

North Tyneside Health & Wellbeing Board - November 2021

North Tyneside Carers Survey 2021

Understanding the carers' experiences during the pandemic



North Tyneside
Carers' Centre

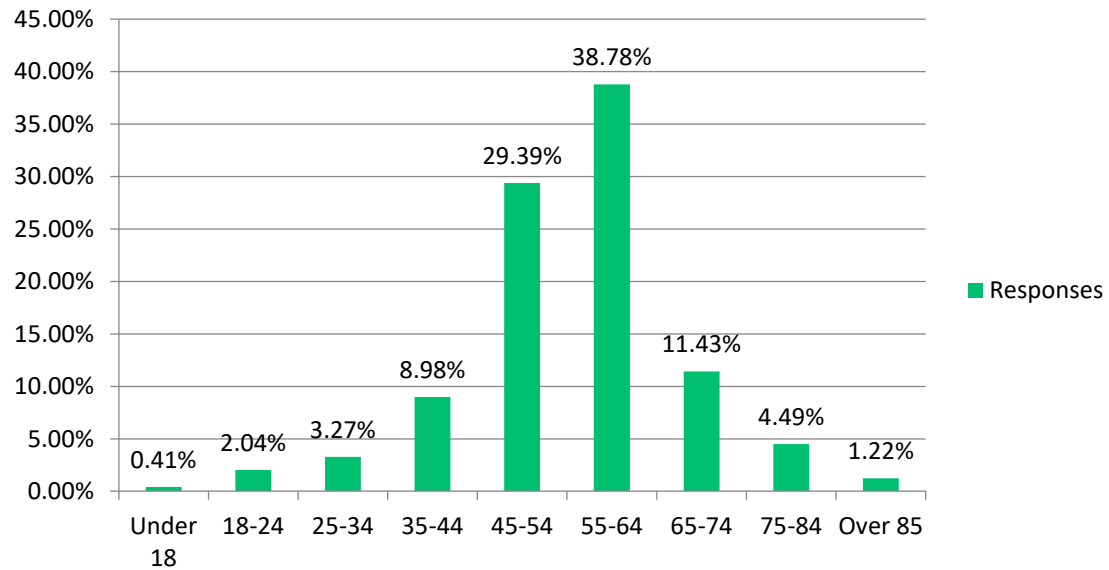
healthwatch
North Tyneside

Background

- This survey was undertaken by North Tyneside Career's Centre and Healthwatch North Tyneside on behalf of North Tyneside's Carers' Partnership Board
- It was an online only survey running between 17 May and 23 July – we are conscious that not everyone could have participated.
- We received 258 responses from residents who are unpaid carers. People did not answer every question so total responses don't always total 258.
- This is part of ongoing activity to ensure carer's voices are heard, one of the key priorities for the Carers' Partnership Board
- We have presented these findings to the Carers' Partnership Board, Future Care Board and other strategic board in North Tyneside.

Who we heard from

What is your age range?



