

Who Cares for the Carers?

October 2023



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Background

Healthwatch Stoke-on-Trent is the city's independent health and social care champion. We are here to listen to the experiences of local people using local health and care services and about the issues that matter to the people of Stoke-on-Trent.

A carer is anyone, adults or children, who looks after a family member, partner or friend who needs support because of their illness, frailty, disability, mental health or addiction. The care that carers give is mostly unpaid. According to 2021 Census data, there are around 4.7 million unpaid carers in England who care for a friend or family member. This equates to 8.9% of the resident population aged 5 years and over in England.

The 2021 Census data shows that, 10.2% of Stoke-on-Trent residents reported providing unpaid care to a family member or friend. With a population of 258,400 residents that means that approximately 26,000 people in Stoke-on-Trent are providing unpaid care. With 4.3% of Stoke-on-Trent residents (aged five years and over) reporting that they provide up to 19 hours of unpaid care each week.

Many carers don't see themselves as carers and it is suggested that it takes them an average of two years to acknowledge their role as a carer; this is because it can be difficult for carers to see their caring role as separate from the relationship they have with the person for whom they care, whether that relationship is as a parent, child, sibling, partner, or a friend.

The Stoke-on-Trent Joint Strategic Needs Assessment 2022 update, reported that:

- 66.3% of carers in Stoke-on-Trent who received support or services were satisfied whilst 15.1% were dissatisfied (England 66.4% and 16.4%).
- 14.5% of local carers said they don't do anything they value or enjoy with their time (18.3% in England).
- 13.8% of carers felt they had no control over their daily lives (15.7% in England).
- 12.7% of carers felt they were neglecting themselves (19.5% in England).
- Over a quarter (24.5%) of carers felt they had no encouragement or support in their role (compared with 22.8% in England).
- 60.9% people cared for by carers are retired (56.7% in England).

- 22%) had a longstanding illness themselves (29.4% in England), 16% had sight or hearing loss (16.4% in England) whilst a further 22% had a physical impairment or disability (20.2% in England).

In the section 'Ageing Well' it stated that older people experiencing good health can be a challenge depending on where you live and what disposable income you have, allied with a higher-than-average chance of living with a long-term condition.

- 19.1% of local carers felt socially isolated (17.4% in England).
- 35.2% of local carers had a longstanding illness themselves (29.8% in England).

The Stoke-on-Trent Joint All Age Carers Strategy 2021-2025 was developed by the City Council and Stoke-on-Trent Clinical Commissioning Group (CCG) in partnership with young and adult carers, and health, voluntary and community organisations. The aim of the strategy is to ensure that carers have the support, advice and information that enables them to maintain a balance between their caring responsibilities and their life outside of caring.

The strategy sets out five key priorities over four years and will inform the strategic planning, service delivery and commissioning of support for carers across the city. The 5 priorities are: identification and recognition, realising and releasing potential, a life outside caring, supporting carers to stay healthy, and young carers.

Healthwatch Stoke-on-Trent, through its engagement activity, have received feedback from carers about their experiences of accessing services as carers. The result of this intelligence is that we decided to undertake some broader engagement with the aim of understanding how closely their experience relates to the stated priorities and objectives outlined in the Carers Strategy. The objectives of this study are:

- To understand the experience of being a carer in Stoke-on-Trent.
- To understand the quality of a carer's life in terms of their health and wellbeing.
- To understand carers' experience of accessing support to help them maintain their health and wellbeing and carer/life balance.
- To identify and understand the barriers which prevent carers from accessing help and support for themselves.
- To identify any gaps in existing service provision and to share these findings with Commissioners and Providers.
- To raise awareness of support services that are available within Stoke-on-Trent City Council to those people with caring responsibilities who may not currently access services due to lack of awareness of what is available and what they are entitled to.

What we did

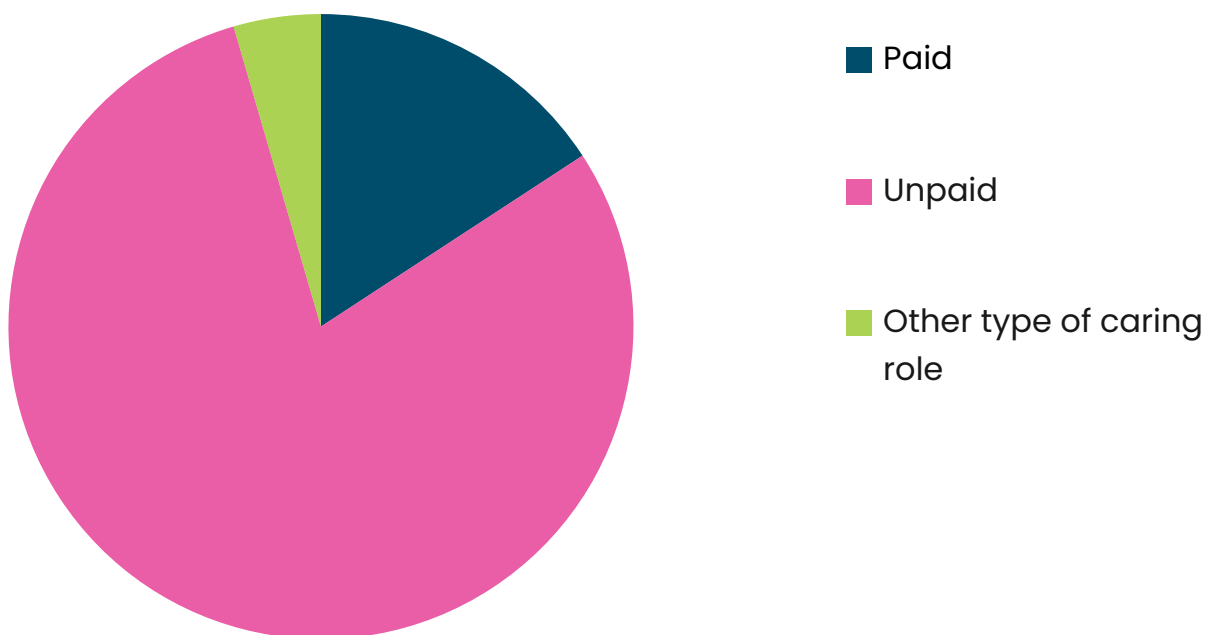
We used a structured questionnaire to gather the experiences of carers in Stoke-on-Trent. Within our questionnaire were several questions which have been used in our other key projects undertaken throughout 2023 - 2024, which we refer to as 'golden thread' questions. The 'golden thread' questions remain consistent throughout our projects and relate to issues around access to services, including digital exclusions, accessibility standards and the availability of services and the impacts of not having access.

Throughout July to September 2023, alongside making the survey available online and promoting through our digital channels, our team attended 19 local carers groups run by organisations such as: North Staffordshire Carers (NSC), Approach, MS Mondays, and Parent Engagement Group in Stoke-on-Trent (PEGiS). We also attended a young carers group to ensure we capture the voices of those who are carers and under the age of 18.

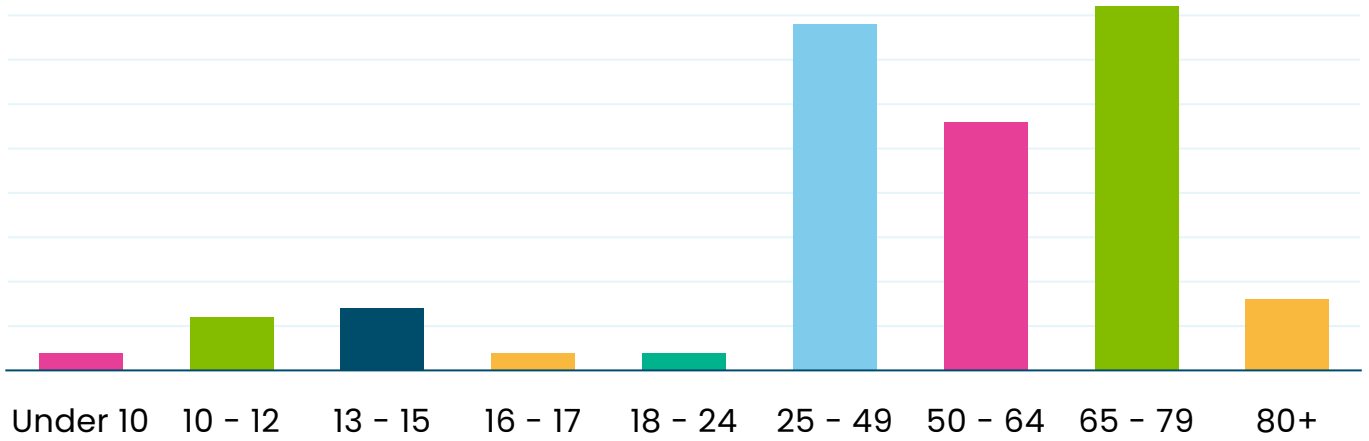
Who we spoke to

We received a total 135 responses to our survey online and through attending local carers groups. We gathered additional feedback through these groups and attended a young carers group where we spoke to 22 young people aged between 7-17 years which has been included in our analysis of this study.

