *"During the pandemic, all care services stopped, started again, stopped. During long spells our son was at home all day. Our overnight respite service stopped around start of pandemic, it has only just resumed in August 2022."*

## 3.2 Support services

We asked care givers if they had accessed any of the support services available during the Covid pandemic, and if they had, what they had thought of them.

We analysed the data for where services had been good or excellent (positive responses) to see if there was any specific good practice to recommend, and what had been poor or very poor (negative responses) to look at where improvements could be possible.  Most comments made were about the overall issues with care, and not necessarily about an individual service.

**Figure 18 Support services accessed**



Not surprisingly, the services contacted most often had been medical services – GPs, community nursing and hospitals.  In total, there were 121 positive and negative responses for these services, and in all cases there were more positive responses than negative.

The only comment left about any of them was a comment from one respondent that the GP had been unaware of a diagnosis. This may have been due to the diagnosis having been made by another service and not yet sent to the GP.

Social services (social workers, Day Care Centres, respite care and home care services) had been accessed by about 30 people each. There was general positive feedback for respite care and home care (64% of users). One respondent commented that

> *"We didn't access any support except carers that we employ via a direct payment."*

Day care centres were mentioned by 24 people and their opinions were evenly split between positive and negative feedback.

For social workers, the picture was slightly different. Feedback was positive in 7 cases, but negative in 12 instances.

One respondent, at the end of her tether, had gone to a charity to seek support for a couple of hours a week so she could take a break.

The charity *'got the ball rolling'* and the Council involved, but she felt the council '*were totally rubbish'* as they would '*not visit to do an assessment, but did it over the phone*'. The respondent said she *'eventually got an hour a day m-fri and 2hour respite on a Monday*'. She also got a direct payment, but did not feel it was explained to her, and '*(it) turns out I now owe the council £1500 even though I provided 23 hours of care every day and even gave my job up to look after mum*. As a consequence, since she had *'no income, I had to cash in a pension to live on'*.
Other respondents said

> *"I've found out since that if mum had been diagnosed with cancer earlier when she started collapsing she would have got all the care and nursing for nothing."*

> *"I even did it when she needed 100% nursing care along with the carer as there were not enough staff available and they said the alternative was to go into hospital or a nursing home."*

> *"There were no services offered to us."*

> *"The council were to modify her home but changed their mind and installed a chair seat that she only used for 2 weeks then she fell."*

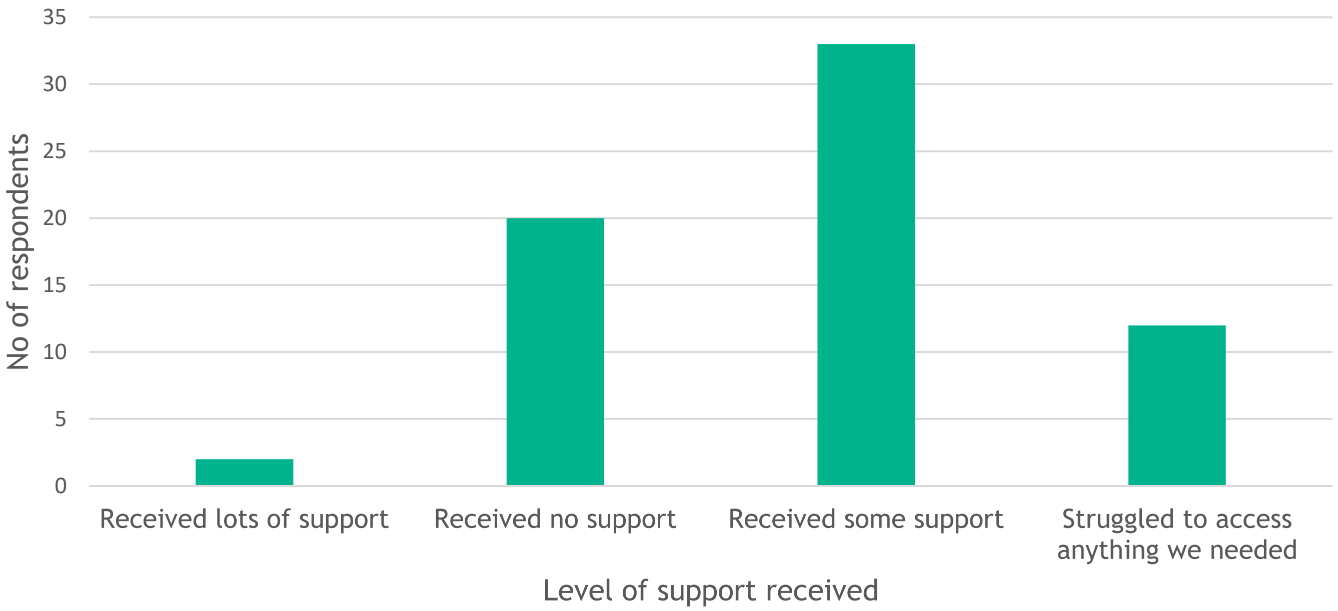
> *"Previous social worker was poor & clearly didn't understand her role. Our new one (name given) is fantastic & has helped to secure continuing case funding for (the person we care for), which is making a huge difference in terms of care support."*

We also asked people if they felt they had been able to access the level of support they had needed.

Opinions here were mixed.  Just 2 people felt they had been able to access a lot of support, and 33 people (49% of those who answered the question) felt they had received some support.

However, 12 people felt they had struggled to access anything they needed and 20 said they had had no support at all.

**Figure 19  Level of support**



One person said that no support had been offered, but it's not clear if any had been sought.