Female - 79%

Male - 20%

Non binary – 0.5%

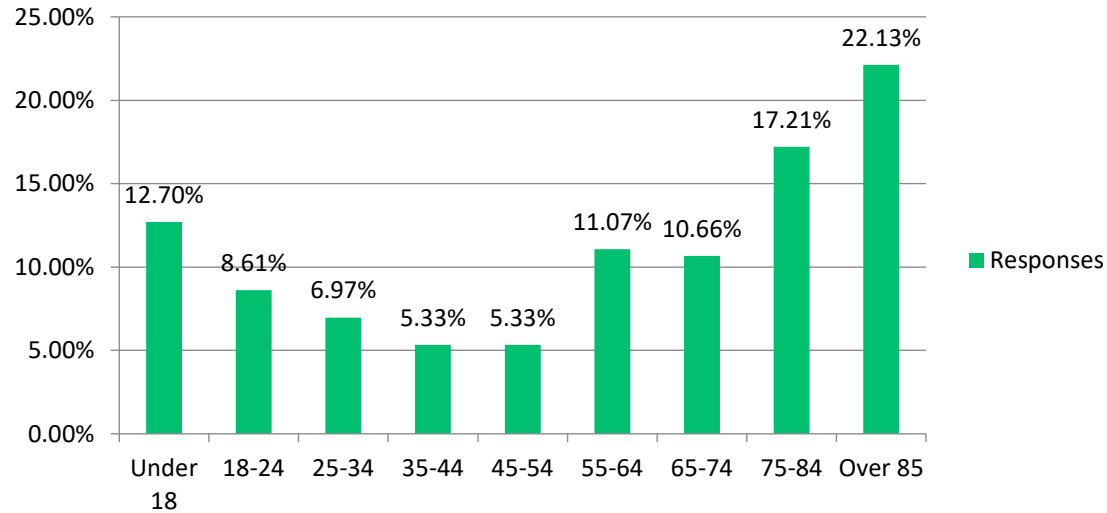
Other responses – 0.5%

How many people do you care for:

One	75.82%
Two	16.80%
Three	4.51%
More than three	2.87%

Who are you caring for?

What is the age range of the person you care for?

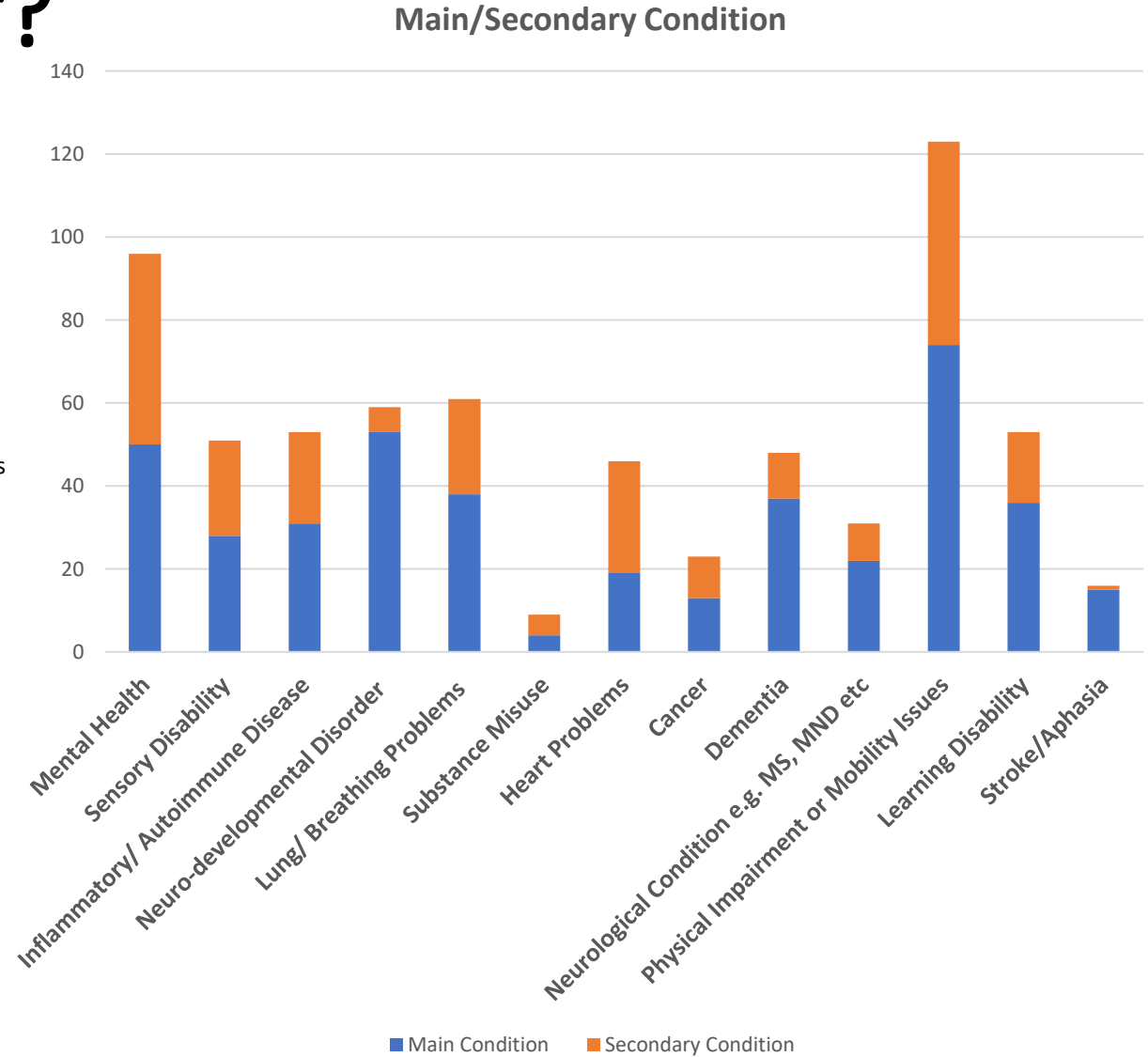


Shielding:

47% asked to shield

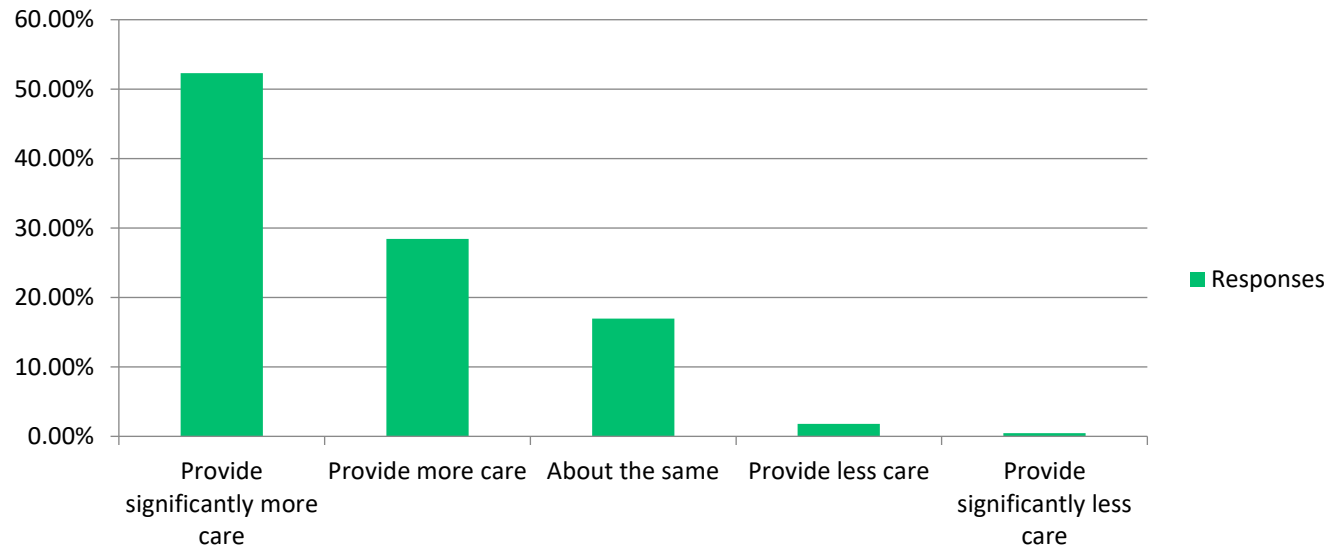
22% chose to shield themselves

31% were not shielding



Care during Covid

During the pandemic, how has the amount of care you provide changed?



114 carers advised they were providing significantly more care. 90 carers added a comment – key themes included:

- Services closed – 30%
- Shielding – 24%
- Deterioration in condition – 19%
- Covid isolation – 14%
- Services cancelled by carer due to fear of catching virus – 6%
- Other – 7%

Carer Quotes:

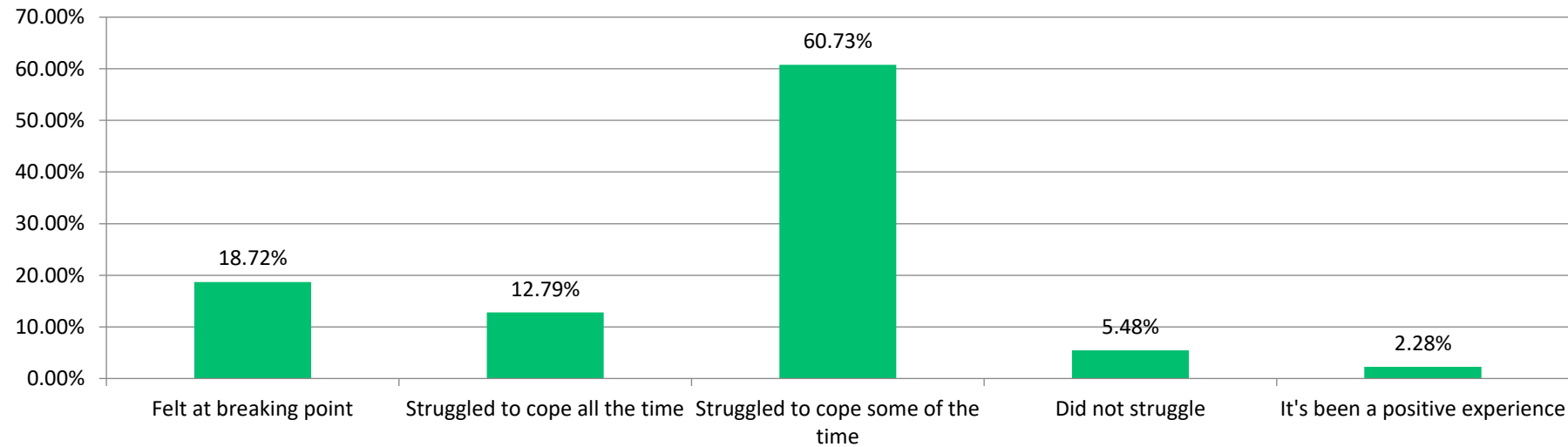
“Severe anxiety increased his vulnerability to self harm.... inability to sleep living in fear needed constant reassurance & supervision to maintain health at home.”

“Not able to see doctor, hospital check-ups cancelled and radiotherapy delayed for additional cancer to the inoperable cancer.”

“Because all support was stopped or significantly changed.”

Carers' experiences during Covid

Please select the statement which best describes how you have felt over the last 12 months