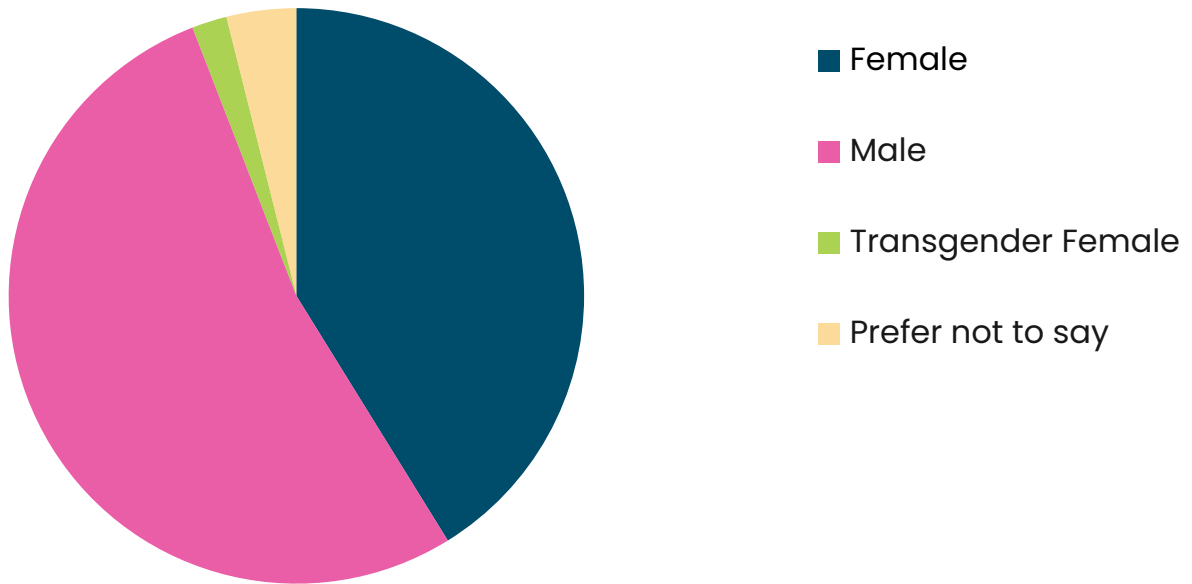
1. Type of carer.



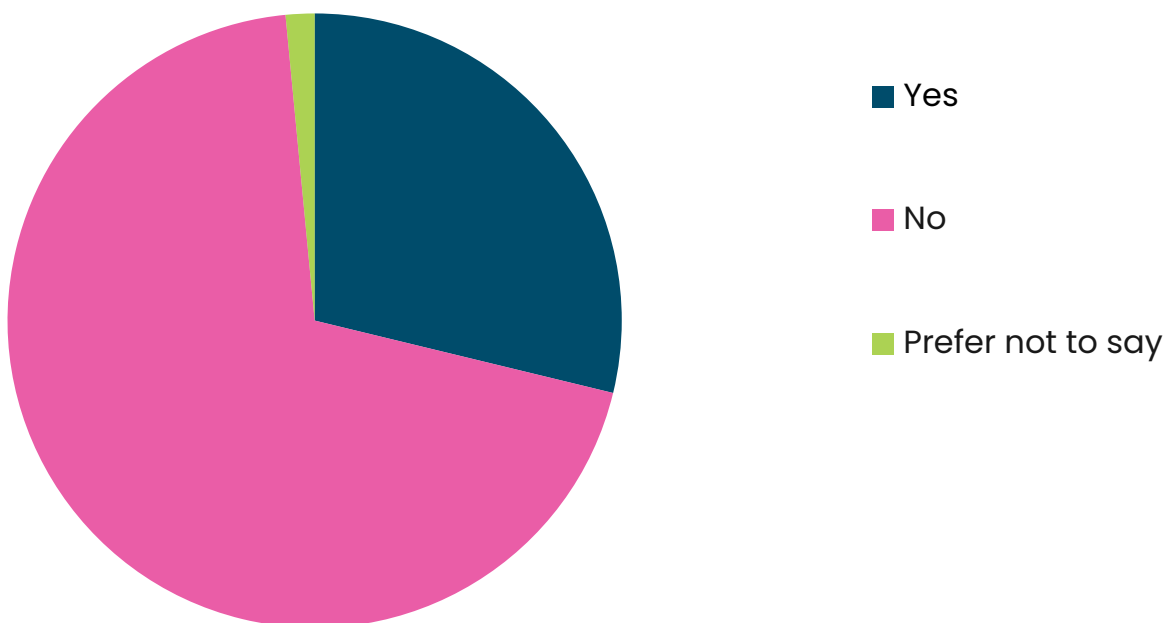
2. Age of carers.



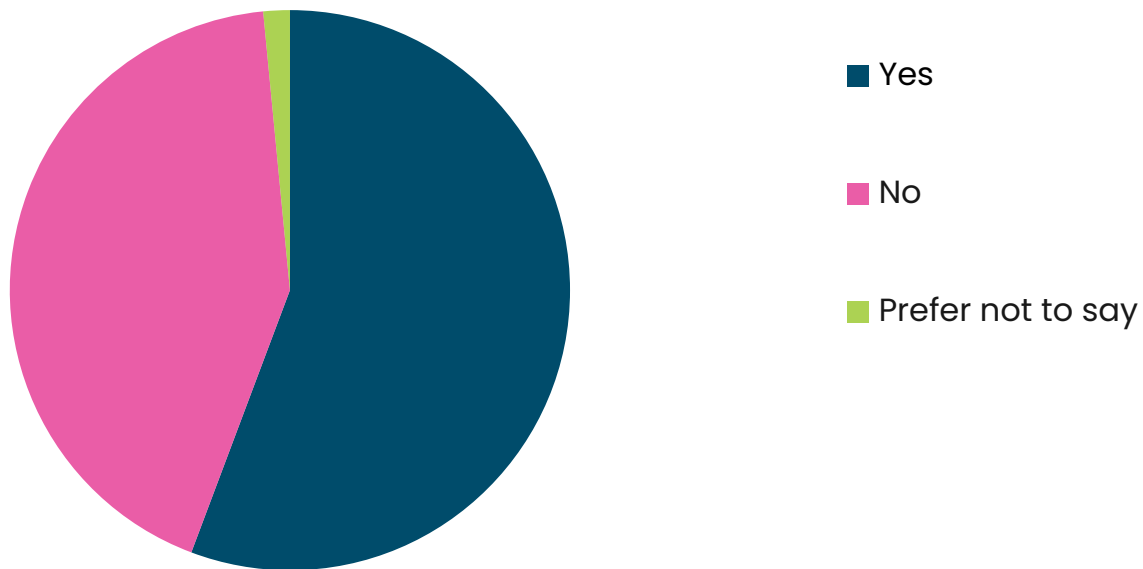
3. Carer's gender.



4. Carers with a disability.



5. Carers with long-term conditions.



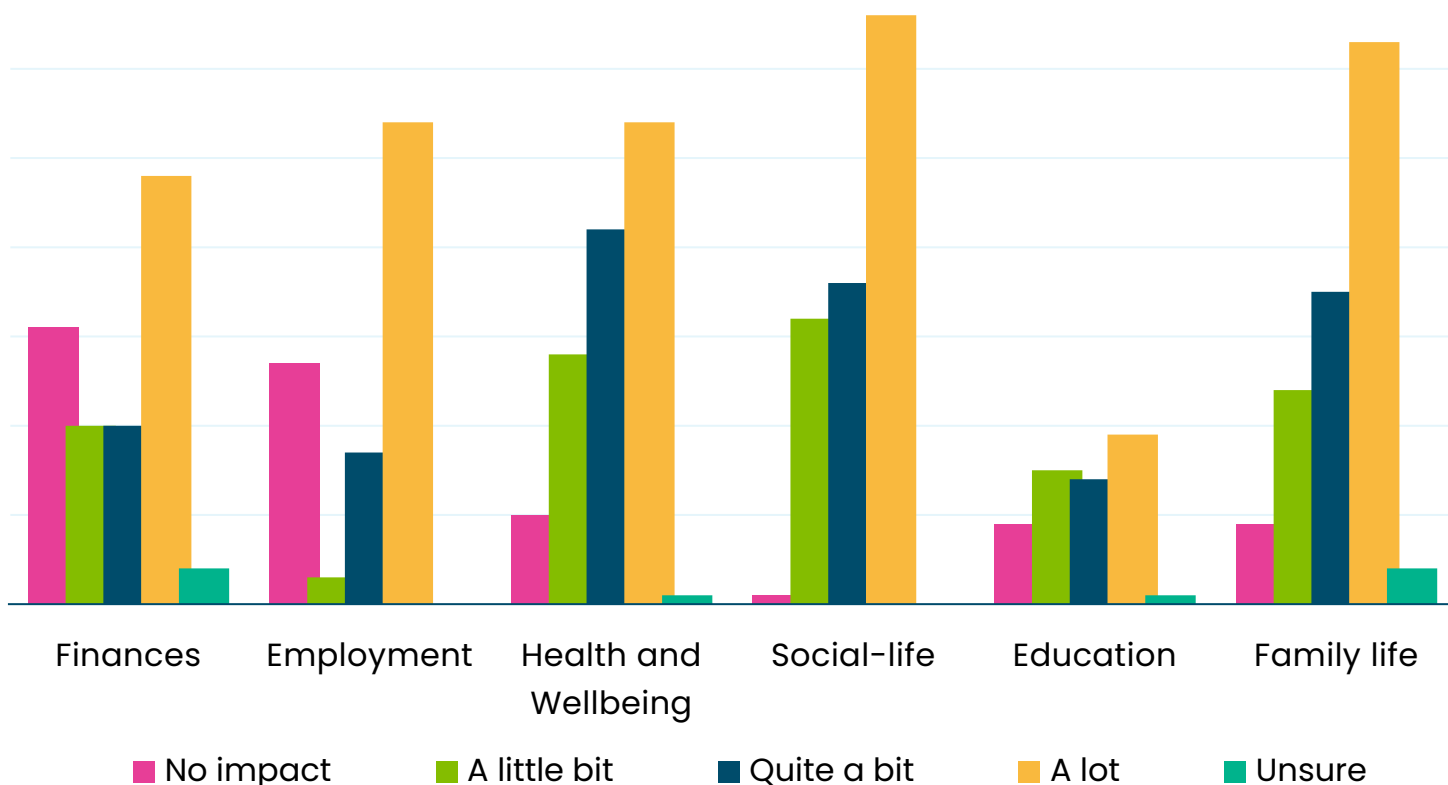
The figures outlined above were collected through our survey responses. In addition, most carers we spoke to at carers groups were unpaid, older female carers who cared for a spouse or a parent. Several cared for both parents and one young carer told us that they were the main carer for their whole immediate family.

