

What matters to Young Carers in North Tyneside 2024

Key findings and actions

1. Background

Healthwatch North Tyneside is the independent champion of users of health and care services in North Tyneside. We are committed to ensuring that carers voices are heard in the designing and reviewing of services and support in North Tyneside. We are a member of North Tyneside's Carers Partnership Board (CPB) and, on behalf of the CPB, conduct annual surveys of carers in North Tyneside – one year focusing on adult carers and the next focusing on young carers. This means that we can see how things have changed for carers over time, as well as getting a snapshot of current issues.

To do this work we rely on the support of other members of the CPB. We would like to particularly thank the young carers team and North Tyneside Carer's Centre and the young carers themselves for taking the time to support this work.

We conducted this research in April and May 2024 - this was during the local election period, so promotion was limited. We asked very similar questions to our 2022 survey so that we can compare data and see if any progress has been made. You can find the results of the 2022 young carers engagement [here](#).

It's clear that the survey was quite difficult to complete for many of the young carers – it was too long, and the questions were too complex, particularly for the youngest participants. We will review this in the future to find a better way to gather the views of all young carers.

2. About the people we heard from

83 people completed the 2024 survey. We heard from 103 young carers in 2022.

92% of the young carers we heard from are caring for a parent/guardian or a sibling or both. This shows that caring responsibilities are mainly within immediate close family.

68% of the carers are caring for 1 person, 25% for two (often a parent and a sibling) and 8% of the people we heard from told us they are caring for 3 or more people.

As stated above, 54% of respondents told us they were caring for a sibling.

In terms of the conditions the people needing care have, the most common responses were:

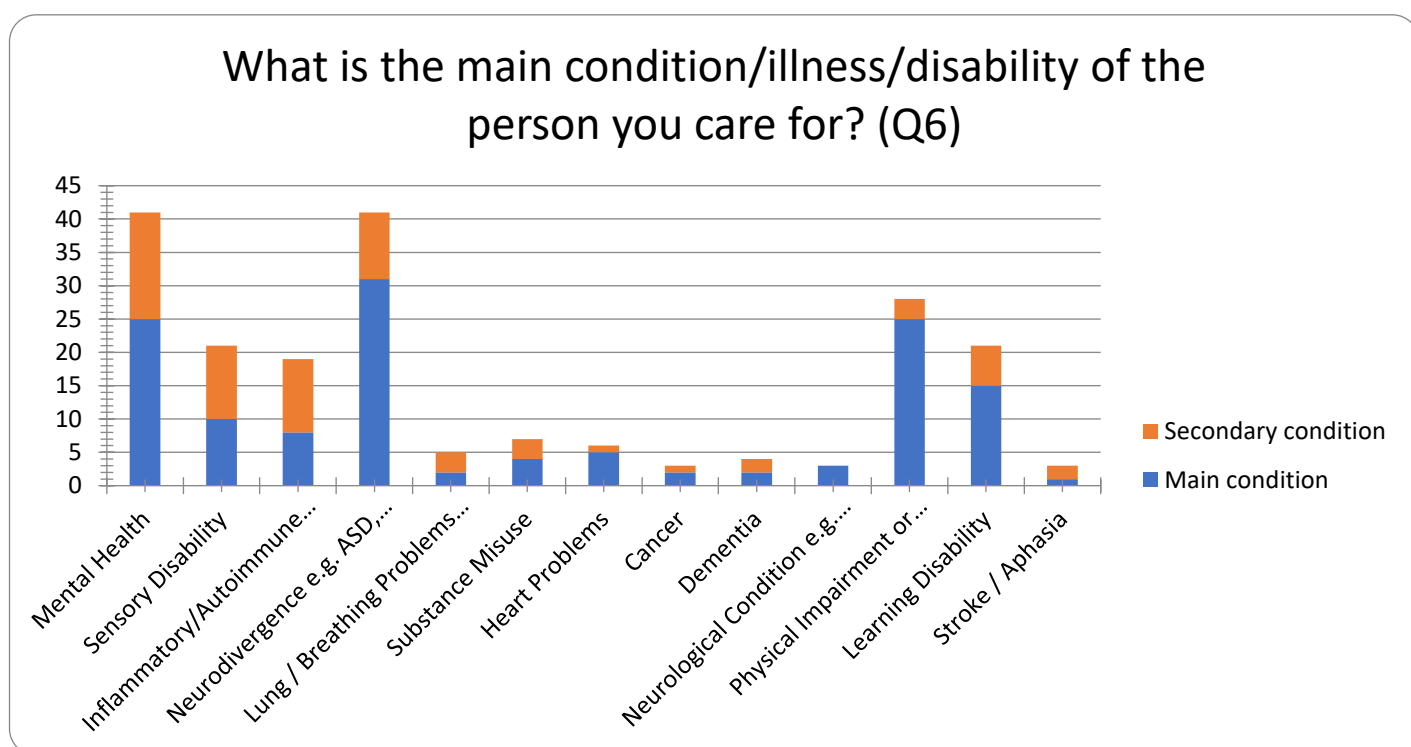
Mental health – mainly of parent/guardian, but also of sibling