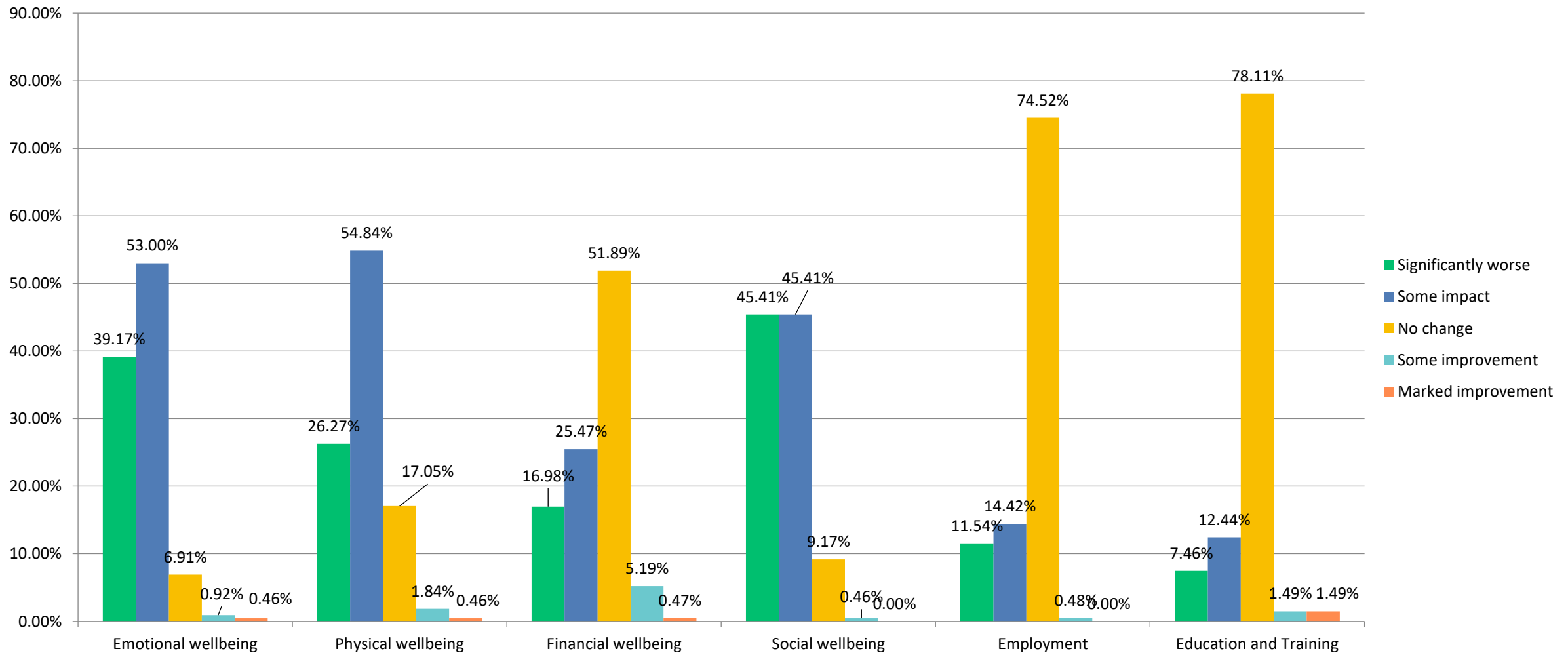


Quotes from carers

- *“Struggled to remain calm - pushed to my limit emotionally.”*
- *“Living under extreme constant stress has affected my mental and physical health.”*
- *“Pressure cooker situation.”*
- *“I wake up in the morning and think not again – but you have to get on and deal with it.”*
- *“System weakness have been magnified by the pandemic.”*

Impact of the pandemic

How has the pandemic impacted on you in the following areas?



Key issues

Loneliness and Isolation

- Limited informal or formal support networks or none
- Missing physical contact – a hug
- No life outside of caring – no time for self
- Being unable to do things that usually improve mental wellbeing e.g. spending quality time with family and friends, leisure activities

“Daycentre closed so I had no respite for 9 months.”

“Being alone caring for my mother whose needs have increased significantly. I have no life now. Cared for 8 years. I've missed out on precious years with our grandchildren that I cannot reclaim.”

“My son is a baby with significant developmental delay, cerebral palsy and hearing loss. I have been unable to be supported in appointments by my husband because of the one parent/carer rule..... It has been a very lonely time.”

Covid anxiety

- Anxious about bringing infection into the home – work, social care, health care, shopping and other services resulting in
 - Carer taking on more
 - Increased carer stress
 - Decline in condition of the person cared for
- Escalating behaviour of person cared for – lack of understanding, needing reassurance
- Confusing government guidance and uncertainty about the future.
- Worried about what will happen if carer is ill – not able to put an emergency plan in place

“My wife had an operation and caught covid in hospital. Fortunately she was not too ill but she gave it to me. I ended up in critical care, and nearly didn't survive. Making sure she had appropriate care while I was very ill and then recovering was a challenge.

“Severe anxiety increased his vulnerability to self harm, inability to sleep, living in fear needed constant reassurance & supervision to maintain health at home.”

Key issues

Juggling working and caring

- Balancing family and the person cared for alongside working from home
- Using annual leave to fill gaps - due to lack of support or services being closed
- Having to leave work due to significant deterioration in carers' wellbeing
- Worrying about returning to the office in the future

“Lack of support acknowledging unpaid carers role, having the extreme stress of choosing between work & leaving my son unacceptably vulnerable!. Trying to care & manage his needs while fearful of losing my job or making us homeless!!!”

“Disruption to schooling has resulted in having to leave full time employment to be full time carer.”

Money pressures

- Financial hardship due to giving up work
- Being furloughed and uncertainty about future employment.
- Coping with little money and higher bills

“Losing my job because of Covid 19 and struggling to make ends meet. They used the fact I wasn't flexible in the redundancy process to get rid of me, I am not flexible because I am a carer.”

Positives to come out of Covid

- Family time
- Wellbeing time - gardening, reading, cycling, mindfulness
- Working from home – less stress
- Sense of community spirit
- Access to the Carers Centre resources and support
- Vaccination
- More familiar with technology
- Time to reflect on what is important
- Asking for help

Lots of carers said there were NO POSITIVES

Experiences of services closing or changing

No let up - people said that closure of services resulted in them providing significantly more care.

Schools – parent carers highlighted their important role - *“Special school being open was a lifeline’*. At least 7 people said, *‘School was shut and although my son was entitled to go to school through SEND/EHCP they didn't have the staffing to offer a place.’*

Day centres and day services – the biggest miss appears to have been day services – lunch clubs, day centres etc as there was no replacement support when these services closed – adding pressure to carers and impacting on service users.

Community activities – people highlighted missing going to the pool, gym and fitness classes as well as other social activities.

Online activities – were highlighted by 6 people as being an important alternative during Covid.