It is of note that over 60% of carers themselves have a long-term health condition. This is a reflection of national data from Census 2021 and Carers UK which showed that, 59% of unpaid carers are women, and that women are more likely to become carers and to provide more hours of unpaid care than men. Other studies show that more women than men provide high intensity care at ages when they would expect to be in paid work. 60% of carers report a long-term health condition or disability, compared to 50% non-carers. These figures are in line with national data and in some cases are higher in the Stoke-on-Trent area than nationally.

Key Findings

Respondents were asked a series of questions, including both closed and open text questions, about the impact caring has on various aspects of their lives.

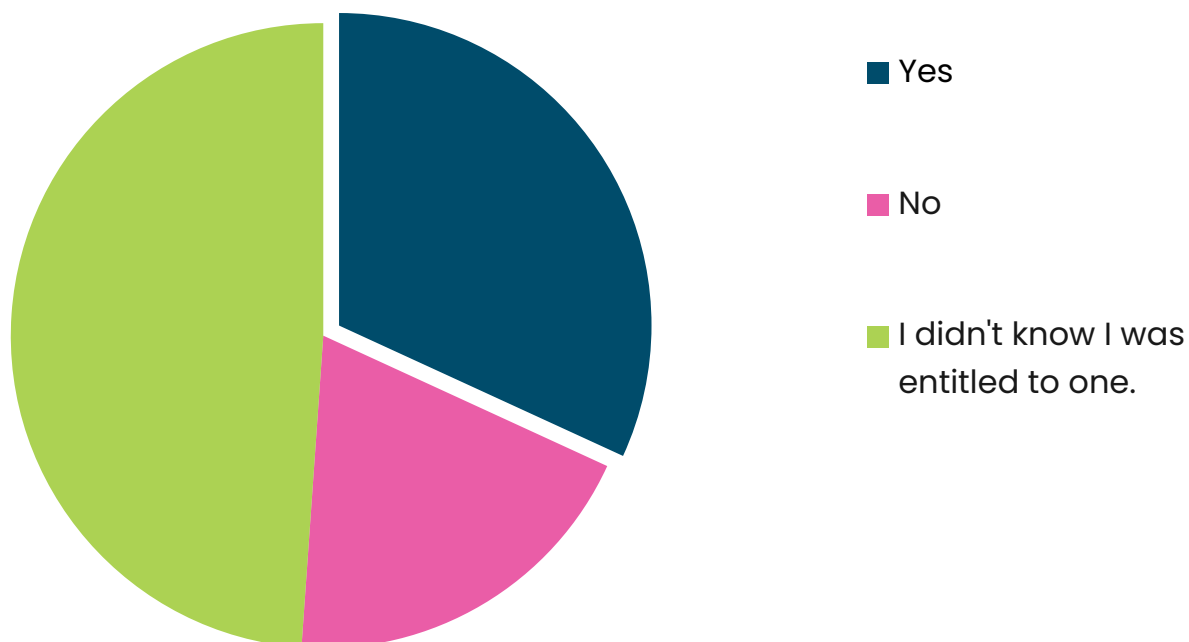
1. How would you rate the impact that caring has on your:



The data gathered through our survey mirrors the findings from the Carers UK study. Most of our respondents reported that they have been affected quite a bit to a lot in each category other than education which for most did not respond or marked as 'not applicable' as respondents were adult or older carers. Many of the young people we spoke to however mentioned education as being the area they were most impacted by and mentioned particularly the lack of support in school as being a main area of concern.

The data shows that more than half of total respondents were impacted negatively around family life, finances, health and wellbeing social life and employment. The level and degree of this was reflected in many of the comments received in later questions.

2. Have you had a social care carers assessment via The Stoke-on-Trent City Council?



Many respondents, 49%, reported that they were not aware that they were entitled to a carers assessment whilst 19% had not had one. Some of those were still waiting for an assessment. comments received included.



"I have been waiting for an assessment since 2021."

"I haven't applied as I wasn't aware I could have one."



A small number of respondents were unclear about whether they had received a carers assessment as they had no recollection of that term being used.



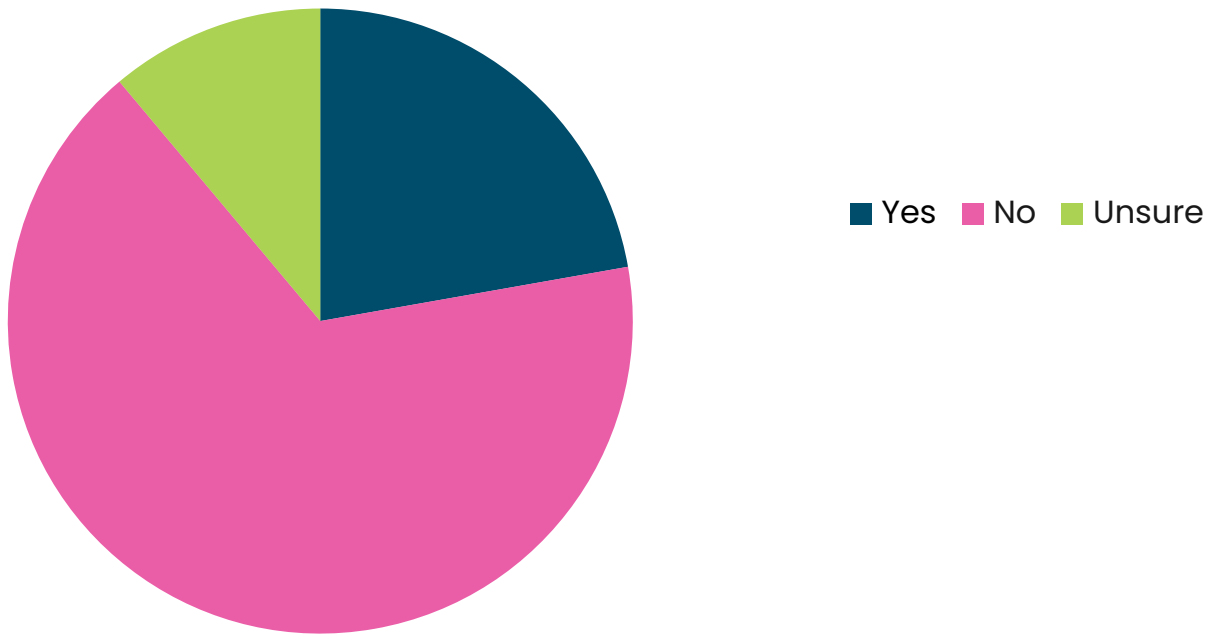
"I don't know if I have had one or if I am waiting for one."

"I think I had one because I get carers allowance, but I am not sure."



There may be several carers therefore who have had a carers assessment but are unaware of it as the communication and information may not have been very clear.

3. Were you given enough information on available treatment and support for yourself and the person you care for?



Over two thirds of carers did not feel that they had been given enough information about the treatment and support available either for themselves or for the person they cared for.