The biggest number of comments was about the shortage of care workers

> *"Got a few month of support from a member of staff from a care agency however it was only 3 mornings a week, and a few hours on an evening but still had to support staff as they only had one member of staff available."*
>
> *"Lots of family and friends helped to look after her and even had to buy sanitary equipment and disposal sanitary products. We had to ring around all departments as they didn't seem to talk to each other."*
>
> *"6 hours a week from carer's trust. No other support as people not allowed in your home. No supporting independence service due to self-isolation being required."*
>
> *"Over 2 years when we had no access to respite provision."*
>
> *"Carers Trust started during the pandemic, but really struggled to get a placement for children in school. Was badly needed for their needs."*

Negative comments about clinical services were also made

> *"My daughter was at her worst, her 'mask' slipped, mental health issues - nobody would listen. Wanted to be referred for ASC/ADHD diagnosis, one doctor (GP) said 'You make eye contact, you are not autistic."*

## 3.3 What support was most helpful?

We asked respondents what support they had found most helpful. Twenty six people gave us some feedback.

Nine people mentioned 'carers' , but without specifying which organisation they were talking about. The respite that extra carer time provided was very much welcomed. Some of the most valued support was simple, like help with shopping, meal deliveries and services reopening.

The morale boost of door-step singing support & phone support was valued by one respondent.

Clinical services were also mentioned by one respondent - *'when we actually got an appointment*', but this respondent felt that '*only scheduled for one appointment a year which is not enough'*.

Voluntary organisations were valued too.  The Bensham Memory Hub, the Stroke association, and Grove House (a respite facility) were all mentioned.

And social services support was also mentioned positively – once in respect of child with special needs, and one person just said *Social worker helped*

## 3.4 Communication with the hospital

We know from other sources that there were issues with admissions to and discharges from hospital during the pandemic, and that communication with the hospitals had been an issue for some.

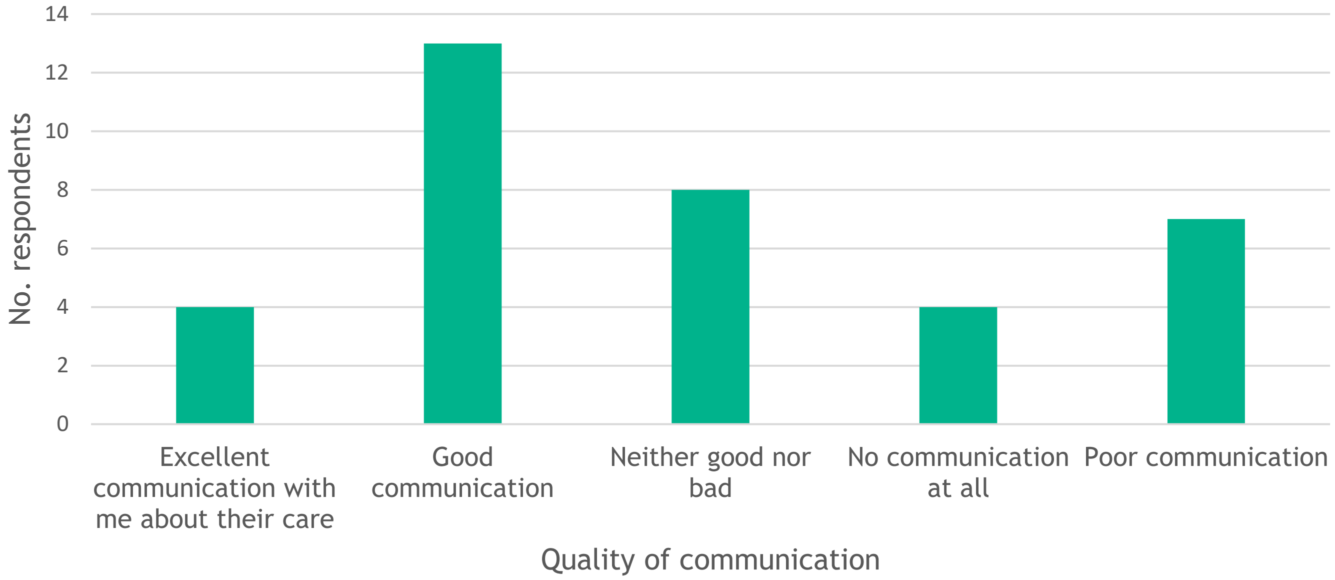
We asked care givers what their experience had been, if they had been involved with someone admitted to hospital.  We also asked them for any recommendations about improvements.

We did not ask which hospital comments related to, and respondents did not generally say.

Thirty six respondents gave us feedback.

Seventeen respondents (25% of the total) gave a positive response to this question, and eleven (16%) were negative.

**Figure 20 Communication from hospital**



The remaining 8 respondents had said communication had been neither good nor bad, but also left comments suggesting they had in fact had problems and these were their recommendations for improvements:

> *"Hand over from ambulance to A&E."*
>
> *"Someone needs to be appointed to communicate and bringing persons together."*
>
> *"I always had to do the chasing for information. When you were only allowed to book a 1 hour slot, they knew you were going to be here, someone should have been there to discuss things."*

Examples of good communications included being able to be with loved ones

> *"She was struggling to breathe and died a few hours later due to Covid and the hospital rang to inform us and let us go be with her."*
>
> *"Being able to visit hospital especially when the relative concerned had memory and hearing problems."*
>
> *"Nurses and consultants were specialists on their field and they seemed to know exactly what would concern me and addressed any apprehension I had straight away."*

> *"They rang to inform us everything was ok and went well."*

There were also some qualified comments, although reported as good communication.