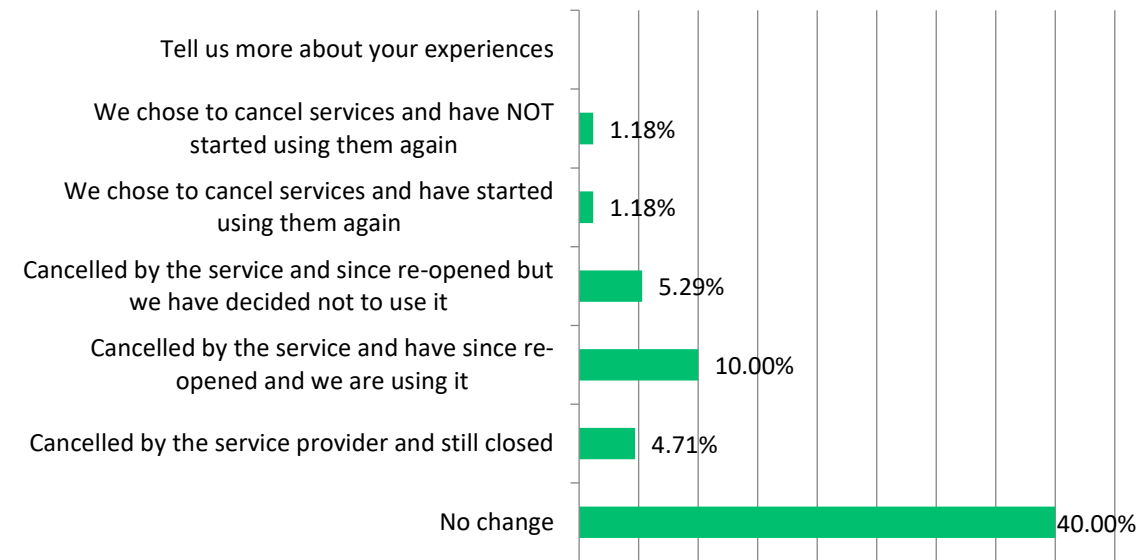
Gaps in support - people highlight that only emergency support was available during the pandemic and even then only when pushed for. Several people credit the Carers’ Centre and other VCS organisations with helping them get support when at crisis point.

Challenges of going back –difficulty in getting back into accessing services. – *“Extreme difficulty getting my son to leave house or accept support from services prior to pandemic. will be impossible now. going take long time to be assured safe.”*

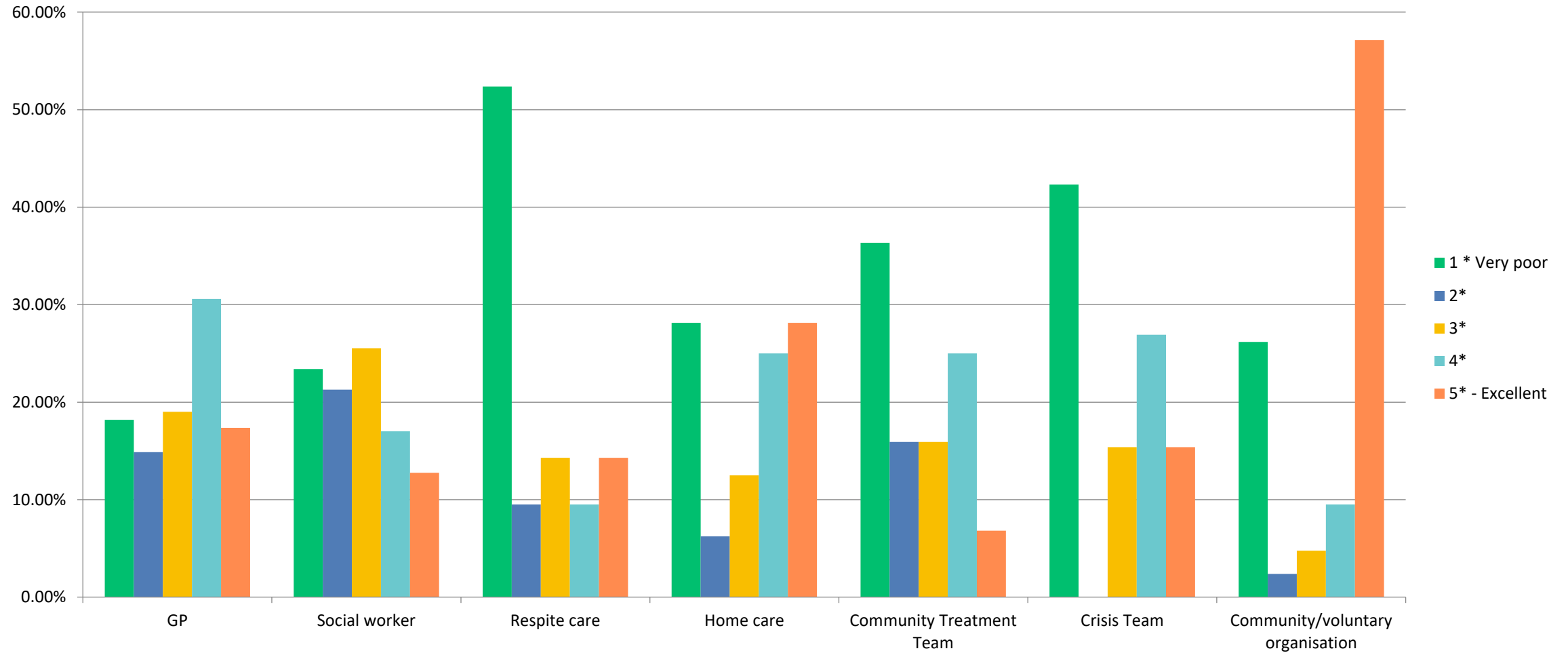
Fear of Covid - Some people told us that they cancelled services themselves due to the fear of brining in covid – *“cancelled any additional help due to risk of infection.”* Others said they didn’t ask for help because they wanted to manage the risk of infection or thought that *“We wouldn’t get help.”*