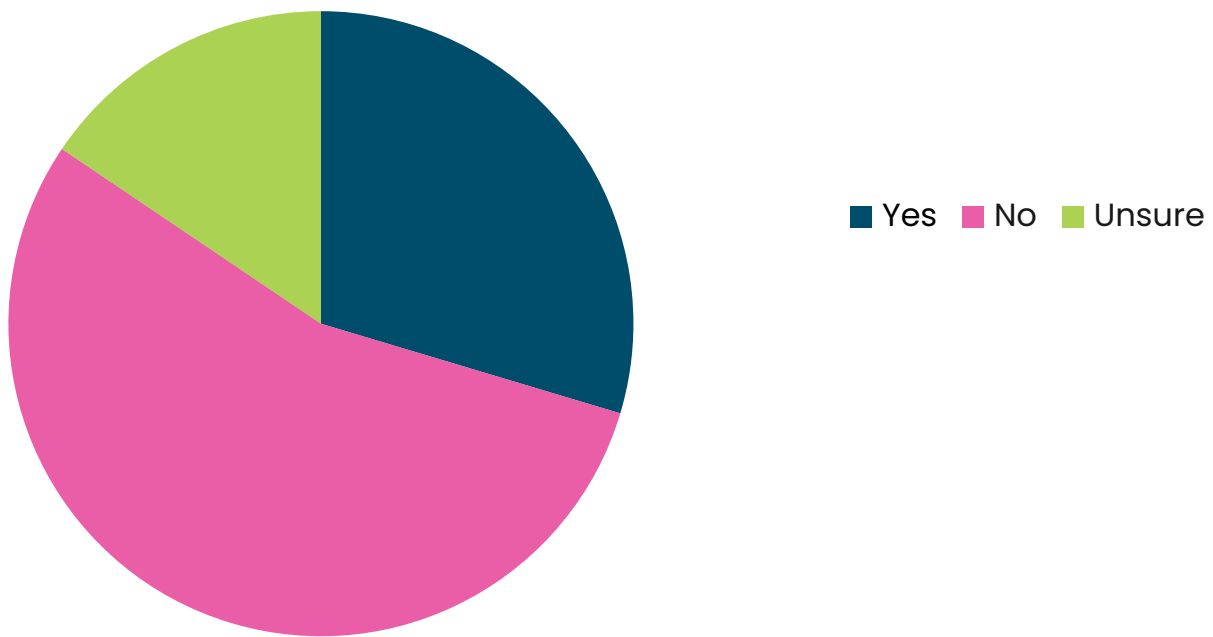
We included an optional text box for anyone who wanted to provide more information, where 59 respondents left additional comments on the information that was or wasn't provided.



"I was not given any information as a carer. I was just left to get on with it."



4. Was the information you received clear and easy to understand?



Of those who had received information commented that although they had been given information, it wasn't necessarily accessible to them due to either the formatting, overwhelming quantity or even poor timing. Given that carers have many responsibilities they often are left with limited time.



"I had to give up work to care for both my parents. It was a struggle to find out what help was available , no-one rushed to help so I had to give up work."

"I was given pages and pages of information and it was not in clear language, and there was too much of it."



Additionally, due to a carers often having a close relationship to the person they care for there is an added emotional factor that can make the role of being a carer more difficult and can take time to adjust to their new responsibilities.

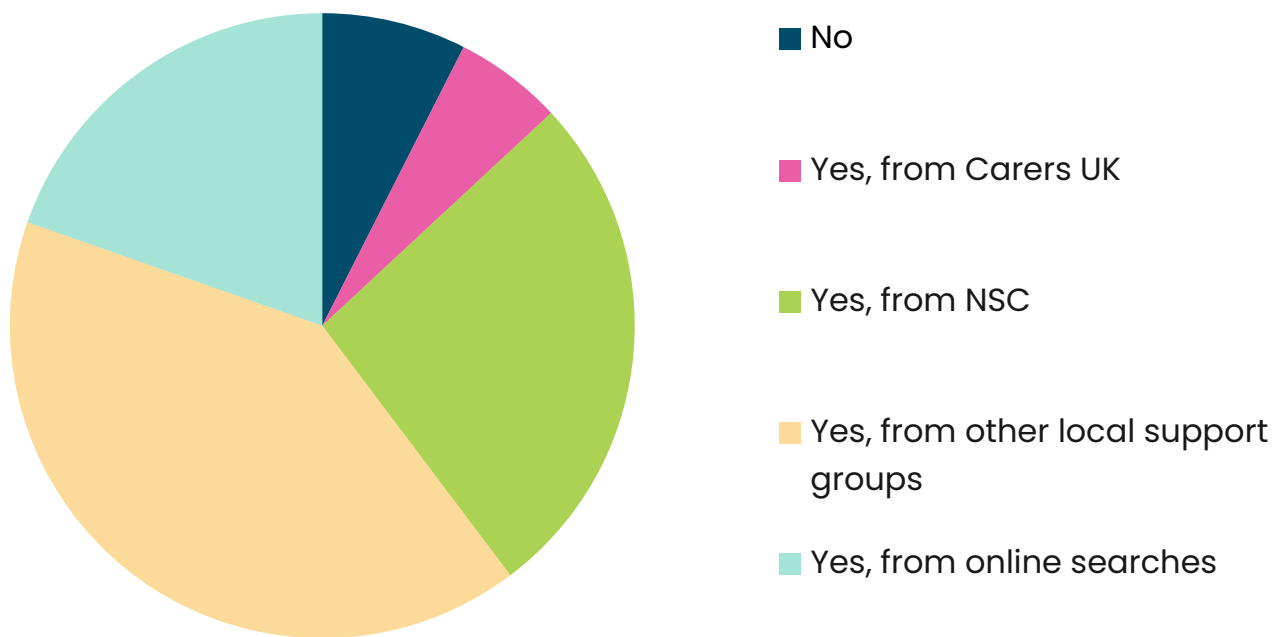


"I was given leaflets but couldn't read them as it was all too much at the time."

"Initially the information seemed a bit overwhelming, but after a while I found I could appreciate it."



5. Did you need to find information elsewhere?



Most of those who commented on not having received enough information had shared that they had to go to other community-based groups to get information and praised the services for their help in providing information and ensuring that it was clear and understood. When asking respondents if they needed to find information elsewhere only 12% had not, with the remaining 88% having sought information through many sources.

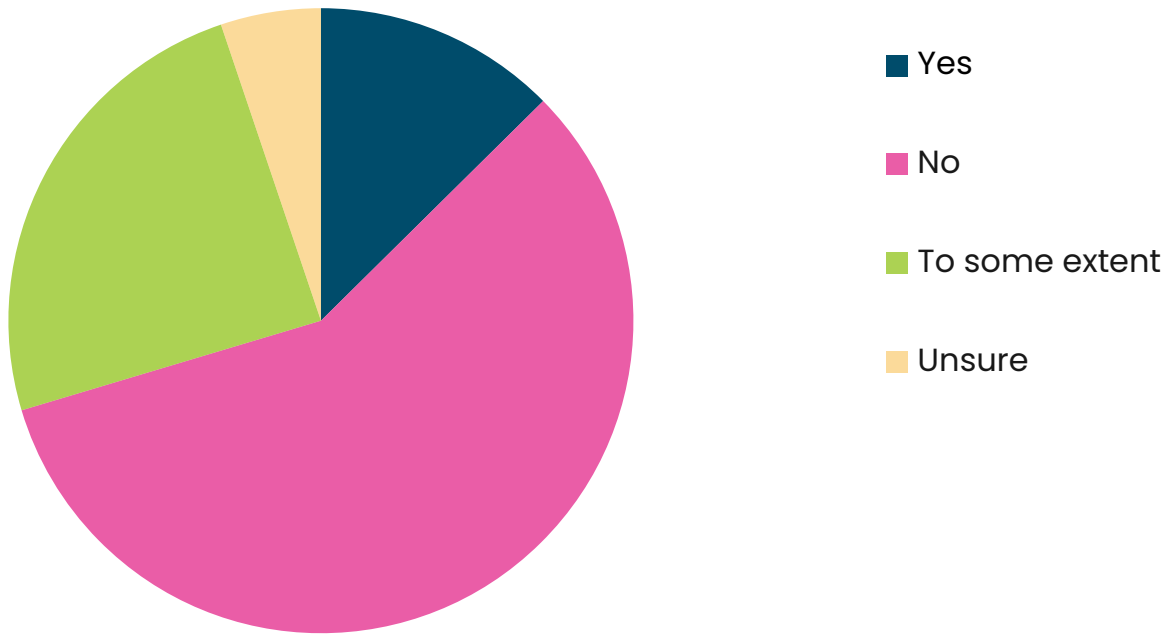


“Thank goodness for Approach. They have been fantastic. Without them I would still be floundering”.

“I eventually got some information from other carers and the internet but because I wasn’t used to it, it was difficult to understand at first. North Staffs Carers and Approach helped me a lot once I found out about them from going online.”



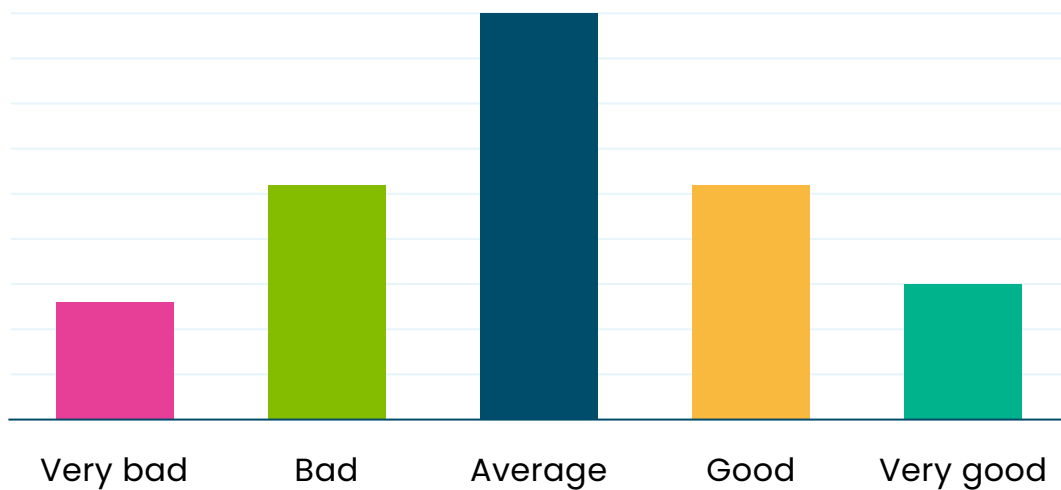
6. As a carer, do you feel that you receive enough support to balance your caring responsibilities with work/education and to have a life outside your caring role?