> *"Some staff excellent at dealing with my child. Others clueless."*
>
> *"Waiting (for) surgery & communication has been poor, but that's because it's utter chaos so we understand why."*

On the other side of the question, negative comments included

> *"The whole episode could if been better with a little empathy and care for the person and communication with family."*
>
> *"No time frame, no update."*
>
> *"Giving a list of medication and when to take it.  However my mother had a fall and it was 2 weeks later the community nurse notified me she had fractured ribs, the hospital did not tell me this and my mother suffered with the fractures without my knowledge."*
>
> *"The (name given) hospital mam stayed with a fractured arm were awful. Terrible staff.  Left mam waiting to use commode.  Awful doctor.  Saying she was stone deaf."*

One respondent who said there had been 'no communication at all' told us

> *"I stayed with mum in the hospital all day for 2weeks. because she had communication issues they allowed me in.  I wore full PPE all the time.  I still can't believe they let me stay with her but I'm so glad as she would have died for sure in there as the care for elderly is terrible. It was verging on neglect."*

The majority of people did not have a big problem with communication, but the biggest single recommendation that comes out of the responses we had was

> *"To be kept informed."*

## 3.5 What has been most difficult?

We asked people to tell us what they had found most difficult over the last couple of years and 53 respondents shared their feelings.

These were necessarily all negative responses, and no one suggested a solution, though other suggestions have been made in this report.

Men said what had been most difficult for them had been.

> *"Trying to work full time and be a full-time carer."*
>
> *"Reduced social opportunities."*
>
> *"Requirement to isolate and inability to see family during lock-downs - loss of personal freedoms."*

Two men also mentioned issues with their own health.

The focus of what was found most difficult mentioned by women was slightly different, and, with larger numbers of care givers, covered more areas. Several respondents mentioned more than one of the issues detailed below.

There were three main stresses identified.

The first, also mentioned elsewhere in this report, was the deterioration in the health of the person they cared for (eight people) and their increasing care needs

> *"Had to give a lot more care, very stressful."*

and for the emotional impact it had.

> *"Watching my husband slowly deteriorating."*
>
> *"Watching someone you love decline - and the abuse you can sometimes get from that person when you are trying to help."*

For others, the single most difficult thing had been coping with their own health needs (seven people) and its impact on caring as well as any deterioration in the health of the people they care for.  This had also been isolating.

> *"Getting older and not able to be as active as I used to."*
>
> *"My physical health has got worse, husbands physical health worse, son's physical health worse as no physio."*
>
> *"The last year has been very difficult for my own health because ill for so long with Covid."*
>
> *"Trying to cope with so many health issues on my own and no support network."*

Eight people specifically identified isolation as the most difficult thing they had had to deal with.  This included being unable to see friends and family whilst shielding and feeling they had to cope alone.  Lack of information was also an issue for one of these respondents.

> *"I have been alone all through the pandemic."*
>
> *"The housebound people I looked after got phone calls but I never got any help as they relied on me."*

One person also reflected on the restrictions on any social activity.
There were several other issues mentioned by women, but each by only a few.
Four women mentioned feelings of being overwhelmed by their situation and 3 others also mentioned the relentlessness of providing 24/7 care.

> *"Being my mum's daughter, carer, nurse, social entertainer, chiropodist, hairdresser, therapist, translator, administrator etc."*
>
> *"Constant 24/7 Responsibility"*
>
> *"Caring for my mum 24 hours every day relentlessly.  but I always loved being with my mum so that kept me going. And I know I saved her from going into hospital or a home"*

> *“Feeling overwhelmed and the feeling of helplessness”*
>
> *“Trying not to snap and be abrupt with my son due to my pain and fatigue especially carrying out care tasks”*

One woman commented

> *“Lack of understanding from family/society about how hard it is to be a carer & not enough practical support (though this has improved with continuing care funding)”*

Access to services and lack of help were issues here and have been raised throughout this survey too.

> *“Accessing support services when needed ie GP, health advice, medication information, etc.”*
>
> *“Generally accessing services, getting support. Self referral - excessive information request.”*
>
> *“Services being closed/ limited. No saliva tests available which has meant my son being constantly refused access to things. (he won't do a pcr) feeling totally forgotten.”*
>
> *“No access to info about what is even available, never mind accessing what is available”*
>
> *“It’s the same day in and day out. the fights appear to get harder, services and provisions seem to want to provide less. I do feel severely disabled are to be not heard and not provided for”*

This comment about information was echoed by others who also found it difficult:

> *“Getting accurate advice”*
>
> *“No signposting to care organisations or peer support”*
>
> *“Getting all departments to talk to each other.”*

> *"Obtaining support and advice.  Left to get on with it with no support."*

## 3.6 Positive things from the pandemic

Having looked at so many problems, we asked care givers if there were any positives coming out of the pandemic for them.

Fifty people responded to this question and 29 of them (58%) simply said 'No' (3 men and 26 women), but offered no other comment.

Nineteen people cited a number of positives for themselves, some perhaps unexpected.

There were some comments about appreciating the good things in life like nature and one person said the positive thing for her was

> *"Re-focusing on the things that matter most - family, friends, living for the day."*

Five people were positive about being able to work from home,

> *"Working from home allows me to look after my mum.  I don't think she would have been able to live with me if I had to go into work so she may have had to go into a home"*
>
> *"Working from home is more acceptable now, which really helps. We need one of us at home realistically in case our daughter needs collecting from school."*

and a further two were keen on the benefits of hybrid working.

> *"Hybrid working is helping me to support my parents and son as they live close and the support from my line manager and employer"*

Four people commented on the value of family and how much they had enjoyed that closeness.