Neurodivergence – mainly in siblings

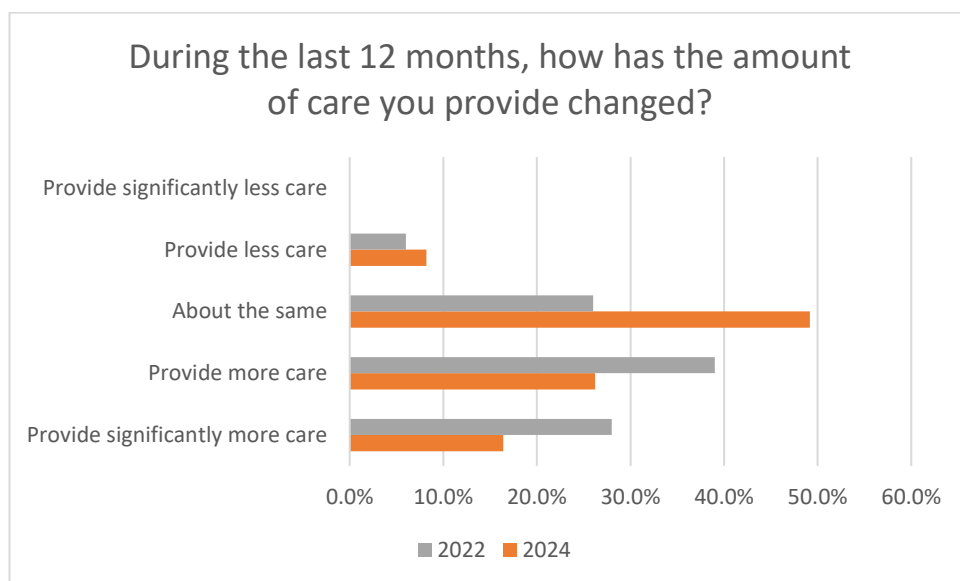
Physical impairment or mobility – mainly in adults (parent/guardians or grandparents)

Learning disability – mainly in siblings and often linked to neurodivergence.

This is similar to the response we received in our 2022 young carers survey, but we have heard from more siblings this time.



3. About the experience of young carers



The 2024 data shows that 42% of respondents said they are providing more care than 12 months ago, in 2022 it was 67%.

It appears that patterns of care have been quite stable for 49% of young carers in the 2024 data.

