

Caring in North Tyneside in 2022

Themes and issues Summary report



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Background



- This survey was undertaken by Healthwatch North Tyneside and North Tyneside Carers' Centre on behalf of North Tyneside's Carers Partnership Board.
- Online and paper survey running between 12 December 2022 and 8 February 2023. Promoted by Carers Partnership Board members.
- This survey was aimed at adult carers. We plan to hear from young carers again later this year.
- We received 681 responses from residents who are unpaid carers, three times as many than our previous survey during the pandemic in 2021.
- Where we can we have presented a comparison between our latest survey – Caring in North Tyneside in 2022 – and our 'caring during the pandemic' survey carried out in 2021.
- This report provides a summary of the responses we heard and includes a lot of quotes (in pink and blue) from carers themselves. It includes sections about:
 - Key messages and suggested actions which have been reviewed and tested with a group of carers and members of the Carers Partnership Board
 - Who we heard from
 - What people said about being a carer
 - What people said about support for the people they care for.
- Where we can we have presented a comparison between our latest survey – Caring in North Tyneside in 2022 – and our 'caring during the pandemic' survey carried out in 2021.
- The Carers Partnership Board have agreed to produce an action plan to respond to the key issues.
- More detailed feedback about care pathways and services is available and has started to be shared with decision makers.

Key messages



- The Carers Partnership Board had assumed that the Covid pandemic had a significant impact on the responses people gave in 2021. We expected that, as lockdowns eased, responses and experiences would improve. We have not seen the predicted improvement in the 2022 data. Across almost all of the themes we asked about, the responses are similar or worse to what we heard in the pandemic survey.
- Carers tell us they often struggle to cope. The data for 2022 is very similar to that in our 2021 pandemic survey.
- Isolation continues to be a major issue for carers with 41% of respondents saying they felt more isolated than the previous year (which was during the pandemic) with 46% responding 'just the same'.
- Carers tell us they are providing more care than before. This appears to be because the needs of the people they care for are increasing, resulting in needing more support from their carers. This is exacerbated by delays in NHS treatment and challenges in organising care packages, which result in greater pressure on carers.
- Cost of living challenges are a massive issue within the feedback – heating, transport, special diets etc.
- People told us that their emotional, financial and physical wellbeing is significantly worse in the last 12 months. Only 'social wellbeing' appears to have improved in comparison to responses to the same question in the pandemic survey.
- Most people say support from services has improved in comparison to the pandemic survey. There are some really good examples of professionals working hard to provide support in very difficult situations.
- Carers tell us they often do not feel valued for the vital role that they play.
- Carers described the key challenges as: 1) Knowing where to get help when they need it. 2) Getting timely support. 3) The impact of their caring role on their own wellbeing. 4) Joined up care and support for themselves as carers and the person they care for.
- Carers and work – we added more questions about work and there is a real mix of responses highlighting positive support from employers to people feeling forced to leave work.
- Carers have fed back that they feel there is not enough support for carers available in the borough.

Suggested actions for the Carers Partnership Board

1. Improve access to information:
 - Better information for carers about all the support that is available and how to access it. This needs to be promoted by all services across North Tyneside.
 - Review how to create a single front door for carers - web page, phone number.
 - Work with carers to co-produce this.
 - Marketing shared and direction across all services.
2. Review the capacity of carer support across the borough, service integration for all carers and benefits/finance support.
3. Review the North Tyneside Carers Charter, reaffirm commitments and publish.
4. Continue to develop a 'carers passport' for use across all the North Tyneside Health and Care system.
5. Improve signposting and referral systems to carers support from all health and care services.
6. Develop and implement a self audit tool for all services and pathways to test how well carers are recognised and supported. Carer friendly quality mark.
7. Mandatory training for all health and care professionals about carer identification and support services – renewed every 2 years. Including – Communications with carers, involvement of carers, identification, connecting with support
8. Review the planned 'parent carer support pathway' to reflect the feedback in this report and then implement.
9. Develop an approach to identifying and checking in with carers who are not actively receiving support
10. We want to have a **coordinated offer of support** for the person they care for and the carer. Including, improved crisis planning so that people know what to do. Also getting the help they need with the person they care for – including more social worker support and priority access to GPs.

Caring in North Tyneside in 2022

Who we heard from

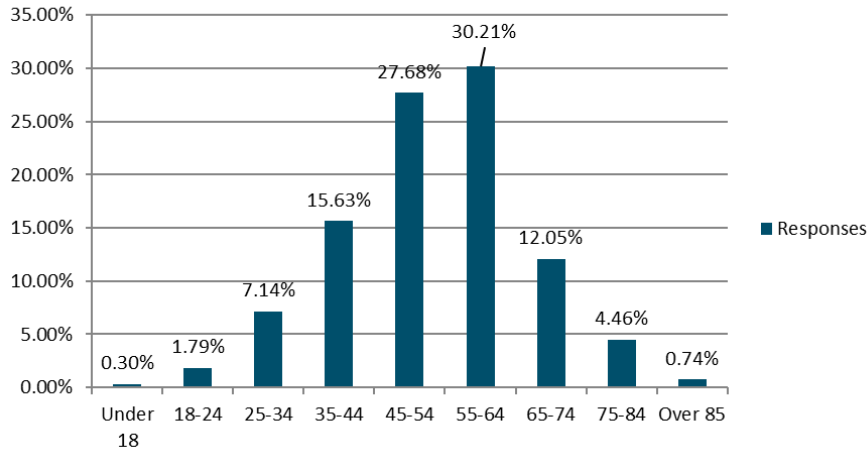


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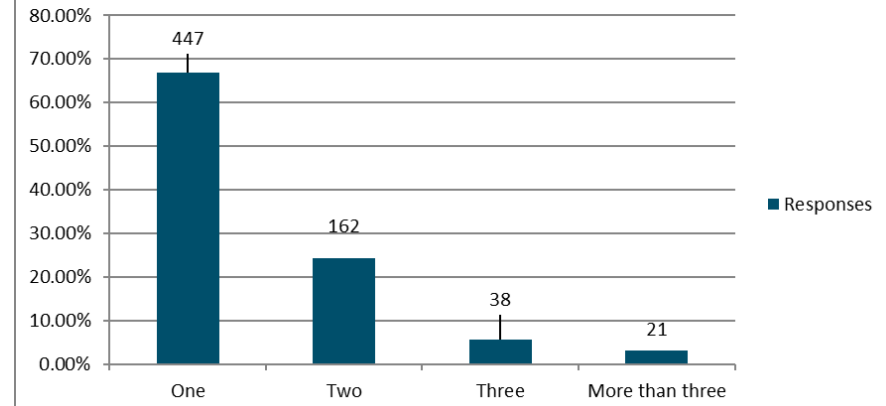
About you, the carer

What is your age?