In Q19, 106 people answered and 64 left text responses. It’s clear that the respondents understood this question differently to the way we had intended and closure in services is mentioned widely in other parts of the survey.

Q19 - A lot of services were closed or reduced during the pandemic. What was your experience?



Rate the support you received



Accessing healthcare and treatment

Approx. 60% of the respondents mentioned that the condition of the person they cared for deteriorated during the pandemic, particularly around mental health, mobility, being unable to access support/services and progression of illness. A real mix of experiences emerge from the data

"It's just been me and my 100 year old Grandfather. GP's been good. District Nurse has been good to absolutely amazing. Paramedics/ambulance unutterably magnificent when needed. I don't really know what to say."

GPs - Some people have had very positive experiences with their GP *"Our GP was very good in arranging home visits as they were aware it was difficult to get to the surgery and always were prompt in communicating."* However, the common comments about healthcare were about needs not being met by GPs either because appointments were virtual or responding to need – *"Having to battle to get a GP to my husband."*

Mental health services and CAMHS - A lot of feedback about older people's mental health services, working age mental health (Community Treatment Team and Crisis Team) and CAMHS. Mainly negative due to difficulty in accessing support and decline in people's condition during lockdown.

Hospital services – were highlighted as being cancelled, delayed or difficult to get support– *"Community Physio services just abandoned him and RVI consultant hasn't spoken to him even over the phone for over a year (let alone seen him) about ongoing problems and although GP is trying to be helpful, this is not his area of expertise and he doesn't talk directly to the consultant so we get referred back and forth."*

Cancer - We heard from 23 people about cancer. There is limited details about cancer treatment specifically but the detailed comments were negative – *"I can't say we got any care for my wife at all not even from the hospital only at chemo she got care and that is once a month in the form of chemicals pumped into her and sent home with injections for me to give her, this is all the support we got."* and *"Husband has inoperable cancer, then in Feb 2021 diagnosed face cancer still waiting for radiotherapy and it is July - I have been waiting 6 months for physiotherapy."*