Other young carers say that the needs of the person they care for are increasing and they are having to meet these needs. *'Mum has been poorly and needed more support.'*

Increased mental health needs and increasingly challenging behaviours of people with Neurodevelopmental conditions are highlighted by young carers as common reasons for providing more care, this also adds to the impact on the young carer. *'Behaviours have changed, she's now more aggressive.;* *'I have to play with her more to stop her from having melt downs when mam is busy in the house.'*

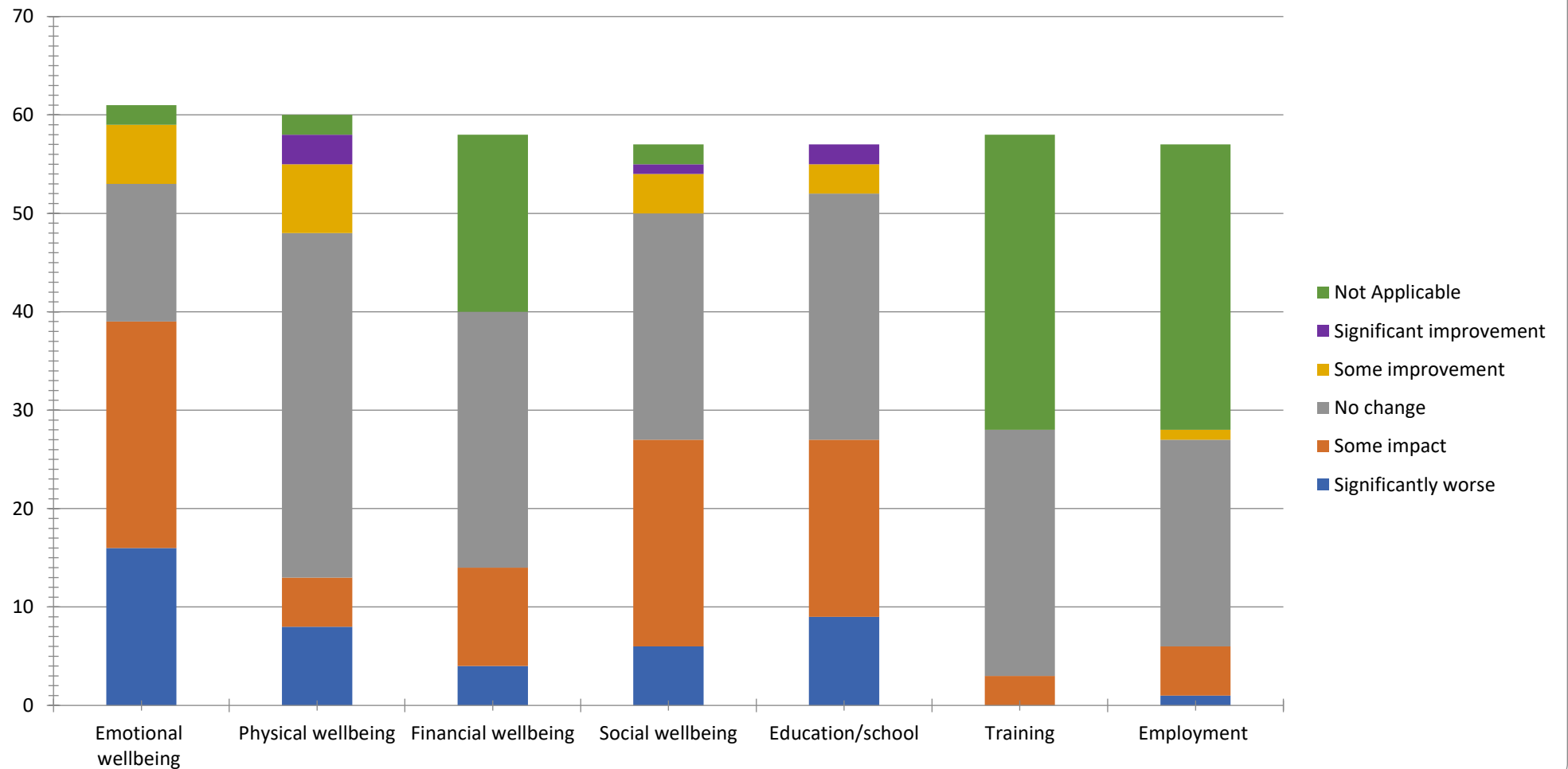
A small number of young carers indicated that the caring role is taking a significant toll on an adult carer, resulting in some young carers providing more support. *'Looking after sister is becoming more challenging, Mam has been getting worse mentally and physically.'*

A small number of carers point to changing expectations and abilities as they themselves get older. This results in a greater caring role - *'Mam's condition has deteriorated. Since finishing school and starting college, I am home more now so I*

can help her.' or a reduction in caring duties 'My mam has a partner who helps her, I've started the process of moving out.'