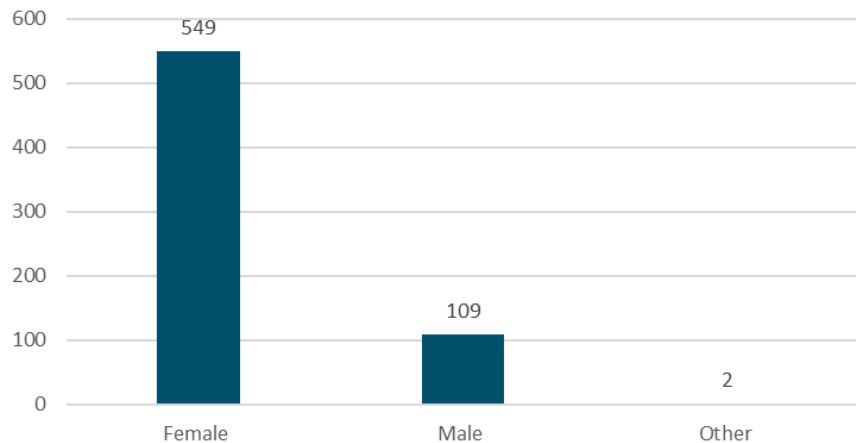


Answer Choices	Responses
Under 18	2
18-24	12
25-34	48
35-44	105
45-54	186
55-64	203
65-74	81
75-84	30
Over 85	5
Answered	672
Skipped	9

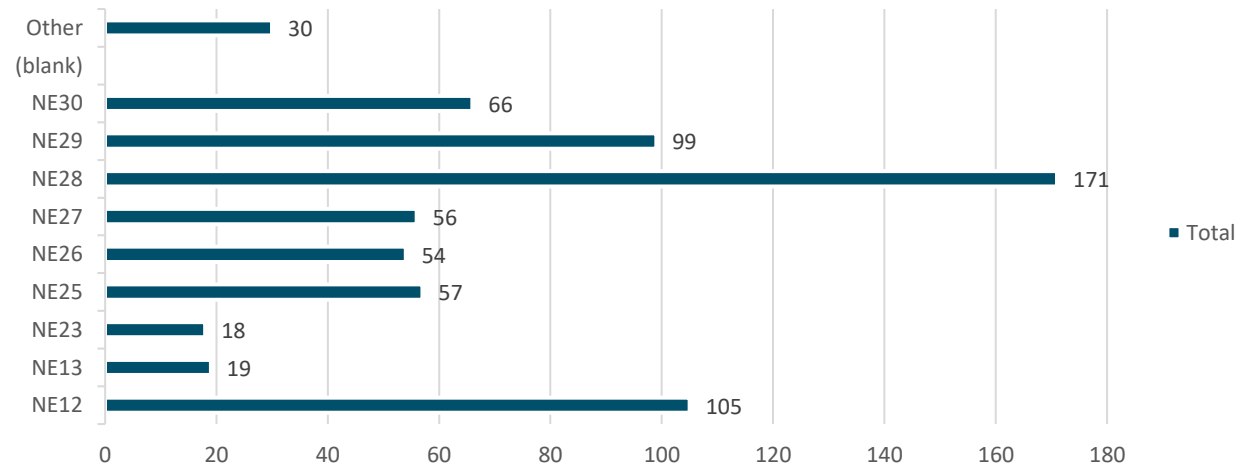
How many people do you support with an illness or disability?