> *"So glad I was with my mum all the way through.  We actually had some lovely times.  I have so many happy memories."*

> *"We spent time as a family which is priceless"*

People coped differently with new digital ways of accessing health care, but two respondents were definitely in favour. One man liked the increased promotion of digital means in health settings and one woman commented

> *"We love telephone appointments. I hope they continue, especially with fuel and parking costs being introduced for blue badge holders"*

One other woman commented simply

> *"My computer skills have increased."*

One respondent said

> *"Pandemic made no difference, actually easier because everyone else was in lockdown and I feel in lockdown for life as a carer"*

## 3.7 Concerns going forward

We asked care givers what concerned them most going forward, now we are learning to live with Covid.

The biggest group of comments were about Covid itself, another outbreak and more restrictions. Care givers were concerned about both catching the virus themselves and passing it on to the people they care for and what that could mean. For example:

> *"That I catch it and pass it to my mam"*

> *"The fear that everyone seems to think it's gone / it's ok whereas it would kill either of my parents should they catch it."*

> *"Now that people with the active disease can go out & about in the community and not wear a mask I worry about catching it / my parents catching it."*

> *"Catching covid and dying leaving no one to look after disabled daughter"*

> *"Worried that covid cases increase again and we have to go through lockdown."*

> *“Having to constantly isolate and services being closed”*

Some people were also concerned about long Covid, although no one said they were suffering from this now (one person cared for was cited as having long Covid). Again, it was seen through the lens of caring responsibilities.

Concerns were also raised about the impact of another major outbreak on access to services and the strain on the NHS.

> *“Access to healthcare when needed”*
>
> *“Impact on everything if lockdown happens again“*
>
> *“What the future holds with regards to NHS”*
>
> *“Things have changed for the worst e.g. care company stretched to the limit and GP is non-existent apart from phone call. District nurses stretched to the limit, mistakes are being made.”*
>
> *“Going to appointments, all at different times, no organised care”*

One person commented on the treatment of different patients

> *“Concerned about the attitude of the NHS towards disabled people after the DNRs placed on some during covid”*

Some respondents were worried in a more general sense about the unknown, but one respondent said.

> *“It's best to just take one day at a time + try not to worry about things that have not happened yet.”*

## 3.8 What helped you and might help others?

We asked care givers if there had been anything during lockdown that they felt had helped them and might help others in future. Twenty two people shared their thoughts.

One family live streamed their favourite bands during the lockdown

> *"This was a great thing that helped us feel less isolated"*

People really appreciated being able to do things again after lockdown when social activities were possible again, but some had taken the opportunity to pick up new skills like painting.

> *"Equal Arts phone support and weekly activities"*
>
> *"Have begun to access age concern lunch club once a week - a lifeline"*
>
> *"Hobbies, exercises, phone calls from family, walks"*
>
> *"I started to cook scones and cakes and apple crumbles and give them to my neighbours."*

Using technology worked well for some people in health care.

> *"Continue the telephone appointments pls"*
>
> *"The telephone appointments I shared with a therapist help me cope with my anxiety issues."*

Or via Zoom or Teams to keep up with friends

> *"Using Zoom, Teams"*
>
> *"Doing online Teams catchups every week with friends"*
>
> *"Linking with family and friends more often"*

One respondent also said she was able to access online shopping, but it wasn't clear if this was something new for her.

There were mentions for two charities by name too – the Stroke Association and Crossroads for the care they provide but,

> *"They also give some information about how all the services link together, who does what and what you should try and claim"*

## 3.9 Improvements for the future

As our final question, we asked respondents how they felt support services for care givers could be improved.

Thirty five people (4 men and 31 women) offered suggestions which we grouped into themes.

**Table 3 Improvements for the future**

| Issue | Respondents |
|---|---|
| Capacity issues, including: | 18 |
| Carers assessments | 1 |
| Co-ordination | 1 |
| More money | 1 |
| More staff | 1 |
| More carers | 5 |
| More service (different areas) | 8 |
| Being informed | 6 |
| Being listened to | 7 |
| Needing funding | 3 |

One comment suggested that carer assessments are not actually taking place in Gateshead

> *"Gateshead need to conduct carer assessments"*

Another suggestion was there should be more co-ordination of services. This has also been mentioned in other sections.

> *"Coordinated approach to care requirements"*

Five comments related to the availability of carers/help

> *"More care available"*

> *"More in-home support and understanding - I worked from home.  I believe domiciliary care saw that as I was available to provide personal care if care staff issues arose."*

> *"In the future carers need to have better service during pandemics, or even on a weekly basis. The lack of carers to your home isn't good, insufficient carers"*

Nine comments related to different services and all related to the need for more service provision.  This included

- home based support (frequency of visits), respite
- creative activities
- emotional support (for care givers) during difficult times, not just in a crisis
- time out
- dementia cafés or similar
- mental and physical health care

Two other suggestions in this area included

> *"Getting longer appointments with GPs, so all issues can be discussed holistically."*

> *"Support services need to be able to offer more face to face time"*

In terms of getting a good service, people wanted to be better informed.  One suggested information should be visible

> *"GP surgeries, hospitals, libraries, social media.  We need to swamp Gateshead with information to ensure everyone knows where to turn if/when it happens to them"*

Two people specifically wanted to be better informed of the options available, how to access support rather than care,  and for it to be made easier.

> *"Pathway through GP more information needed"*

> *"Provide information for carers, signposting for parents/carers"*

Accessible information was requested by one respondent, asking for services working together and joined up.

> *"Give clear information and not use management terminology. Tell you the best way to care, support and claim benefits instead of only giving snippets of advice. Show they actually care and not just want to fill out their forms."*

Seven people wanted to be listened to and have their actual issues understood and addressed, including responsibilities for caring in amongst others.