Few people who said their situation was the same or they provided less care have left a free text response explaining why this is the case, but those that did said that other family members are providing more help, so they have to provide less, the family circumstances had changed or that the person/s they care for conditions' has remained stable.

How has caring in the last 12 months impacted on your....



What has worked well for you in the last 12 months?

3 people replied 'nothing' to this question.

Several responses focused on getting more support or learning techniques to manage the person they care for

- 'Having someone in the house with him at all times.'
- 'Brother going to respite.'

Learning techniques to look after themselves as a carer

- 'Setting some boundaries. Taking bits of time for treats where I can.'
- 'Making sure I leave enough time for me to relax.'

Having support from other family members

Peer support

- 'Started being able to meet with friends more - develop friendships going to young carers forum.'

Support through school and support organisations - covered in more detail in section below

- 'Support from the carers centre and my well-being advisors in college but also my friend and family.'
- 'I like the carers' club at school. It is every week during a lunch time. We do fun things.'
- 'I also get to go to the Toby Henderson Trust Sibling Superstars group, where I do fun things with my friends there.'
- 'Able to talk more about my worries to parents and support from school, makes me less worried.'

Several young carers mention the Ease Card as being really positive

- 'The Young Carer Ease card has been a big help.'
- 'I have an Ease Card which lets me take a friend (for free) to go swimming and stuff.'

What have you found most difficult?

Dealing with challenging behaviours of the person they care for was mentioned by 14 young carers, some described being physically injured, for some of the respondents this is clearly frightening and upsetting.

Feeling responsible for someone else

- 'Worrying about my mam and my nana in case they get hurt.'
- 'Being worried about the people I care for (due to doctor appointments) which causes me to be more worried and anxious about the situation.'
- 'Money, I worry about money and my mam because she holds in lots of bad emotions which affects her mental health.'
- 'Feeling embarrassed when she sings and is loud in public, dancing in the street without noticing other people. Some people call her names at her school and I don't like that.'
- 'Feeling like I'm not doing enough.'
- 'Getting passed my separation anxiety.'

Feeling sad about the situation

- 'Watching her being unwell and unhappy and makes everyone sad and upsets my mam and we don't get to go out much anymore.'
- 'Seeing mam finding it harder to do things all the time.'
- 'Seeing my mum and dad stressed and upset.'

Finding time for self, including time to focus on own school work

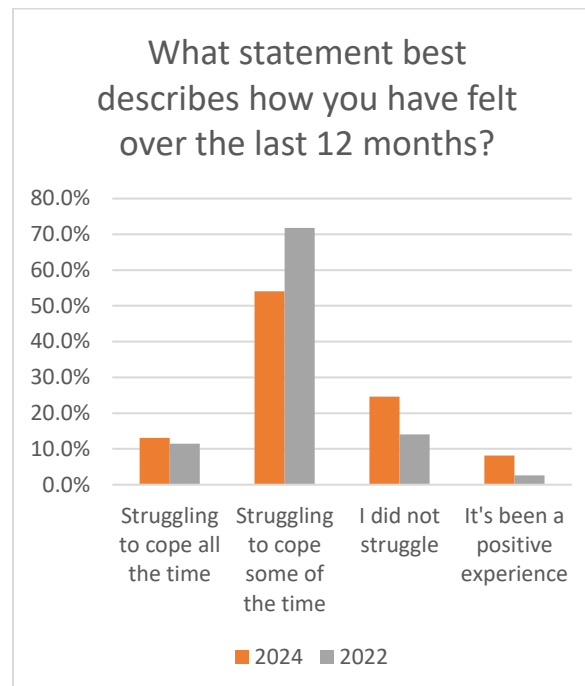
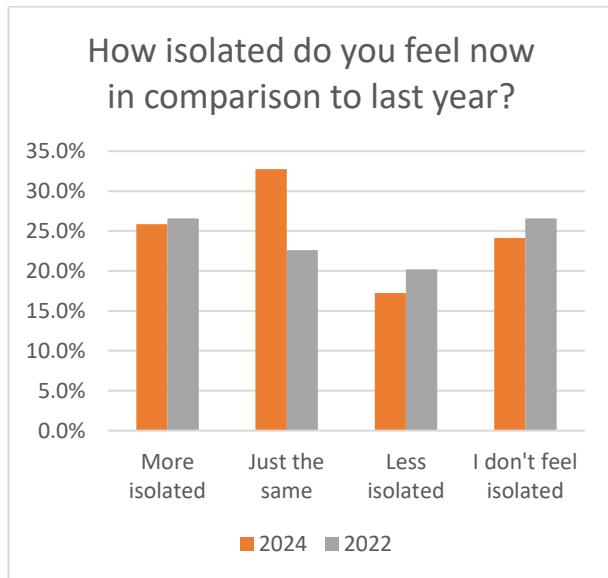
- 'I have found maths difficult and trying to not get distracted by my younger sister some of the time I don't have time for myself.'
- 'Finding time to do my homework, whilst also helping with my sister and social life.'
- 'Making friends so I can play out.'