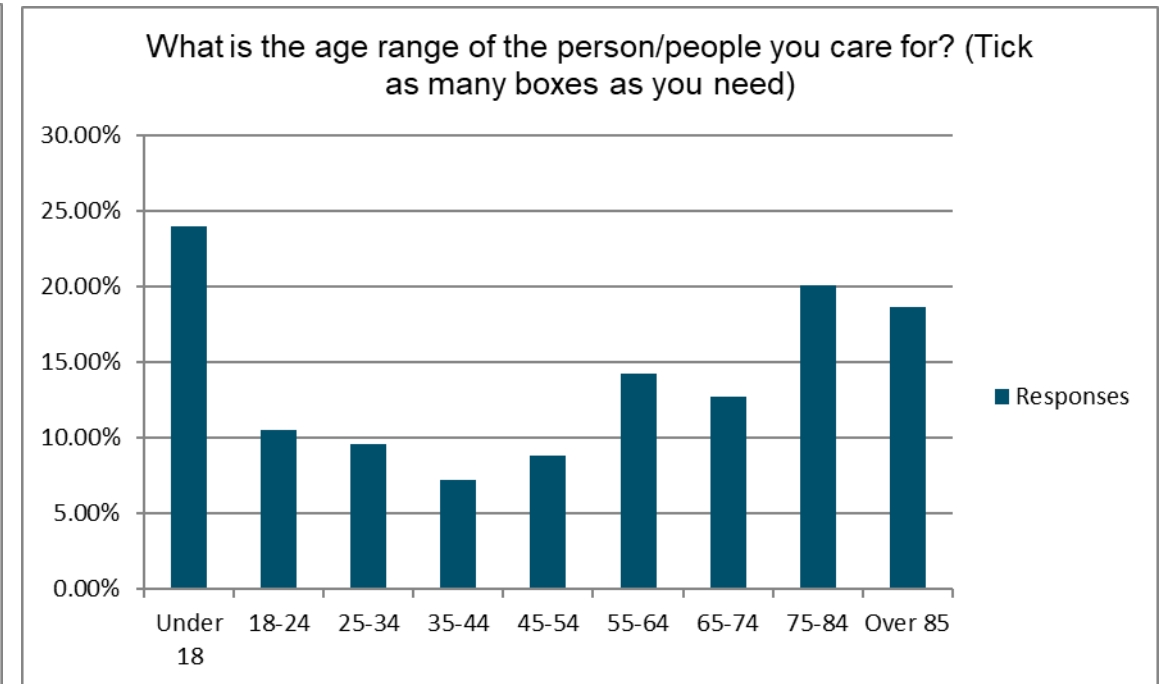
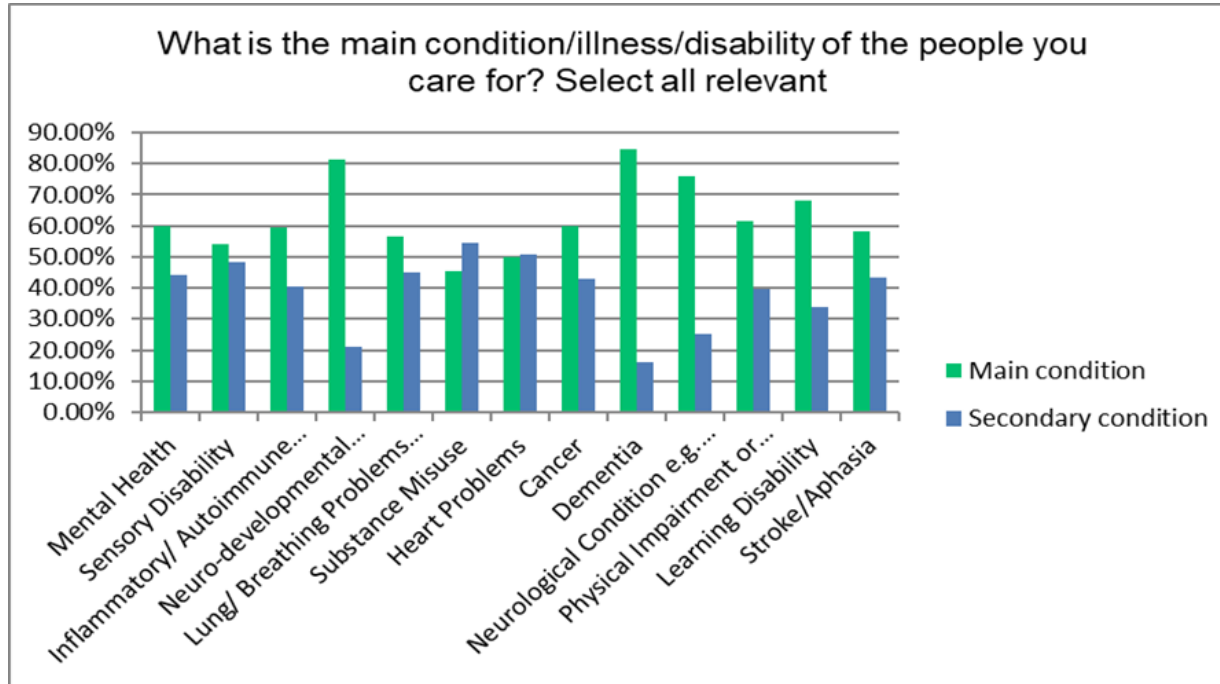
What gender do you most identify with?



Postcode



About the people you care for



- The main condition of the person cared for in the 2022 was dementia, followed by neuro-developmental disorder. In 2021 the main condition was neuro-developmental disorder and mental health.
- This is reflected in the age of the person cared for data. In 2021 age 65+ numbers were very low in comparison with 2022.
- Parent carers caring for someone under 18 was the highest response rate for the survey.
- Carers of older people are also well represented in this data

Caring in North Tyneside in 2022

What people said about being a carer

'Carers take a huge weight off the health care system and also ensure kids are in school, adults are in work and we pay the price. We should be cared for better and given more respect in doing this. We need time, money and care to look after ourselves to be able to provide this or we end up in the same cycled system.'

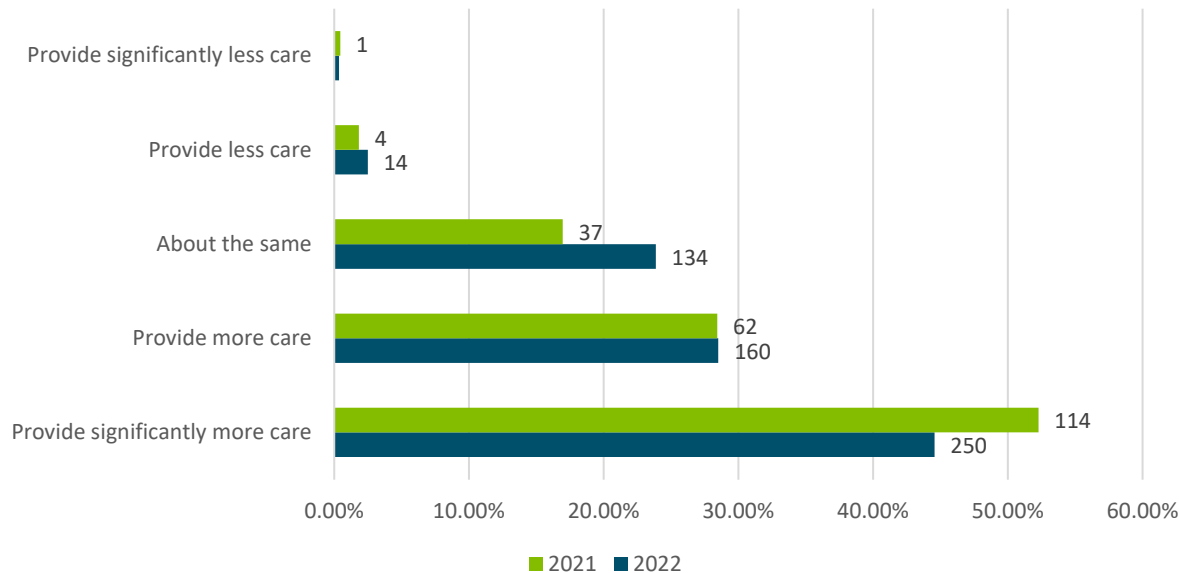


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Carers tell us they are still providing more care

How has the amount of care changed in the last year?