> *"Not having to fight when they do not believe you."*

> *"Ask what people actually need. Rather than a carer, it might be help cleaning the house. Would be cheaper to provide also."*

> *"Have an understanding of how hard our role is. Our care agency took experienced staff out and put untrained staff in who couldn't peg feed! Despite us/carers raising it, they did nothing, so I had to arrange the training with the community nurses myself for my employed carers - shocking!"*

> *"I need people to hear that I am finding it extremely difficult to cope with caring on my own as it's not just about the cared-for person being able to get upstairs, get washed, dressed, etc. It's about taking medication, memory, communication, anger management and better mobility and not being isolated."*

> *"It would be great if you could reach out to persons that are often forgotten. The ones with loved ones that cannot access typical sessions/breaks."*

> *"Listen. Crisis team should have got wife into hospital sooner. As psychiatrist has done the past 30 years."*

Two care givers wanted quality improvements, and similar comments have been made elsewhere in this report.

> *"If they stopped making mistakes for caregivers to have to pick up the pieces then there would be a lot of support. Care company's to take on more responsibilities"*

> *"To put it bluntly Local Authority need to get their act together big time, they are an absolute disgrace!!"*

Three people put in pleas for more resources

> *"Automatically send out PPE to household they know require pa or carer support so that there isn't a break in provision due to lack of equipment*
> *Help with transport and activity costs"*

> *"Increase in Carers Allowance.  Provide clubs for young disabled people, they can access on an evening or a weekend e.g. ages 20-40."*

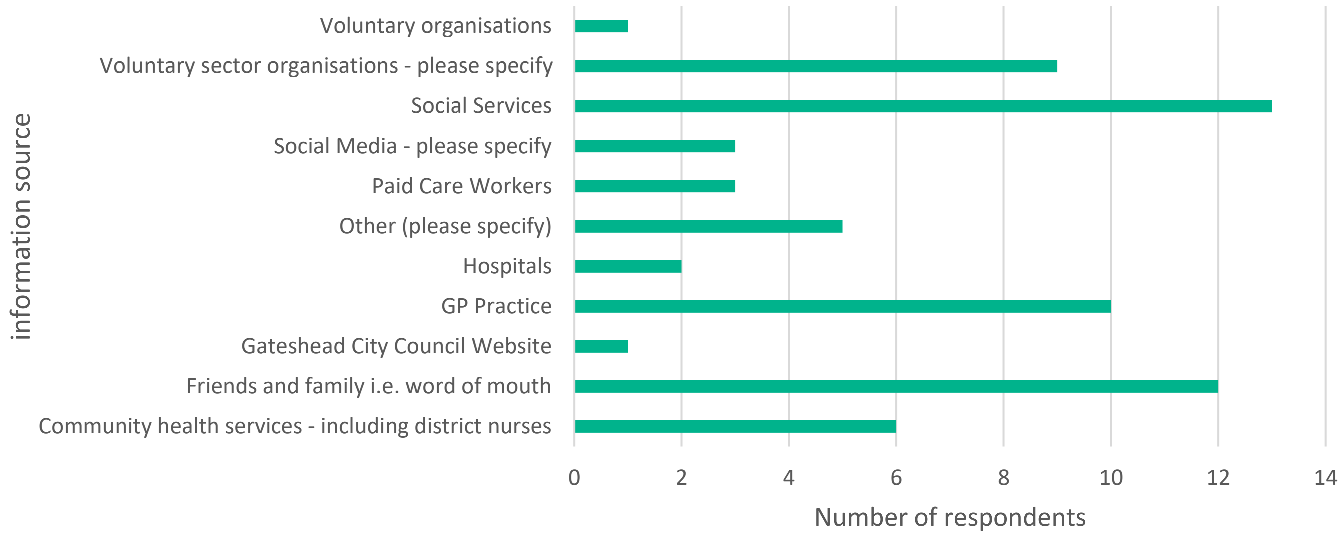
# 4. Information sources

Throughout the pandemic and since, there has been concern about how people can access accurate information. People also have diverse opinions on what is a reputable source for information.

To explore this, we asked the care givers where they get their information from, based on a list of suggestions, but also offering space for other suggestions and comments. We were well aware that people get information from a variety of sources, but we were interested in their most favoured source and how reliable it might be. Few people go to only one source of course, and some respondents ticked most or all of the options offered, so no main source could be identified.

We received 65 responses to this question from 57 women and 8 men.

**Figure 21 Source of information**



The most frequently mentioned source of information overall was social services (13 respondents, 20% of the total), followed by word of mouth (i.e. from friends and family – 12 respondents).

One respondent told us

> *"I rang Gateshead Council adult social care and they have responded to every enquiry."*

But, she added

> *"I have also heard about other aspects e.g. benefits through friends and family"*