Over half of the carers did not feel that they received enough support to balance their responsibilities as a carer with their personal life and daily activities.

7. How would you rate the support you receive from:

a. your GP?





"Getting appointments with the GP was very difficult..."

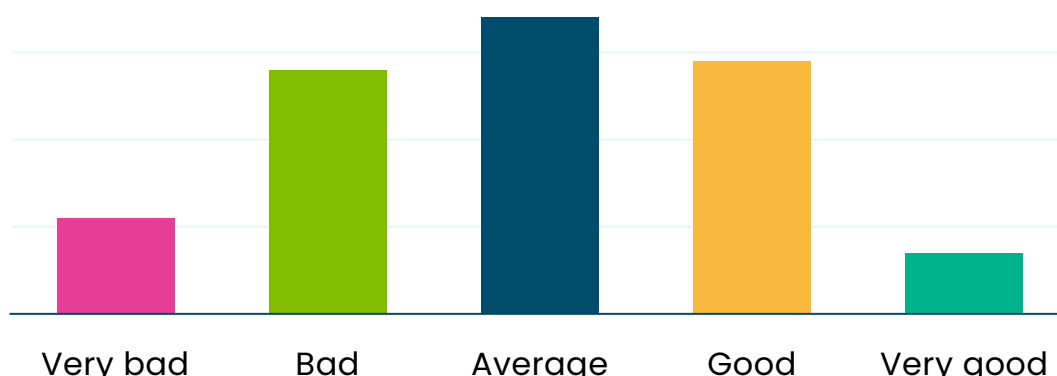
"GP has been ok and is the main person we have contact with."

"GP has been very unhelpful.."

"My GP has been the best help we have received so far."



b. Hospital?



"There's been very little help from the hospital following diagnosis."

"My last 3 appointments have been cancelled."

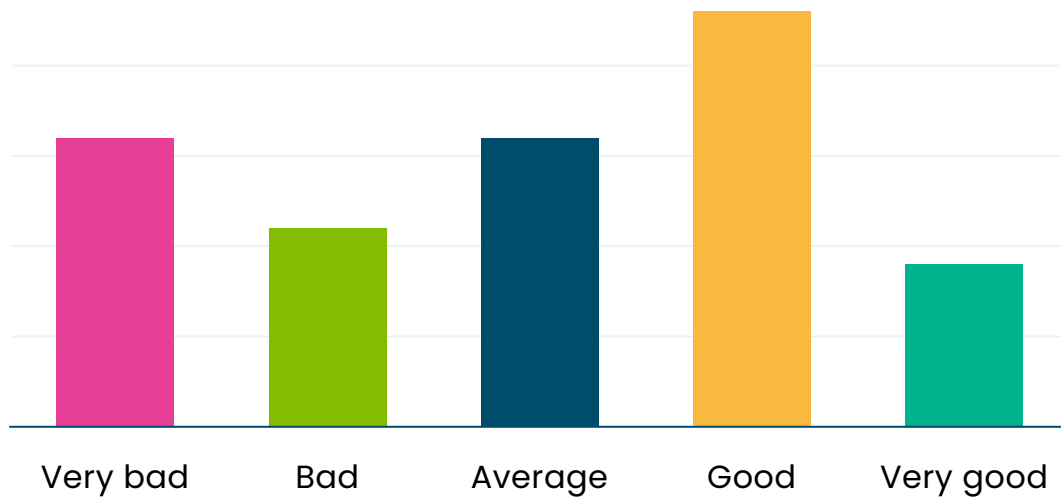
"I've had no follow up from the hospital since diagnosis."

"Not had any contact with anyone other than the GP and hospital, both of which were not great at giving information or assistance"

"I ended up paying privately to see a consultant as the waiting list was far too long."



c. your dentist?



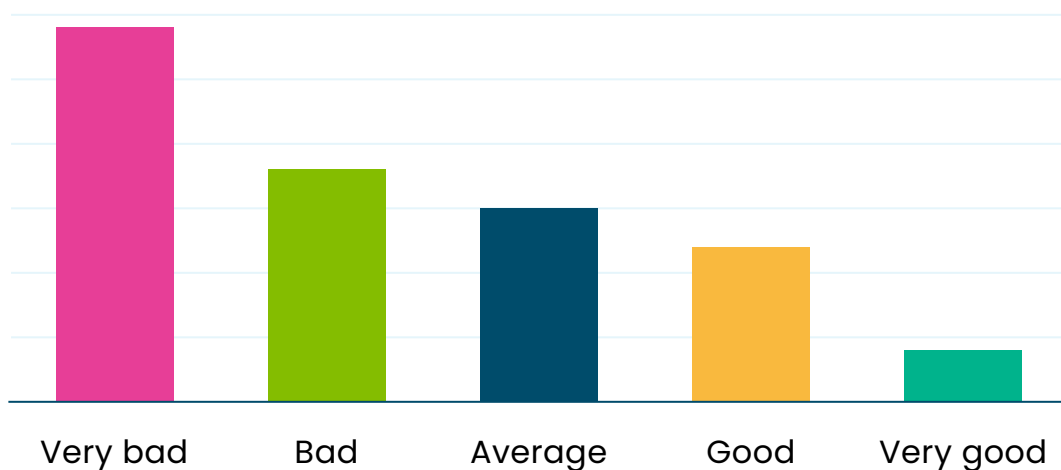
“My dentist was good, until they decided to accept private patients only and discharged NHS patients leaving us without a dentist!”

“I had a terrible time finding a dentist.”



60 respondents did not rate the support they received from their dentist. We asked people to explain their answers through additional comments and found that many did not have access to an NHS dentist.

d. Mental Health Services?





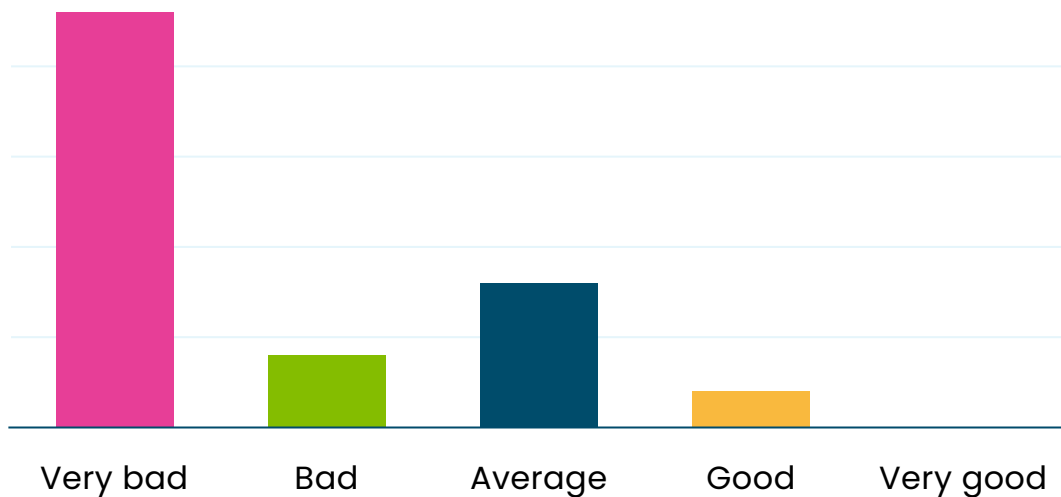
“I have had to wait for months for a face-to-face appointment with the mental health service.”

“There’s a huge waiting list for mental health support. I’ve been waiting 9 months now but not a priority.”

“Limited mental health support available. I had a couple of calls and then told I wasn’t bad enough to get any more help.”



e. CAMHS?



“Still waiting for an assessment from CAMHS. I was told that there is a long waiting list.”

“CAHMS seem to take too long to do anything.”

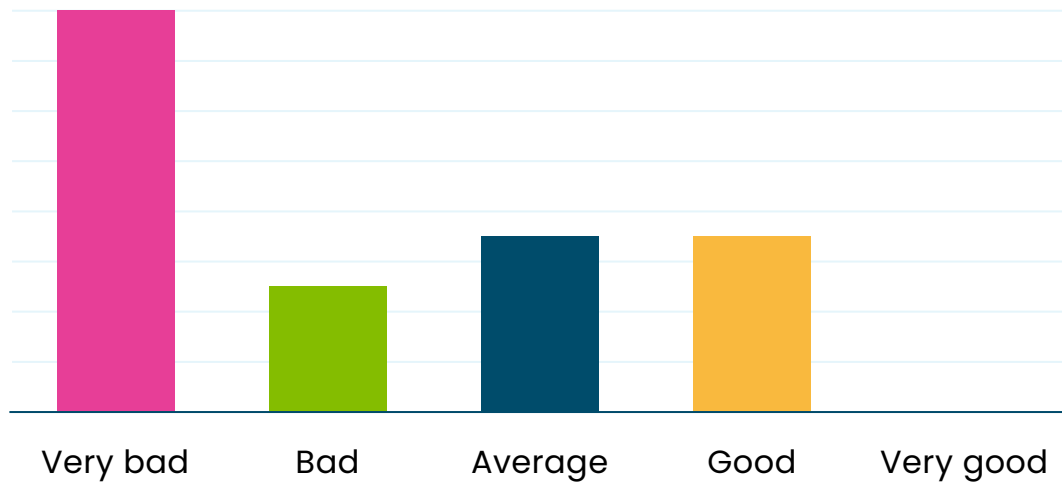
“We had one appointment with CAMHS and then they discharged us.”