- Comparing this year (2022 in blue) to the year before results (2021 in green) which reflected the impact of the pandemic.
- 410 carers told us they are providing more care in 2022 – something of a surprise given people previously said Covid forced them to provide more care.
- The 2022 free text feedback indicate people’s health is declining/their condition is worsening, resulting in greater care need and greater calls on carers.

‘My son's circumstances haven't changed. He still lives with us, never leaves the house and my husband and I support him emotionally, mentally, are basically his only social network. We make sure he is fed, has a home etc.’

‘My husband was in hospital and a care home initially following a stroke and delirium. He came home and is gradually worsening and now has a diagnosis of dementia and needs much more support.’

‘Aging has caused more needs to be identified and more struggles.’

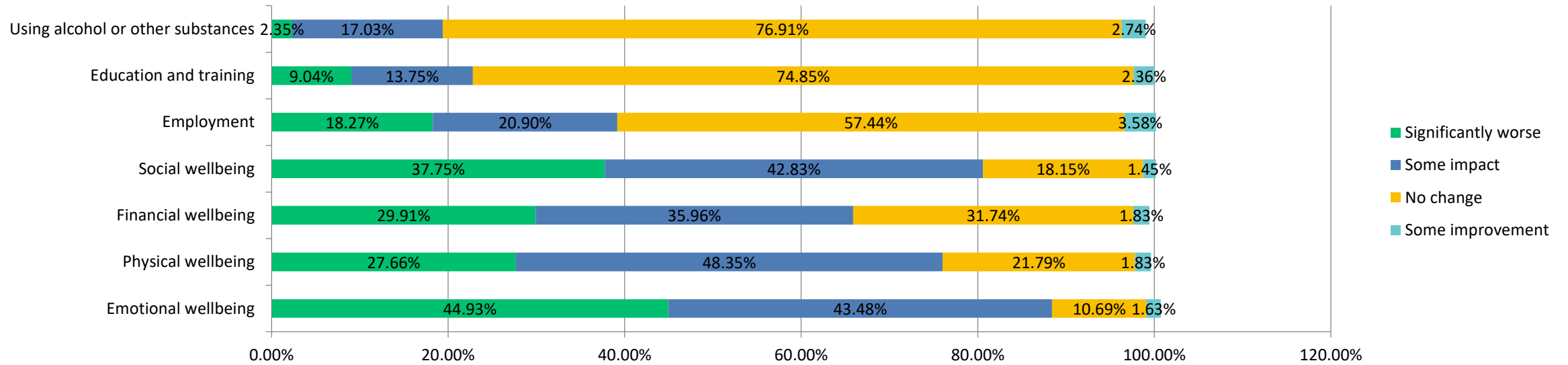
‘Requires more transport to hospital and doctors appointments.’

‘My father has become less able to do every day tasks himself therefore I am doing them for him now.’

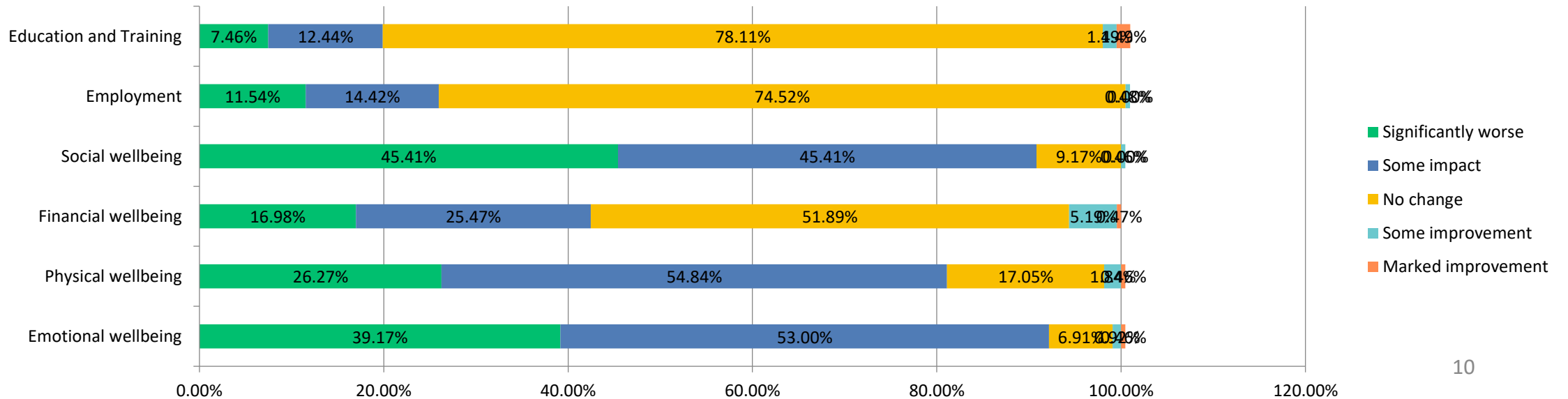
‘Mum has been ill far more frequently.’

Impact of caring

2022 - How has the last 12 months impacted on you in the following areas?



2021- How has the pandemic impacted on you in the following areas?



Impact of caring

- We have compared our 2022 survey and responses from the previous survey which asked about the pandemic rather than a calendar year.
- People tell us their emotional, physical and financial wellbeing is getting worse year on year.
- We had hoped that the pandemic made people's situations a lot worse and that, as restrictions eased, responses would improve. Unfortunately this isn't the case with carers saying their caring role is having a significant negative impact on their social, financial and emotional wellbeing.
- At the request of public health, we asked a new question in our 2022 survey about people using alcohol or other substances – so we do not have a baseline.
- Responses about **education and training** are very similar year on year. See next slide for more detail about work.
- **Social wellbeing** responses show a 9% increase in 'No change'. Only 1.5% said there had been an improvement. We still have very high levels of some impact (43%) and significantly worse (38%) – a real concern given the previous period was during the pandemic.
- **Financial wellbeing** shows 32% saying 'no change', 36% saying some impact and 30% 'significantly worse' – We can attribute some of this to the significant rise in costs of living during 2022. Other research indicates the costs of living crisis is disproportionately impacting on carers and households with caring needs.
- **Physical wellbeing** shows an increase of 'significantly worse' responses from 39.1% to 44.9%, and a drop in 'some impact' responses – indicating a greater impact than during the pandemic.