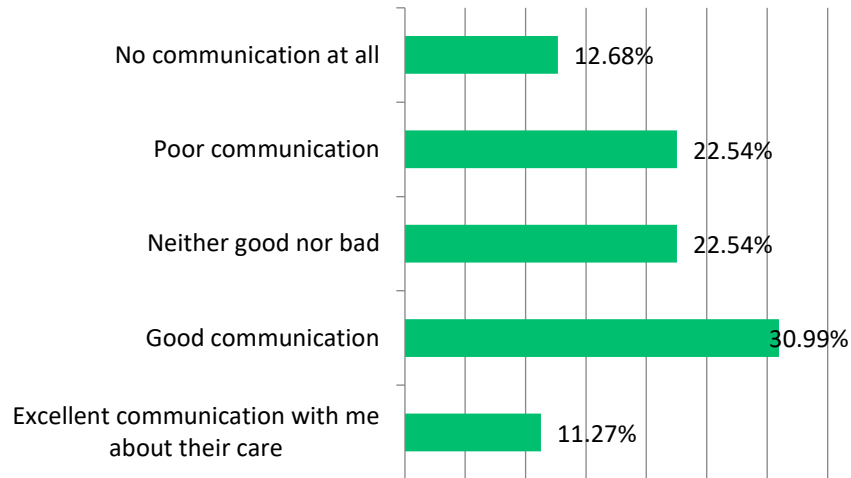
Also mentioned by more than 10 people:

- Podiatry –delays to treatment and waiting list
- Physio – delays or 'poor quality phone appointments – 2 went on to seek private treatment
- Dental – 8 people

Support – limits to visiting has put pressure on carers *"My son is a baby with significant developmental delay, cerebral palsy and hearing loss. I have been unable to be supported in appointments by my husband because of the one parent/carers rule. We have also been unable to be supported by friends and family (even though we could have a support bubble, our nearest close family are vulnerable and 3 hours away). It has been a very lonely time."*

If the person you care for was admitted to hospital during the pandemic, what best describes your experience

Hospital experiences during pandemic - what best describes your experience?



Contacting a hospital

Issues of phones not being answered/difficult to get through and talk to someone who knows what's happening were raised by 9 people *"Staff were unsupportive and didn't communicate. I had to call wards every day it was a battle to get through and when I did I got scant information."* Another said *"I know hospitals are busy, however, they need to understand that they also need to communicate better when the person being treated has a main carer. No matter what the condition. It made me feel guilty having to ring up to find out what was going on. Felt as though I was taking them away from their duties. But they need to communicate properly. If I was allowed to visit then I could have asked questions then."*

71 people answered and 46 left text responses. Key themes in the text:

Visiting/keeping in touch –people mentioned:

Frustration - of not being able to visit and grateful that someone could visit when the rules eventually changed

Use of technology – great for some *"Great hospital wards now have ipads for patients to liaise with their family"* but not others iPad/phone inappropriate for others – *"Ward relied on technology (screen time) between patient and family but couldn't seem to understand that for us it was useless as my husband is 100 and has dementia, and is also almost blind which they did not pick up on."*

Nominated career role – difficulty in choosing the person, pressure on 1 person to do everything for patient and support family *"I was able to stay with him in hospital till he died only 1 family member so it was me who had to pass on messages read letters and support him and the rest of my family before and after his death."*

Involving carers – not being there made some carers feel they were not involved in the care and decisions and that sometimes hospitals could have better communicated with them so they could feel and actually be involved. Particularly a concern where the patient had difficulties understanding or communicating.

Discharge – feeling some were sent home too early, partially in 1st lockdown. Also 7 carers said they were not involved in planning preparing for discharge leading to issues

Good experiences – *"Depending on individual staff members and who was on shift."*

"The first admission in March 2020 was terrible - patient went in alone and discharged very quickly when still unable to care for self - sent home freezing cold in ambulance with no support in place. Recent admission in May 2021 much improved, allowed to be with patient during assessment and admission but not allowed to visit after this."

What is happening with this feedback

- Key themes within the feedback are:
 - Information so that people can navigate services and/or help themselves
 - Access to services when people need them
 - A more coordinated approach so that holistic view of a carers' needs are understood
 - Pre-existing problems have magnified by the pandemic
 - Quality of service for the person they care for is critical
- High level results are being shared with service providers and commissioners through strategic boards.
- Detailed responses about particular service areas – eg mental health, are being shared with relevant teams.
- Triangulation with ADASS carers survey results – similar themes, our survey has much more local detail
- Updating the Carers Partnership Board action plan following the analysis of finding.
- Continued engagement with carers to gather views
- Additional funding for activity at the carers centre and around challenging behaviours and parent carers.
- New information for carers available through the Living Well North Tyneside platform
- A version of these slides will be published