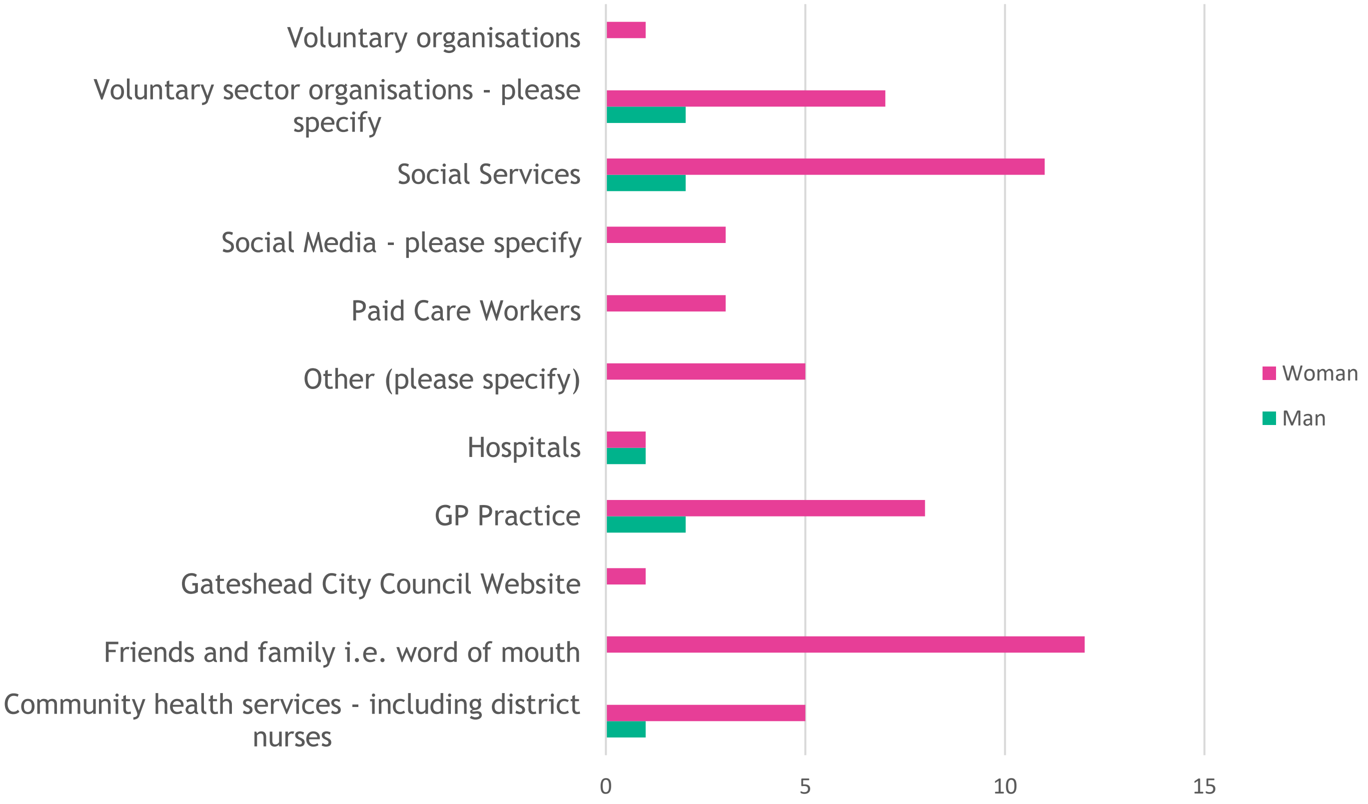
And one other woman told us

> *"Also just find out things by accident from other people"*

This in fact reflects the different approaches by men and women. Although the sample numbers are small, men tended to prefer 'official' sources such as social services, GPs, hospitals, community services and voluntary sector organisations. Men did not mention friends and family, social media or paid care workers for information.

Women by contrast, although they liked the 'official' channels, also liked to use softer sources such friends and family (21% of women), care workers who came to the home, and three mentioned social media (one specified Facebook). Between them, women accessed more of the suggested sources of information, but with an apparent bias to the sources men did not use.

**Figure 22 Choice of information source**



One commented

> *“Carers talk to the people they visit instead of going on the phone all the time”*
>
> *“Care worker phones regularly”*

Compared to another who commented

> *“My GP could be more helpful”*

This use of unofficial sources and hearsay has been a concern because of the amount of mis and disinformation that circulates in the public domain and has been seen to undermine the arguments and public health messages based on research.

Those who chose ‘other’ as their option did not specify, but in comments Google and the Internet were mentioned.

The ten respondents who mentioned voluntary organisations did not generally specify which, but included in the comments were Gateshead carers, and one respondent said

> *“I was previously involved with caring for my father who has Alzheimer's and the Alzheimer's society website provided a lot of information which is now relevant to looking after my mother.“*

Only one man and one woman mentioned hospitals as a source of information, but made no comment. It is not clear if this means they used a hospital website or would have called.

Gateshead Council website was only mentioned by one man.

These two results may suggest that people are not aware of the resources available, or in the case of the council may use a part of the council site with a different name.

Four of the suggested sources of information were not chosen on the table by any of the respondents including social prescribing services, libraries and community centres, Our Gateshead, and the North East Commissioning Service (NECS). However one respondent went on to list everything as a source in the comments.

Some people found information hard to come by at all

> *“Extremely difficult to access information.  When I contact any of these services I'm told there are waiting lists or we don't qualify or there is no support available.”*

Three respondents mentioned an information source not on the list.  These were the Memory Hub, her church and the Care Quality Commission but no explanations were given.

Two respondents told us they worked in a charity or social care so got their information via work.

# 5. Comments and recommendations

Comments have been added in the body of this report under each of the individual questions.  The main findings here are in line with those described in *Carer Facts – why investing in carers matters* [2]

## 5.1 Dealing with care givers' needs.

We have no information about how many unpaid care givers there are in Gateshead Council area, nor how many of them are known to the council.  Depending on the data the council holds, it may be helpful to make sure they know about as many care givers as possible, and not just those in receipt of paid social care services.

Many of our respondents have their own care needs, and not all of those seem to be met at the moment.

Few of the care givers who responded to this questionnaire had had a care givers assessment and the majority didn't know about them.  One respondent seemed to suggest that they were not currently available under Gateshead Council.  Since early 2020 they have been provided for the Council by Gateshead Carers Association, although the Council website says to contact Adult Social Care Direct via a link.  This may be discouraging some possible applicants if they are not currently receiving social care support.