What carers found most difficult in 2022

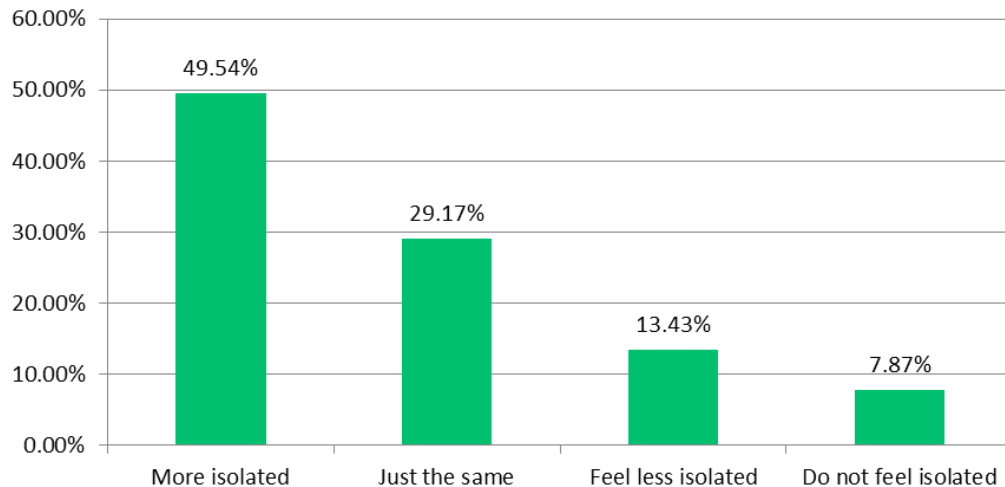
Key Issues

1. Struggled to cope
2. Impact on mental and physical wellbeing
3. Lack of services and support
4. Cost of living rises
5. No time for self
6. Juggling work alongside caring
7. Deterioration in the condition of the person cared for – increased needs
8. Loneliness

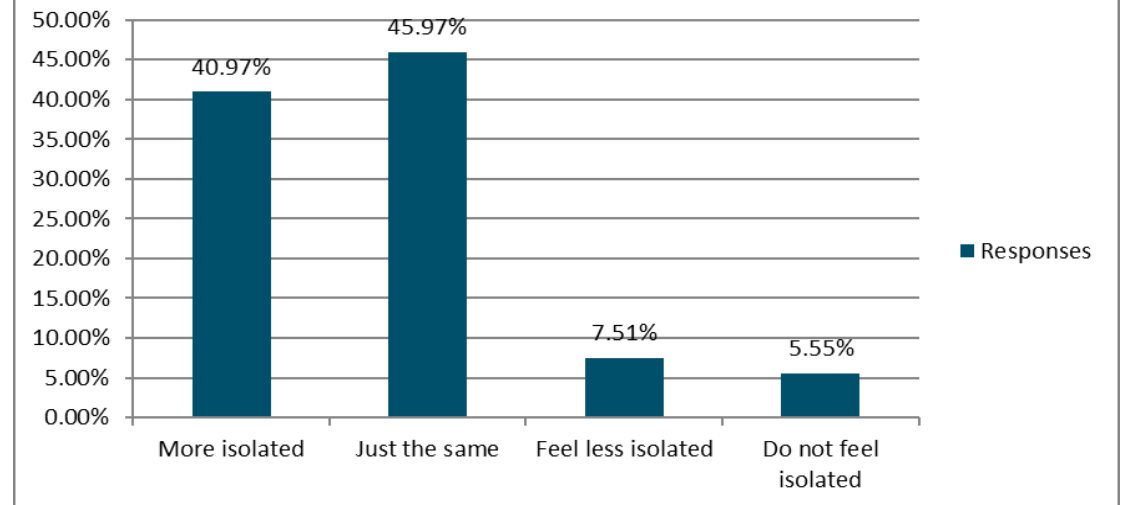
Isolation still an issue after the pandemic

Comparing responses about the pandemic to 2022. Please note the scale of the graphs are slightly different.

2021 - How isolated do you feel now in comparison to before the pandemic?



2022 - How isolated do you feel now in comparison to last year?



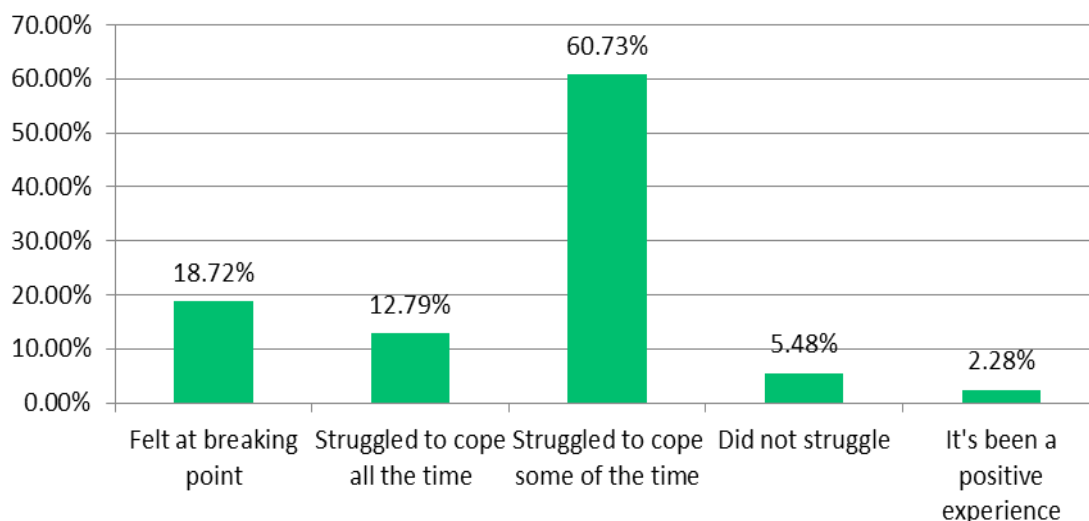
- We thought that isolation might have reduced in 2022. We had assumed that the pandemic was a key reason behind the high levels of people reporting they felt more isolated (as a result of lockdowns, social distancing etc).
- However feedback from our recent survey shows 41% of respondents to this question (229 people) told us they felt **more isolated than the previous year**. The percentage of people telling us they 'feel less isolated' and 'do not feel isolated' have also dropped in 2022.
- The evidence suggests further work is undertaken to understand how to tackle isolation for carers.
- Isolation appears to be particularly an issue for – carers for under 18s and carers for the over 55s.