“It’s absolutely impossible to get help from CAMHS. None of our referrals have been accepted.”

“CAMHS didn’t want to know...”



f. Children's Social Care?



"Had an assessment by social services and got referred to young carers at North Staffs Carers - that was it."

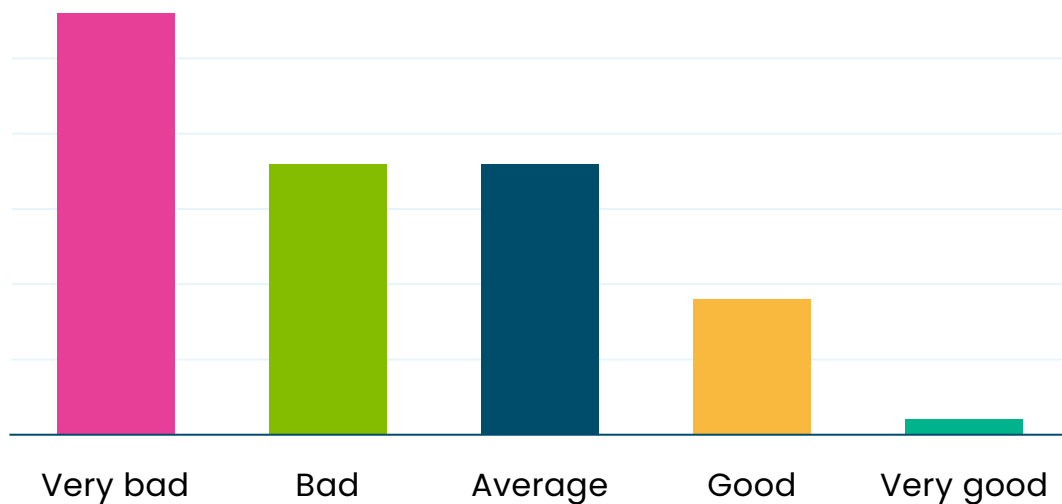
"I got some help from social services with shopping and cleaning and I do the rest."

"I don't get any help from anyone. It's just me caring for my sibling. My parents help when I come to young carers groups."

"I only get support from the young carers group."



g. Adult Social Care?





"I couldn't get through to social care and finally when I did, I was told there was a 12 week backlog. Not good for someone with a terminal illness".

"I have waited 7 months so far to get some equipment for my partner to have a shower or a bath safely."

"I have only tried to get help from social services and am still waiting for some equipment in the house. They encourage you to buy your own, but I am still waiting for someone to visit to advise me on what we require and what is the best things to buy."



The majority of respondents rated support from services as average to bad. 77 carers made comments about their experiences. Most relate to a lack of support from any of the main services.

CAMHS services was commented on as the most difficult service to get access to by young carers and parent carers with most citing excessive waiting times for assessment and then being rejected for help due to not meeting the criteria.



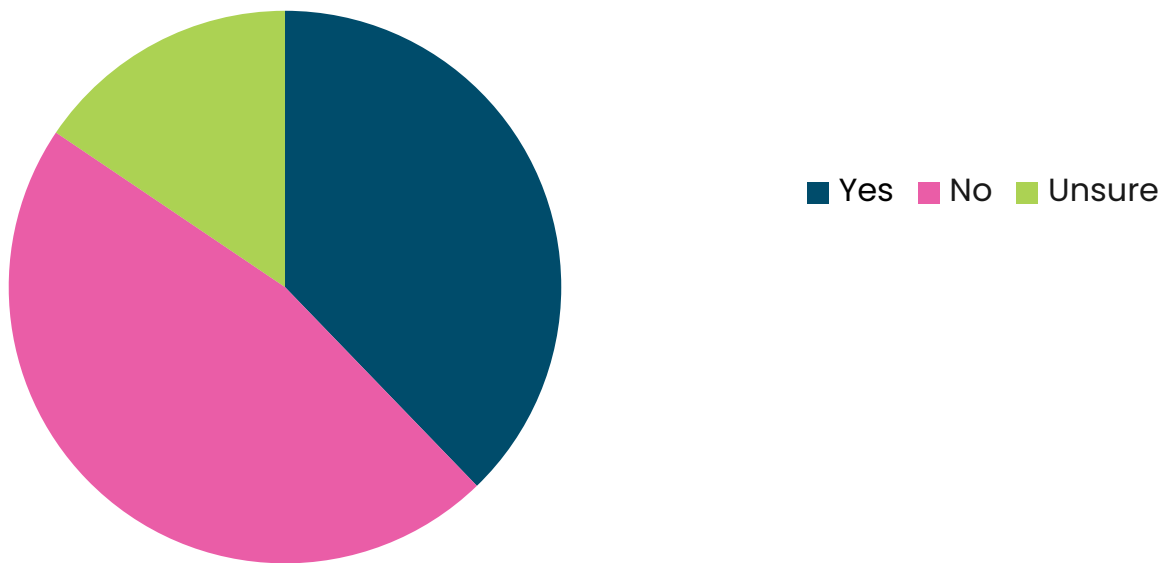
"It's a fight to get any help or information, and you can't fight when you are tired and busy".

"I don't think anyone really takes the role of a carer seriously."

"You have to be very persistent to get any help at all."



8. Do you generally feel valued and involved in the decisions being made about the care and support of the person you care for?



Of the 41 people who provided additional comments on this question, most did not feel valued and involved in decisions made about the care and support of the person cared for. Comments detailed that they did not receive any help or were not able to get help that they felt they needed, so therefore did not feel valued or involved. As previously noted, local community-based groups were mentioned as the main source of support for people in their caring role. Several parent carers who commented felt that they were not listened to and often 'blamed' for their child's problems.

“Professionals think the person I care for is capable of looking after themselves, but my experience is completely different...”

“They don’t believe me...”

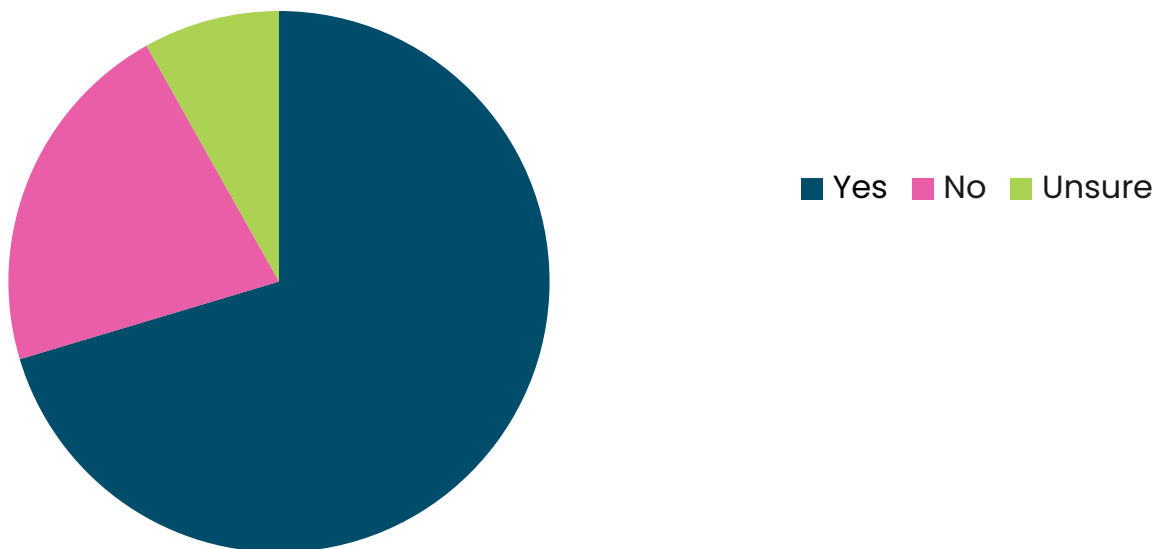
“I feel mostly alone.”

“As a carer I don’t really get told anything or get asked to contribute anything.”