Given the number of care givers in this sample over the age of 75, and the likely number of actual care givers across Gateshead, the carer's assessment could be a boon to those in need of support, and seems particularly pertinent here.

Even if care givers are deemed not eligible for support under this scheme, it would allow the council to better understand the needs of these people and signpost them to support they can access, or to inform future decisions about resources and support services.

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[2] NHS commissioning » Carer Facts – why investing in carers matters (england.nhs.uk)

## 5.2 Impact of Covid on care givers

It is clear from the data presented here that for some the impact of Covid on their caring responsibilities has been significant, and it was mostly negative. This was particularly obvious with respect to emotional and physical impact.

Issues raised included

- lack of (paid/domiciliary) carer support – it was not clear if this related to those who have already been assessed as eligible, or included those who had not been assessed.
- the care givers themselves being overstretched as they try to cope, and indeed the things they have had to give up to look after their dependents
- service provision, and complaints of poor practice. This includes complaints about professional competence as well as attitude by some
- having to chase down services for themselves when they might have expected professional staff who know and understand better to provide some help
- several respondents have had to give up work because of caring responsibilities, thereby also dealing with a reduction in income as well as in other areas of freedom.

These are not all easy areas to resolve, especially around resources and capacity, but there is scope to revisit both assessing eligibility for support and services that would provide support, especially respite.

## 5.3 In bereavement

Care givers are always worried about the vulnerability of the people they care for, and losing friends and family during the pandemic must have been particularly stressful. There seems to have been little appreciation of services like bereavement counselling and people mostly coped alone or with the help of friends.

Where social workers are involved with a family, it may be helpful for them to promote such services as are available in Gateshead or the wider area to families who lose someone, whether it is the person they care for or someone else they know.

## 5.4 Coping with caring

Multiple reports enumerate the value of unpaid care givers to a local care economy as well as the loving care they provide to the people they look after.  As such they should be supported as a crucial part of local care for the vulnerable.

This report suggested that almost the same number of care givers said they were coping and/or managing as those who said they were not, but both need to be feel supported to help them do the job they do.

There are a variety of support services available in Gateshead and promoting them widely in accessible formats (not just online sources) is particularly important to those who are not coping.  The benefits of support are likely to ease the emotional burden of caring in particular, and being part of a care givers community offers support of itself. Loneliness born of isolation was a problem for nearly half of our respondents and a useful focus for looking at new ways to help care givers and maintain their health and wellbeing.

## 5.5 Care recipients needs

Many of the care givers who responded to this questionnaire were caring for people who individually had complex and multifactorial needs, as well as coping with more than one person.  Few described being a ‘sandwich carer’ (i.e. looking after both a person older than themselves and a person younger), but the sheer quantity of diagnoses across the people cared for is striking when set out like this.

This diversity makes it less easy to formulate particular recommendations beyond those already raised above. It highlights the depth and diversity of support needed by care givers and may offer scope for working with charities dealing with specific health needs (the Alzheimer’s Society was mentioned, for example) as well as more general ones.  Where there are local support groups for individual diagnoses, these can be recommended and promoted to care givers whose needs match.

## 5.6 Care givers main problems

The comments we received about the main problems faced by care givers in Gateshead are listed in Appendix A.

It is clear from the data that some care givers are known to social services and receive social support, but it appears some are not. Carers assessments are not common for these respondents though it may bring them some support if done.

Care givers may also be eligible for a carers allowance. We did not ask about this (or any other financial issues), but it may be a relief to anyone eligible but not claiming it. They can also register as a care giver with their GP so that the practice is aware and will take that into account when seeing the care giver.

All of these possible benefits should be promoted to all care givers, and the council is in a prime position to do so both through social workers, care workers and online and paper media.

Complaints about care workers and their unreliability or attitude (or those of the company which employs them) are something the council should follow up to avoid harm to both the person for whom the care worker has been commissioned and the care giver trying to deal with any perceived deficiencies.

Some similar complaints were also made about GP services during and after the pandemic, and this is now compounded by general shortages of staff in GP practices.

## 5.7 Shielding

Whilst shielding may have been for the sake of one person in the household, the restrictions it imposed will have affected everyone.

For some, the concerns that triggered shielding have not gone away, even though the recommendation to shield has been withdrawn. This feeling of insecurity can impose ongoing tensions for households. How to reassure both the vulnerable and their care givers is difficult, given that our data show women in particular get information and advice from non official sources for preference.

Reassurance for those still concerned, and allowing care givers to return to a fuller life will take time.

For some, there was concern about a lack of information and poor communication or co-ordination. In part this could be because so much advice and information was available only online, and that is not accessible to everyone. The need to manage effective communication with those who are not online is an ongoing issue in health and social care, especially in areas of deprivation.

Some services may have metrics informing how well their online communications work and can make adjustments based on that.

## 5.8 Changing care needs

Our respondents told us that the amount or level of care they now provided had increased due to the deterioration of the health of the people they care for, in some cases exacerbated by deterioration in their own health over time.

Alongside this, there was a perceived reduction in service provision/support, in particular social work and paid carers. Again, the shortage of care workers is an endemic problem unlikely to be better in the short term.

## 5.9 Communications with the hospital

We did not ask care givers to identify which hospital they had dealt with when answering this question. We would expect their answers to apply mainly to the two local hospitals Queen Elizabeth Gateshead (Gateshead Health NHS Foundation Trust) and the Royal Victoria Infirmary (Newcastle Hospitals NHS Foundation Trust).

More people were satisfied than not, and negative comments focussed on lack of internal communication and sharing information. This will be fed back to the two Trusts.

## 5.10 Most difficult issues

Some of this has been discussed above, but one of the striking issues raised in comments was about the relentlessness of caring and feeling overwhelmed, especially where care givers did not see support. This included feeling isolated and fewer opportunities for social contact.