Lack of support from external agencies and school support and understanding

Challenges for time and support within the family

- 'Brother's care needs have increased so much that he needs at least 1:1 support. This has impacted on parents being available less to for me.'
- 'I feel I don't get enough attention at home, skipping free time so my parents can take my sister to clubs and activities, not getting as much help with my homework as I would like.'
- 'Not being able to have people round to our house, not being able to go out as a family (my parents have to take turns to take me out, while my autistic brother stays at home) and it is not so easy to meet up with family or friends.'

- 'Mum and Dad are often tired because looking after my brother can be hard.'
- 'Mummy and Daddy don't always have time for me because they are helping my brother or trying to calm him down.'



The 2024 results are similar to the 2022 results. The focus of the free text comments is about relationships with friends. We see very different situations with different carers.

Feedback from people who are more or continue to be isolated includes

- Difficulty in relating to people who aren't carers – 'My friends don't understand.'
- Lack of time to spend with friends – 'I feel like I'm barely getting out apart from school.' 'I still cannot meet my friends and do what my friends do.'
- Prioritising the needs of the person needing care 'Because my brother got more anxious than he used to be, around people, so we can't do a lot of the things we used to. This makes me really sad.'

Other young carers said that things have improved for them 'I have a better support system around me.' and 'I have time to go out with friends and talk to them most of the time.'

'I don't always get time for myself but since joining young carers at school I get time with my friends to have fun.'

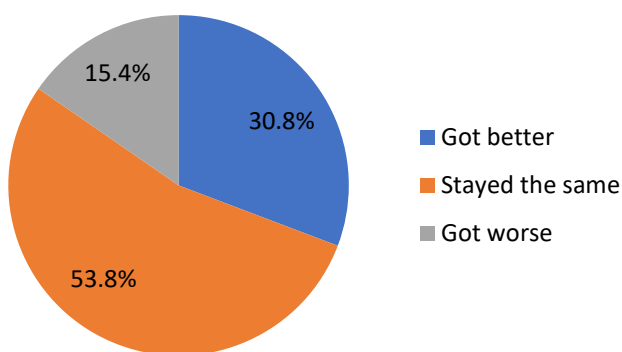
Pressure dealing with medical appointments with the person they care for – 'Periods of depression and more intense anxiety due to greater worries about caring but this only occurs sometimes when they have a doctor's appointment or are worried about something in their life.'

3. Getting support as a Young Carer

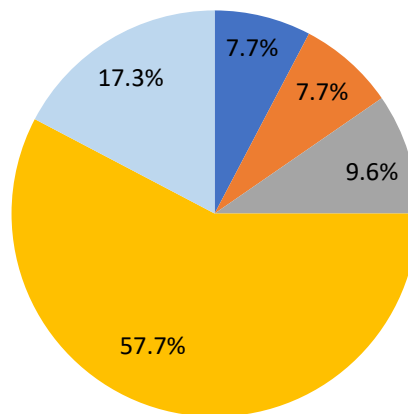
We focused more of the 2024 survey on understanding what works well about young carers support and what can be improved.