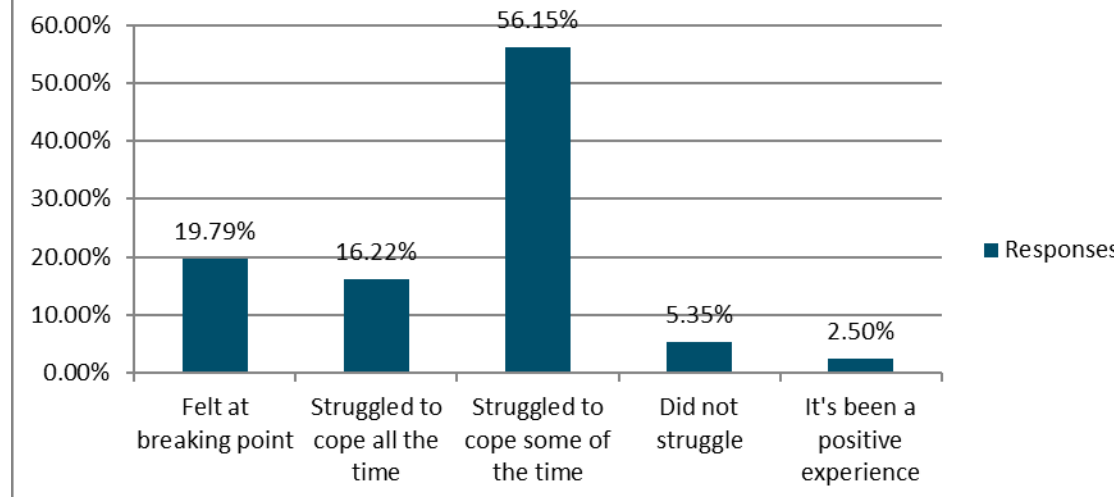
Carers are still struggling to cope

Comparing responses about the pandemic to 2022. Please note- the scale of the graphs are slightly different.

2021 - Please select the statement which best describes how you have felt over the last 12 months



2022 - Please select the statement which best describe how you have felt over the last 12 months



- 111 people said they 'felt at breaking point'. 91 'struggled to cope all the time' and 315 people said they 'struggled to cope some of the time' in 2022.

• Some common themes in the feedback:

- Impact on whole family of caring for multiple people
- Challenge of caring for different people in different households
- Balancing caring, family, work etc.
- Adjusting to change and health conditions deteriorating
- Challenging behaviours
- Not getting help when asking for it
- Pressure of organising paid carers and managing care packages
- Toll on carer's health, work and wellbeing
- Cost of living adding extra pressures
- Feelings of guilt
- 'Missing the person they once were'
- Passing the buck, services saying 'I cant help you with that'

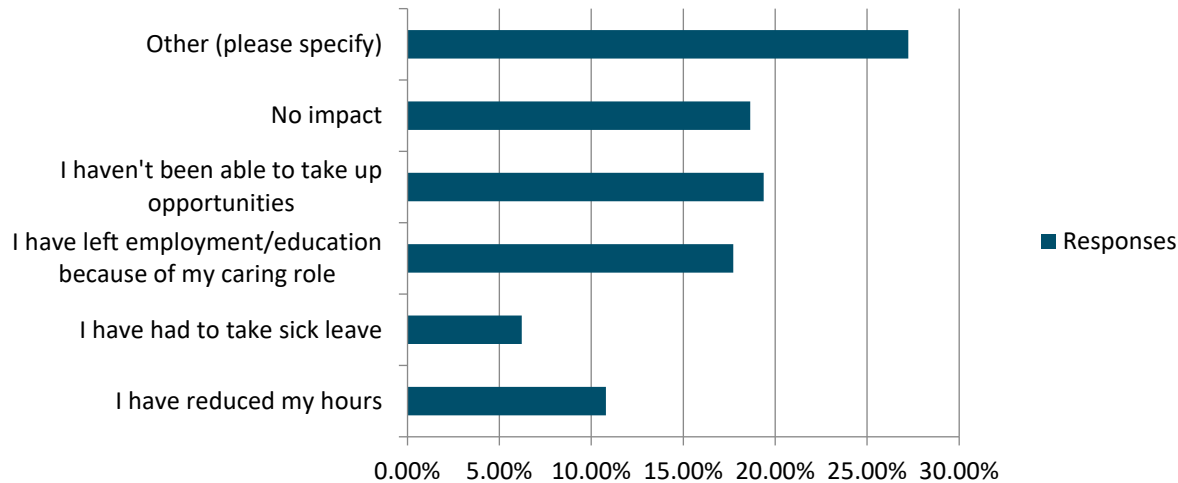
Carers and work



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Has your caring role impacted on your work or education? (Tick all the relevant statements)



- We asked a new question in the 2022 survey to better understand carers relationship with work or education
- We had 547 responses to this question
- We see a real mix in responses. Some people highlight how flexible and supportive their employer is, others say how difficult this relationship is.
- People who had retired told us that they struggled to balance their time and had stopped volunteering or other activities. Several said they **'took early retirement because of care needs.'**

Impact on work

'I've had to reduce my hours, WFH, take sick leave due to stress and not considered for a team leader role due to my circumstances.'

'It has impacted on where I work but not really on doing the work. My manager has been great and allows me to work from home 2 out of 3 days per week.'

'Reduced hours and I am thinking of leaving my role.'

'My employer allows me flexibility in start times and working from home so I can support my son. This is a huge help.'

Parent carers

'I can't work longer hours as no childcare available for my son. Unable to take time out for myself.'

'I don't work. I am a full time carer for my son.'

'I have been able to stay at my part time job due to my parents doing the child care while I work.'

Limiting impacts

'I got made redundant because I was inflexible because I am a carer.'