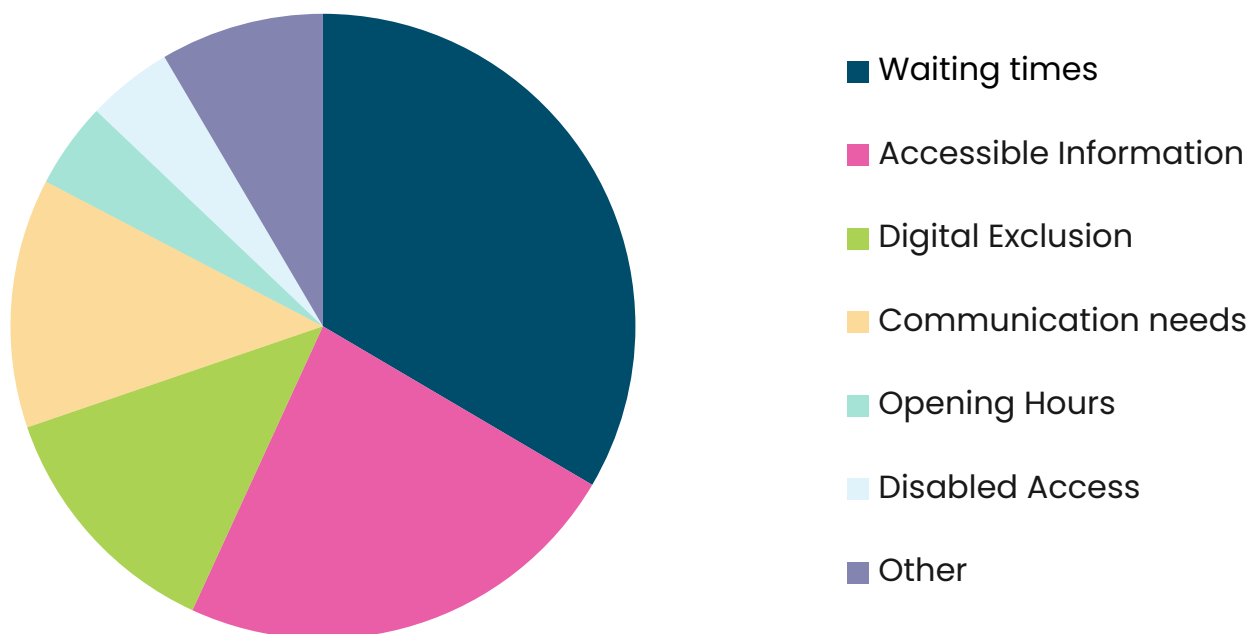
“As the main carer I have been very involved in decisions.”

“Services don’t work together or even talk to each other so nothing is co-ordinated.”

9. Did you experience any issues when accessing the services you and the person you care for need?



a. If yes, what were the issues?



Waiting times was the most commented on issue in relation to access and this was particularly around appointments and assessments for social care services. The following comments are typical of the views expressed.



“Waiting and calling is a big issue, it takes up so much time and causes great stress!”
“Waiting times cause the biggest frustration. Everything is a wait and takes so long.”



Digital exclusion and Communication needs were also commented on with the two areas being closely connected. This related mainly to carers and cared for unable to access information or appointments online due to lack of access to the internet or skills to access online technology.



"...my parents are unable to access the internet and information or help online. I have to do this for them."

"I'm not on internet, so I rely on word on mouth which is not helpful."

"I can't use the internet... so I have to wait for family to visit."

"Not everyone has access to the internet, yet this is the way you are expected to find information these days and that is not helpful to those of us who can't get information this way."

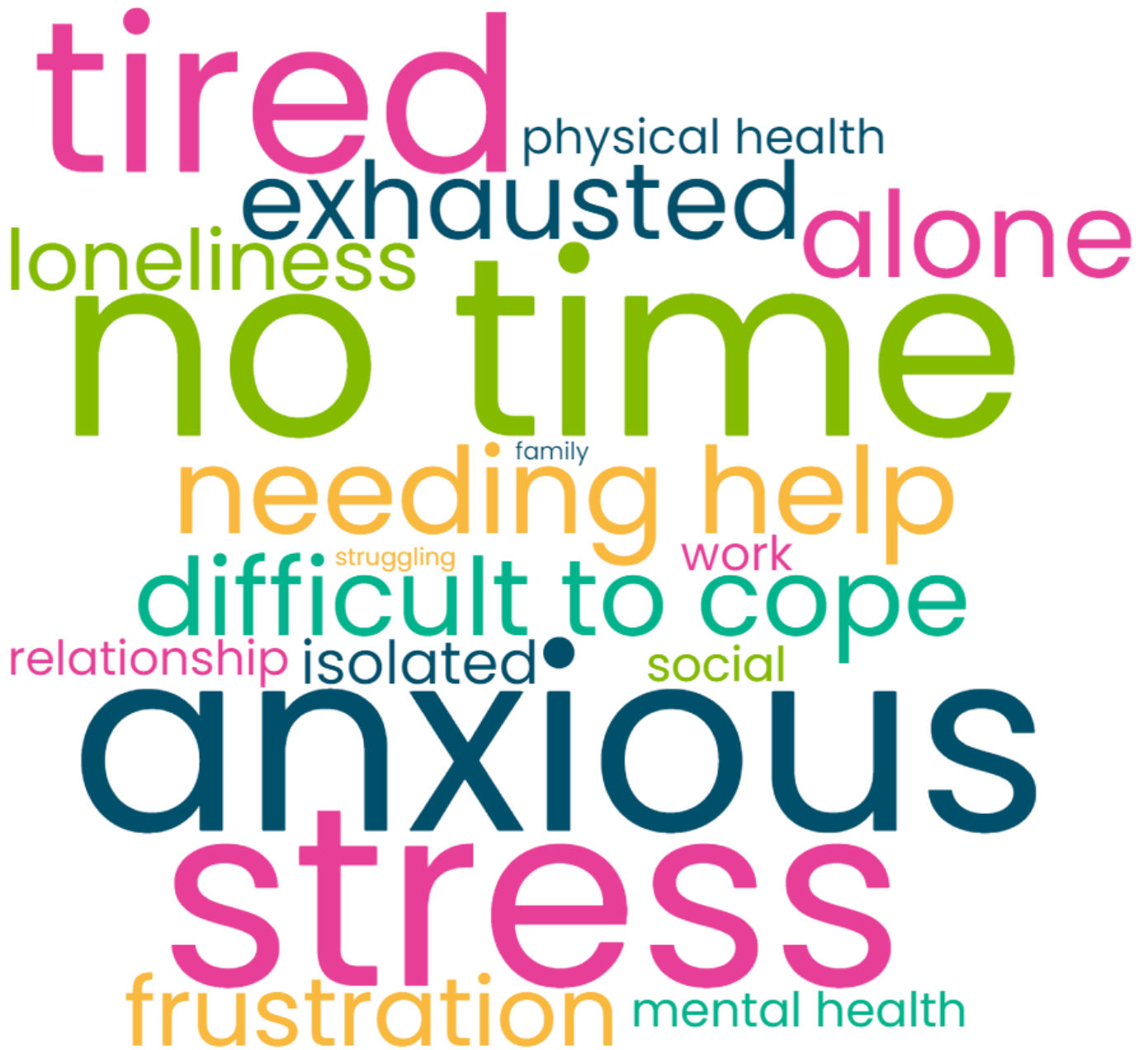


There was a perception expressed at the carers groups that to know what is available and to access services these days requires you to access the internet and that if you don't have access then you miss out on having information and access to many of the service available.

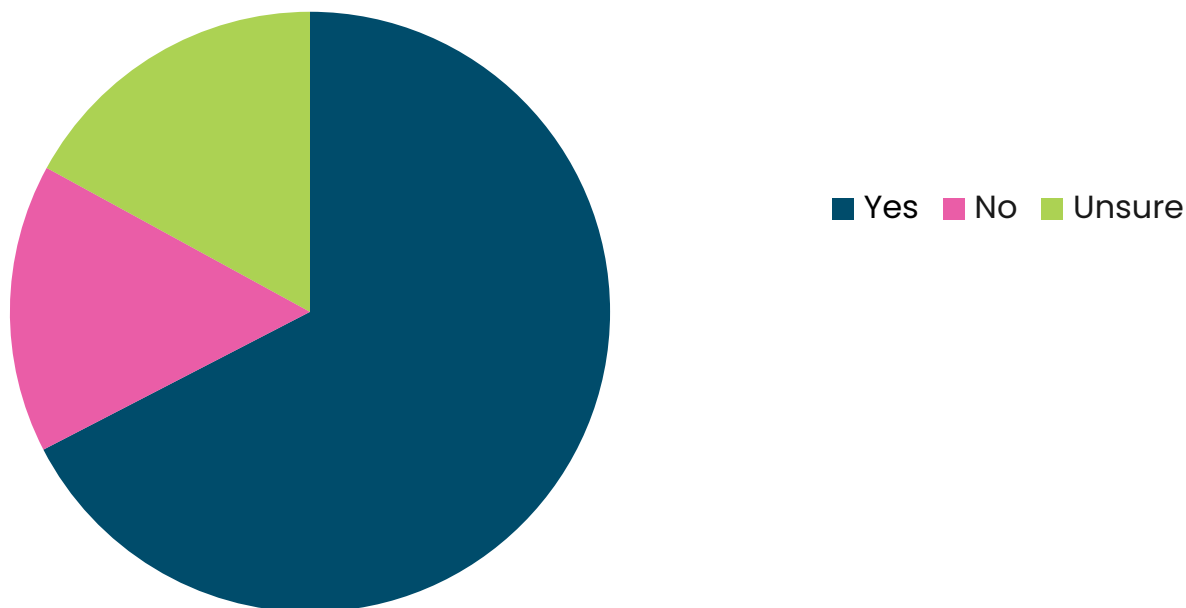
Other issues highlighted included areas such as transport, and early discharge from services without the proper support in place. Many carers expressed a feeling of being 'abandoned' so soon after diagnosis without support and this applied to all services including mental health and CAMHS. The term 'discharged and disregarded' was used by one carer but echoed by others in different forms.