Support in schools, peer support and activities are the main focus of young carers.

Overall, do you think the support you receive as a carer has ... (52 responses)

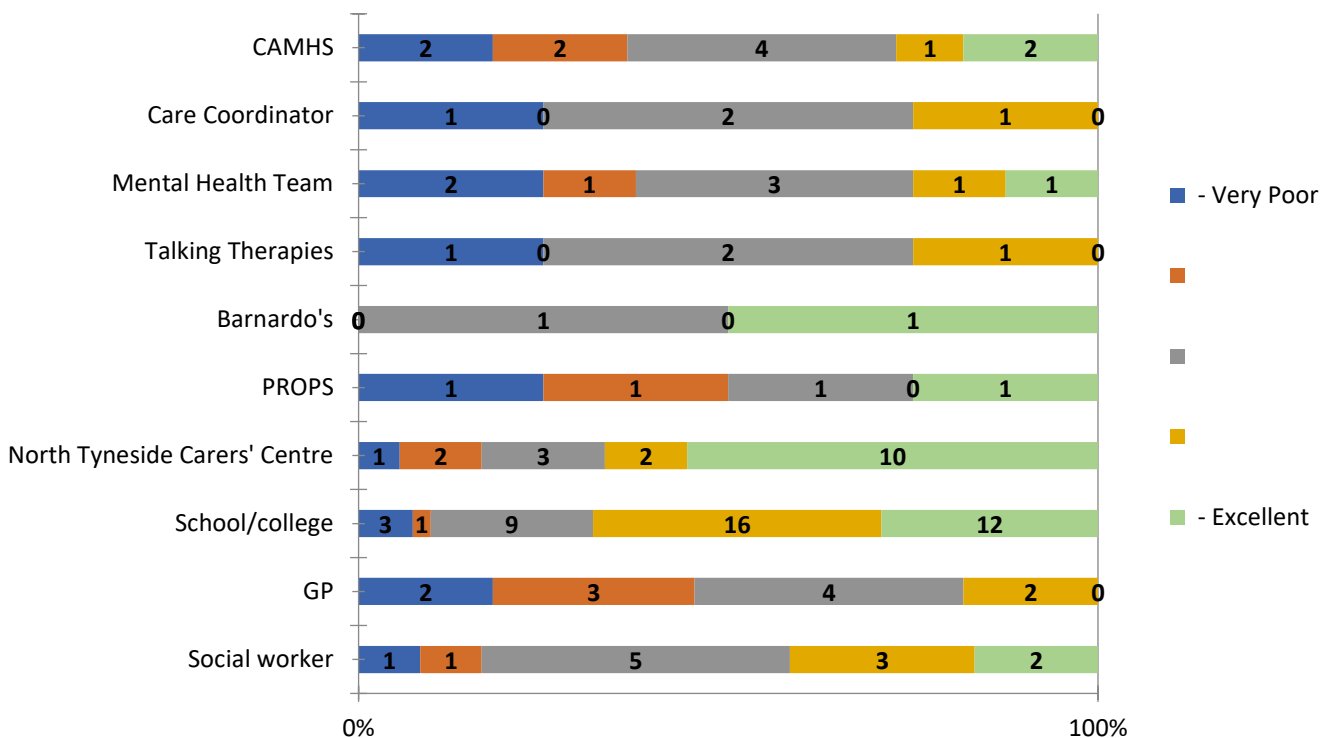


Which statement best describes your experience of Young Carers Needs Assessments? (52 responses)



- I haven't been offered an assessment
- I was offered an assessment but said no
- I am waiting for my assessment
- I have had a young carers needs assessment
- I don't know/can't remember

Have you accessed any carer support during the last 12 months from any of the following sources? If so, how was it?