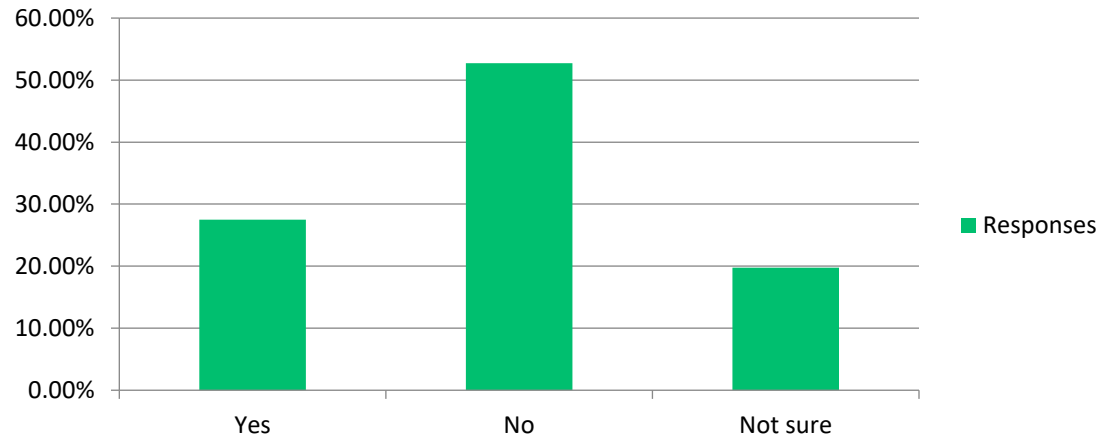
'I haven't progressed because I have taken so much time off.'

'I haven't been able to work due to a combination of my own health and my sons needs.'

'I have had to use my leave or flexible hours at short notice to be there for the people I care for.'

Access to respite care is an issue

Do you know how to arrange respite support if you needed it?



- This question was added in 2022, based on the issues carers raised in the 2021 survey regarding access to respite.
- 556 carers responded. 153 people said 'yes', 293 said 'no' and 110 people said 'not sure'.
- 83 carers answered a subsequent question to rate their respite experience. The weighted response was **3.53** stars.

There was a mixed response from carers telling us about the services they used and their experiences

- 'I have tried to get respite but it was impossible.'
- 'Day centre generally very good. Respite good.'
- 'This wasn't offered when I needed it, when I was hospitalised. I have no faith in the system it's broken, and beyond repair.'
- 'A Macmillan nurse arranged respite with St. Oswalds Hospice. The experience was excellent. The hospice social worker also arranged for my husbands support package to be increased. Further respite break arranged at the Marie Curie hospice. The experience was excellent because my husband was looked after extremely well. This meant I was able to relax and have a short holiday for the first time in 4 years.'
- 'Only just have a personal budget and restrictions of the commitment needed and limited ability for peers to access at the same time, render this fairly inconceivable for a 12 year old.'
- I was very happy with the two weeks of respite care my husband received in a specialist dementia care home in June 2022.
- 'None my dad won't go.'

What carers say about the support they get



- Only 257 people completed this section. This question was towards the end of the survey.
- Missed opportunities to signpost carers to carer support services and help to access carer support
- Many carers tell us that they prioritise the person they care for over themselves. 'I don't have time for myself' is a very common response.
- Some carers said that they found it hard to get support as a carer, they didn't know where to go for support and were passed around – indicating its not easy for some carers to get support. 'Have not really had the time, but the one time I did take the plunge for the possibility of some help by being able to talk to someone I was told to phone a certain number and request a form to complete, which I wasn't going to do'.
- The free text comments indicate that there are gaps in mental health support for carers including wellbeing and counselling. People have told us that they have had to wait over a year for psychology.
- Informal support (family, friends & colleagues) are strongly referred to – something that carers said they particularly missed during the pandemic.
- Peer support is also highlighted as particularly helpful – either through voluntary sector groups or carers network through work.
- There is some indication in free text that getting better support for the person they care for is the best form of support for the carer. 'Why do most carers have to get to breaking point or health deterioration before help is provided. Make service access easier having one form that triggers all the services needed by a person, and gets things moving quickly, have an assessment team that liaise with all services freeing up SW's and OT's for more specialised or detailed tasks. Put measures in place to maintain or help people before a crisis. Provide care that is needed, not just covering the bare necessities and pretending the rest doesn't exist, don't qualify for, or referred to inadequate or inappropriate services, or nothing'.

What could improve support for carers

'I could access support about cared for person's condition but what I really wanted was to talk to someone about how this sudden acquisition of caring responsibilities was tearing my life apart, so that I could try to work out strategies to hold it together and minimise the impact. I didn't want to be talking to friends about this I wanted to talk to a support service so that I could use my friends to do pleasurable activities for respite.'

What support organisations could do

- Better information about carers issues, what support is available and how to access it.
- More mental health and wellbeing support for carers – quicker access to counselling.
- More peer support opportunities.
- Support at different times of the day to fit with people's lives.
- A carers hub.
- Access through ONE phone number.
- Support across the borough 'not just in North Shields'.
- Training for carers – dementia, transitions from childhood to adult hood for carers.
- Support groups targeted at different people – working people, working age, older people, young carers – not just young carers.

What public services could do

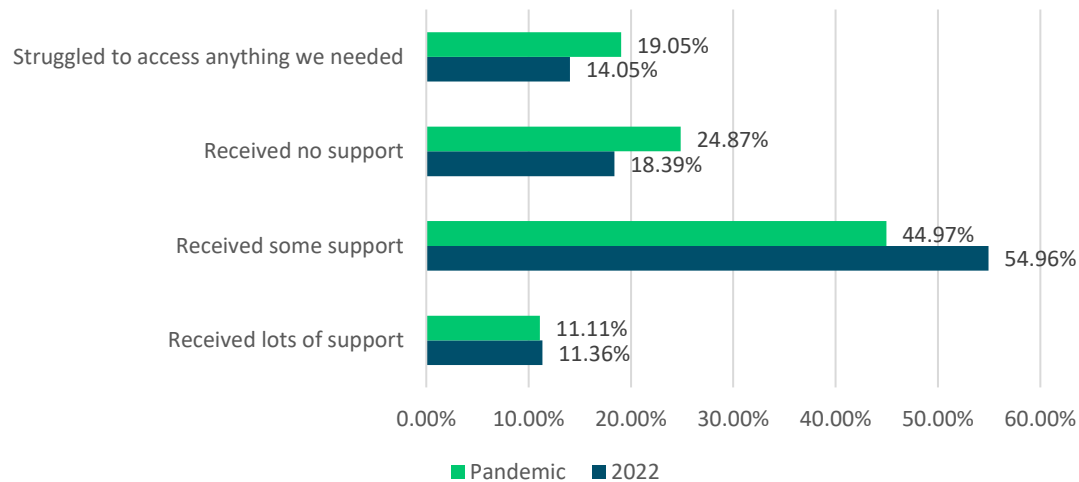
- Coordinated offer of support for the person they care for and the carer.
- Better communications from professionals – being kept informed what's going on.
- Getting the help they need with the person they care for – including more social workers and priority access to GPs.
- Crisis support.
- Medical /care staff to better identify carers and focus on the carer and the person needing care. Information for carers.
- Regular check in calls.
- Benefits easier to access.
- Support to find flexible work.