Several respondents mentioned the isolation of being a care giver, and whilst family and friends may be supportive in general, the lack of services which might provide some respite or personal space for the care givers was often missing. This was mitigated a little as services reopened after the Covid lockdown, but some services have gone completely and some seem to be balancing reduced capacity with increased demand.

Rising demand for services as people become less well, and reducing capacity of services to meet that demand, is a constant theme. The solution of increasing provision is simplistic and not necessarily realistic. However, looking closely at the services available to care givers in Gateshead across both statutory and charitable sectors together, and identifying gaps, to ensure best access for the greatest number would be helpful.

## 5.11 Positive outcomes from the pandemic

The positives identified by care givers speaks to their resilience and may offer ideas for looking at future support themes.

What individual care givers found helped them through the pandemic times are also positives to build on. Some of this was the simple pleasure of contact with others, either online or face to face.

This is also an opportunity to promote the public health messages and support services accessible to all (not just assessed need), to make sure all care givers are aware of what is available and from whom and for whom. One respondent said that Crossroads was a shining example of explaining how services work and this may be a model to look at.

As always, despite the issues involved, any promotion needs to take account of those who don't use online communications as well as those who do.

## 5.12 Concerns going forward

Worries about another big Covid outbreak and its impact on individuals and services are very real. The only protection at the moment is vaccination and any continuation of masks, distancing and hand washing. Although it is not mandated any more, it remains good practice and can still be promoted as such, especially to those particularly vulnerable or worried.

Concerns about capacity within the health and care services are national issues, and local efforts in recruiting and retaining staff have to work within the national shortages of staff.  Where staff competence and attitude have been mentioned, there is scope to ensure that local staff are fully trained in all aspects of their work.

Concerns expressed in comments about the competence and attitude of care workers is something that should be explored with a view to contracts both placed by social services and employed by individuals via personal payments.  A register of validated providers to help care givers would be a useful tool, if it is not already in place.

As always, good accessible information is just good practice, and an essential part of reducing concerns and reassuring the public and the individual care giver.

Sources of information are the choice of the individual, and the validity of information on social media sites has long been a concern.  What is posted by others cannot be controlled, but making sure that all possible sources (online, social media, face to face, on paper) in local health and social care are used to the maximum by all service providers to promote understanding and good practice can help spread correct knowledge and information.  This is reassuring to those who access it, provided they trust the source.

Communication is a two-way street, and services and practitioners should listen to the care givers and the people they care for.  The Expert Patient programme proved that they are often experts in understanding the health and care needs of the person cared for, and their individual circumstances, and play a big part in the quality of a care package.

If care givers are treated as part of the care team for an individual it could reduce stress on all sides.

## 5.13 Improvements going forward

Suggestions for improvements to services and how they work are the flip side of the points made above and are exemplified in the comments throughout the data. They can be summarised as capacity, co-ordination, communication and competence.

There is local scope to look at each of these issues in more detail and implement local improvements on at least some of the aspects reported here. Other issues are national, and that will continue to impact local services for service users and care givers alike.

# Appendix A

*Support during holidays and half term breaks.*

*Road safety . Her not understanding her problem.*

*My husband has dementia - during covid was unable to go out. He isn't comfortable being in house all day*

*My mother suffers from Alzheimer's, depression and anxiety*

*Person I care for has lost confidence and can feel lonely.*

*Not able to take husband out without extra support. My arthritis has become worse recently but I still have to do all tasks and help husband*

*None of the people I care for will accept carers supporting them, which leaves the majority to me and my husband to sort out*

*No help, takes too long to sort help out*

*Needs hoisting/ changing places/ someone medically trained to look after my child due to health needs*

*My mam is hard of hearing and is unable to get bathed by herself*

*My husband's health condition significantly impacts on my day to day life, and my quality of life*

*Moving and handling, controlling her epilepsy, caring for three kids with very different needs (8,6 & 1) with no real family support.*

*Lack of help and support.*

*Husband had brain stem stroke and needs 24 hrs care*

*Hearing loss, cognitive impairment, mobility problems, sight impairment.*

*Struggling to cope on my own as no family and only 4 hours support from crossroads per week (Carer's Trust)*

*He can't stand up for long*

*Having enough time to carry out my caring responsibilities.*

*Have to do everything for him. Doubly incontinent*

*Getting the correct support and equipment in order to assist with my caring role, getting a proper break where I know my son is properly looked after and enjoying being where he is ( he has had one overnight stay in adult services respite) , but said he felt the staff didn't know how to do transfers properly didn't have a peer group and didn't sleep very well.*

*Getting extra help.*

*General care, full-time*
*General wellbeing - cooking, washing, bathing, organise activities, financial care - oversee everything. Healthcare - accompany him to all medical appointments, administer medication when prescribed. Supervision at all times - 24 hours.*
*Doing everything myself*
*Constantly need to be doing things*
*Finding accurate information about how to support the person I care for*
*Advice from health professionals  Erratic support, either excellent or non existent*
*Family - mobility problems, stubbornness, forgetfulness.*
*Friend - carers not complying with care plan, medication mistakes, their family getting nowhere with complaints.*
*Caring for 3 people over 2 households only managing to claim one carer's allowance is financially difficult.  Always doing something for someone else, list of jobs can be overwhelming. Never have time for myself.*
*Carers not turning up from domiciliary care - different carers - was less stressful not having them but as care needs increased could not cope own now.*
*Both children need full supervision at all times & help in every area of their life.*
*As I get older and my own health deteriorates I find it harder to do the physical tasks of both people.  All down to me plays a huge part in my mental and physical health deteriorating.*

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