What young carers said was helpful

- Support in schools & college – individual members of staff, group activities and additional support with schoolwork.
- Support from the Young Carers Team at North Tyneside Carers' Centre is mentioned very positively several times. Also support from other voluntary sector organisations including Barnardo's, PROPS, Toby Henderson Trust and ACORNS.
- Mental health support – through school counsellors or CAMHS. Young carers highlight their mental health support needs throughout this survey.
- Four young carers mention support from social workers.
- Activities and trips.
- The Ease Card.

What young carers want improved in the future

- Mental health services support for young carers – several young carers said they had great support from the CAMHS service. The same number said that they hadn't been able to access CAMHS and felt they were still struggling.
- Greater availability of activities, peer support, groups and trips for young carers. More activities throughout the week.
- Better information about what support for young carers is available and how to access it, including the Ease Card.
- Better identification of young carers – young carers have suggested that professionals need to be better at spotting who is providing care – 'Ask adults who are sick, who helps you at home? Or 'who helps you when you become really unwell? Then they might know about us.'
- Age appropriate support for young carers, focusing on the different needs and interests of different age groups – particularly younger young carers.
- Tailored support to think about their future studies and career options.
- Implementing the actions in someone's young carer's needs assessment.

- Improved support for the people they care for – including respite.
- A small number suggested a ‘listening ear’ phonenumber they could contact if they felt they needed to.
- Better understanding of what it’s like to be a young carer, within school populations (other young people), professionals and the wider public.

4. Further discussions with young carers

We tested the findings of this survey with the young carers forum. They shared their experiences, many of which were in line with what we heard in the survey. The forum’s feedback focused on:

Young Carers Needs Assessment

- Whilst they were pleased to see the number of young carers with needs assessments, they discussed that the name is off putting and sounds more like a test, they suggested the name should be changed.
- It emerged that reviews of the young carers needs assessments are not taking place as standard. One of the young carers explained their assessment was completed 4 years ago whilst at primary school and had not been reviewed since then, they are currently in year 9. Other people had reviews to their assessment, but not regularly.
- Two of the young carers felt that the main purpose of the needs assessment was to get access to support though the carers’ centre.

Breaks and activities

- The young carers highlight the need for more peer support, breaks and activities throughout the week and catering for different age groups and different interests.
- They particularly liked trips away and residential.

Support in schools

- They described some excellent support in school, and the opposite too.
- They said that support could include:
 - extensions to deadlines if they are having a difficult time,
 - all teachers being aware that they are a young carer (using a flagging system on their classroom records)
 - teachers willing to listen when they ask for support
 - mental health support and counselling
 - access to phones so they can keep in touch with their family etc.
 - peer support groups and group activities with other carers.

5. Recommended Actions

The following actions have been co-produced with young carers and were presented to the Carers Partnership Board In June 2024. The Carers Partnership Board have agreed to set up a working group to oversee the implementation of actions to deliver these recommendations.

1. CPB partners involve young carers in a review of the delivery of the young carers needs assessment process to build on best practice, ensure needs assessments are reviewed regularly, ensure the young carer, family and support agencies are involved and informed about the review as appropriate.
2. Review support for young carers across all schools and colleges in North Tyneside and mainstream the best practice: including awareness of each member of staff, flags so that all staff are aware when a student is a young carer, providing appropriate adjustments and accommodations for young carers, access to mental health support and careers support. This could include extensions to deadlines, access to phones so they can keep in touch with their family etc.
3. CPB partners identify ways to increase opportunities for peer support, breaks and activities for young carers, including greater focus on bringing together young carers of similar ages and/or interests.
4. CPB partners remind professionals about the importance of identifying young carers, identifying training/development needs or tools to support this.
5. CPB partners encourage better understanding amongst professionals and families of caring responsibilities within a family, particularly the impact on children and siblings.
6. Improve information for young carers about their rights and the support available, including the Ease Card.
7. Review the need for increased support with challenging behaviours for the whole family.
8. Work with young carers and system partners to review how young carers who are not connected to support can receive help.
9. Develop a check in process for people who may not have been actively worked with for a while.