Caring in North Tyneside in 2022

What people said about support for the people needing care

Getting the support they need

Did the person you care for get the support they needed?



- Comparing 2022 to the data during the pandemic, we see a real improvement in the way people have responded to this question.
- We had 478 responses to this question.
- People highlight increasing needs/decline in condition of the person they care for resulting in the need for greater support.
- Whilst the graph shows things have improved, the free text answers to this question are overwhelmingly negative.
- The equipment loans services receives lots of positive feedback.
- Several carers point out the need for a holistic approach is needed 'My wife has multiple medical conditions the care she receives for all of those is very good individually but I feel that no one person looks at the effects of these multiple conditions as a package. When she is ill the GP practice are excellent.'
- Care coordination continues to be missing from most people's stories. They point to opportunities to provide more joined up support to relieve the pressure from carers.
- Building up a relationships/continuity of care is highlighted in a variety of settings. Building a rapport and trust with care staff is seen as absolutely critical. With doctors, social workers, having an ongoing relationship that does not require stories to be repeated and where changes in someone's condition can be detected, is seen as really valuable.
- The key issues about different services are on slide 30

Support is rated slightly better than last time



GPs and primary care

Significant improvement in the support available than pandemic survey. Access remains an issue for many - getting through to a practice, getting an appointment, phone appointments etc.

Some people say they struggle to get their GP to engage. Some people highlight delays and breakdowns in handover of care from hospital to GP.

District nurses and OT's generally receive high praise.

Social Worker teams – Again better feedback than in last year, but free text is broadly negative - seems to depend on the person you are working with. Feedback also highlights that they feel they do not get much/nothing changes as a result of a conversation with a social worker.

Carers needs being missed – 'nobody asks how I'm doing as a carer.'

Adult Mental Health support – mixed responses about all the services.

We don't get any support – a small number of people say they don't get support and are frustrated at lack of response of the professionals they ask for help.

Other people say they don't know what is available or what they need to ask for .

Voluntary sector support is rated highly – either for the person they care for: Tim Lamb Centre, Admiral Nurses, Pearly House, LDNE etc. or as a carer – Carers' Centre, Parent Carer Forum, Props – 'The support received from hospices, the Macmillan team and the NT Carers has been far superior to anything from the statutory services and home care provision arranged by the council.'

Delays in NHS care

People highlight delays in getting appointments (more secondary care than primary), delayed referrals from primary care and delays in getting results. People highlight that health is declining and care needs are increasing as a direct result of delays in treatment.

Care at home

Some people tell us about difficulties in getting a care package in place – both for private funders and public funded. Also the quality of care packages is mixed with some people very happy, but majority tell us they have had problems.

Reluctance to accept support

A recurring theme is the pressure put on carers by the person needing care not accepting support – 'There was no trouble in buying in home care. It simply didn't help as over a period of about four months, one carer managed to shower my husband twice in the first week, no success after that.'

Children and young people

Particularly highlighted is the challenge of getting mental health support and accessing CAMHS. 'Crisis team came out last year for 2 of my children and was extremely helpful, unfortunately the lack of help when moving over to camhs is very disappointing. The crisis team helped my children to cope and then when they were deemed safe they were moved onto camhs where after saying my son needs a diagnosis we are left again for him to get worse.'

Real challenges about getting an EHCP and then, getting the package of support outlined in the EHCP in place. Gaps in support during school holidays are highlighted.

Experiences of leaving hospital



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Individual services

Support from individual services and individual workers was highlighted as positive. OT's, ALES and District Nurses were particularly highlighted.

Lack of coordination at point of discharge

Some stories indicate a lack of joined up support between services. Several people said they felt pressed into being discharged without support being put in place or assessments being carried out. 'Plans were made for OT and SW assessments before leaving hospital, (this would have been a blessing), these never happened due to acute bed shortages'.

Getting a care package

Delays to getting home care packages resulted in people not getting the care they need or having to go into residential care.

Information at discharge – People raised concerns that they did not have adequate information at discharge – who to contact, what to do if there's a problem, planned actions, copies of discharge letters.

Delays in leaving hospital

'2 extra days in hospital due to waiting for her medication from pharmacy. Blocked a bed on hospital ward then they lost her dentures on the ward. Extra care calls after hospital worked well and hospital staff all brilliant.'

Transfer between hospitals

A small number of people highlighted inappropriate transfers between hospitals due to capacity – 'My dad was admitted to hospital with an infection through A&E. They had little understanding of how to treat someone with dementia and he had a fall and wandered whilst there. The team wanted to transfer him to Alnwick until release which meant we would be unable to see him and were poor at keeping us up to date. They reviewed the physical need but couldn't understand the impact his dementia had on his ability to understand what was happening.'

Inadequate support on discharge

A small no of people highlighted that their loved ones left hospital at inappropriate times and/pr without support 'My Mum was discharged into a small flat and couldn't access the bathroom. It wasn't acceptable at all. She was trapped in a small flat with no shower/ toilet access.'

Having choices and involvement in decision making

Several carers said they were not involved in decision making to discharge and that pressure on hospital bed was put above patient welfare. A small number said they were not given a choice of care homes to consider.

Plans being made but not delivered

A small number of people said the planned care was not delivered due to staff shortages.