The impact of a lack of access

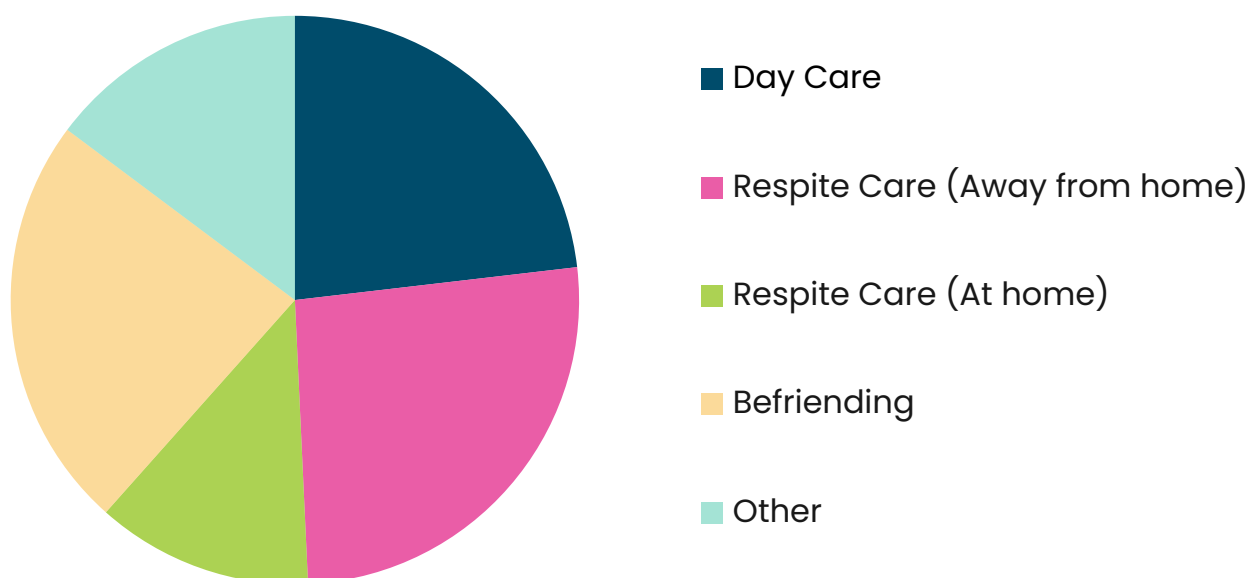
Following on from the questions regarding accessing services, respondents were asked to comment on what impacts the issues of not being able to access services had on them. 55 Carers responded to this question detailing what the impacts their caring role has on them. We pulled out the most frequently used words and terms from the carers responses to determine the common impacts that carers experience.



10. Is there any support that you would find helpful that is not currently available?



a. If yes, what sort of support would you like?



Respite care was seen as a major obstacle for those who had tried to book this in the past to have a break themselves and this included either outside, in the home or in a day care environment.

Several people mentioned the difficulties they encountered trying to book a holiday due to the unresponsiveness of social care to arrange a respite care placement by the time the holiday had to be paid for. Many of the 77 comments related to alleviating the impacts of caring as outlined above and many expressed a wish for just a short break from the day-to-day responsibility of caring.



“Respite care would give me a break now and again and a chance to recharge my batteries”.

“The person I care for is fit and active, it would be good if they could go somewhere to socialise with other people other than me”.

“Both my parents could do with some stimulation outside of home, but this is not forthcoming”.

“I tried to get respite care so that I could go on holiday, but it was impossible, so I had to get my children to help while I had a much needed break”.

“My partner is currently in a care home, and I have been visiting almost daily. It would be nice to have someone to befriend them so that I could have a break from visiting.”



Of those who had other types of support in mind shared that support with daily activities would be very helpful as it would reduce their workload and therefore assist them in their caring roles.



“I would like help to fill in forms to claim benefits I am entitled to.”

“Support with housework, etc. So that I can do the care my family member needs.”

“Advocacy to help me through the system to get help.”



Young Carers

In conversation with the young carers group, concerns were raised about the lack of help at school and a lack of support, awareness and understanding of the impact of caring upon their ability to participate fully in school life including keeping up with their schoolwork. Young carers expressed the need for more to be done to raise awareness of the issues they encounter and the impact this can have on them and their educational attainment.



“Help so that I can get an education.”

“More groups like this so that I can talk to other people in the same situation.”

“Help at school with my work as I don’t have enough time to do my homework.”

“I don’t really feel comfortable talking about my problems at school but sometimes find it hard to keep up with everything so some help would be good.”

“Some teachers are very good and understanding when you don’t hand in homework but others have no sympathy and give you a lot of hassle about it which just makes me more stressed.”



Our Conclusions

This study provides an insight into what we have learned about being a carer in Stoke-on-Trent from the perspective of those with lived experience of caring. What we have learned from this work is that, whilst carers are a diverse group of people from different backgrounds with very different needs, there are many similarities in their experiences of accessing services and the impact that caring has on their health and wellbeing.

When someone begins their caring journey, at the point of recognising or being recognised as a carer, the systems are confusing. This was evidenced by the fact that of the 135 respondents to the survey, 92 had not received a carers assessment and 66 of those did not know they were entitled to one. Similarly, 95 carers reported issues accessing services and the main reasons cited for this was due to lack of access due to waiting times, digital exclusion, and lack of accessible and easy to understand information.

Many carers talked about two key issues: first, finding the information needed in a timely fashion, and then secondly the difficulty of navigating their way through the vast amounts of information that was available to enable them to access appropriate services when they were required.

Of those who commented, most carers felt that the support they received from formal or statutory services was inadequate and did not enable them to balance their caring responsibilities with everyday activities such as work, education, a social life, or their family life. Carers generally found it difficult to navigate through a maze of information and services and encountered barriers when accessing statutory services and support from the NHS, social care services and education in particular. These barriers and challenges are reflected in the comments made about the impact of caring on their health and wellbeing with over a third of carers reporting significant impacts because of their caring role.

There are services out there who provide excellent support for carers, and this was acknowledged in the very positive comments received by carers who were in contact with support services through North Staffs Carers, Approach, Young Carers, and other support groups which people highly valued. Carers particularly valued the emotional support provided in the groups and the practical support such as help with applying for benefits and signposting to other services. There was a strong desire expressed for more of these types of services.

It was evident that carers need good, clear information and more signposting from whichever service they turn to, whether it is their GP, other NHS services, or local community groups. Helping to empower people to meet their own needs may help to prevent a situation reaching crisis earlier than they might otherwise have done had support been provided in a timelier manner.

Some carers, particularly older carers, reported that they did not have access to, or use of, the internet. Some did not want to have to use this method to access information, but others cited cost and lack of skill as a barrier. There was a belief that most information is only accessible via this avenue and therefore they may be missing out on the benefits the internet can bring making them further disadvantaged as more and more information and support is delivered using technology.

It is important to pay attention to the educational needs of young people who are carers and that schools receive information and training on how best to support young people to keep up with schoolwork and participate in school life generally. A high proportion of the young carers we spoke to were aged between 7-11 years and many expressed difficulties in keeping up with schoolwork. Whilst some reported good support from their school, others reported a distinct lack of support with this often reliant on a few good teachers.

In order to meet the range of different needs of carers in Stoke-on-Trent, there are further actions that are required for the carers strategy to fulfil its 5 priorities.

Recommendations

Based on our feedback and findings, we have the following recommendations to help improve services for carers in Stoke-on-Trent:

Carers Assessment

- Review Carers Assessment procedures to prevent carers falling through the net because of a lack of awareness about their right to an assessment.
- Promotion of the right to a Carers Assessment with a clear procedure for accessing this in a timely manner once a person has identified or been identified as a carer. This should be accompanied by information provided about what they can expect once they have one.

Access to Information and Signposting

- Improve signposting and referral system to carers support from all avenues within the health and social care system with a clear procedure to provide concise information to carers at the point of assessment or contact. A single point of contact may assist with this.
- Review systems for providing information to carers about all services and support available, Where, when, what and how and how this can be accessed easily.
- Design processes for carers to be able to access information and referral from whichever service they are accessing. This includes information being available in GP practices through social prescribing, in hospitals through wards and clinics, and through workplaces and schools.
- Clearer pathways to accessing services such as Adult Social Care. Current arrangements need to be simplified so that people who require help in a crisis or want to plan a short break are not facing significant barriers in accessing the help they need.

Young Carers

- Consider ways to work more closely with schools, including training on how to support young carers and ensure they are not falling behind with their schoolwork.

Digital Exclusion

- Look at ways to increase access to technology and educate more people on how to use technology to access information so that they feel that they have equal access to services that they perceive people who can access the internet have.
- Ensure that any services that are available online and through technology are equally available and accessible to those who do not have the means or desire to use digital services.

Response

Cllr Duncan Walker, cabinet member for Adult Services:

Stoke-on-Trent City Council and the Integrated Care Board welcome this report from Healthwatch Stoke and whilst it is clear improvements are needed it is fantastic to see some positive feedback included in the report especially about our jointly commissioned Carer Support Service.

This report highlights the importance of unpaid Carers as well as some of the challenges that unpaid Carers face. We are pleased to be able to share what we have done, what we are doing and what we will be doing to address some of the recommendations that you have put forward.

Carers Assessment

We acknowledge that more awareness is needed around Care Act assessment's, we have been working with Social Care staff to ensure that this is embedded in their practice. We have introduced a clearer, defined process and are implementing refresher training and drop-in sessions for assessment staff which will be regularly available to avoid any gaps in knowledge.

Access to Information and signposting

Our jointly commissioned All Age Carer Support Service is the single point of contact, we will reinforce pathways with our partners in the Integrated Care System via the Carers Partnership Board so that all Carers are given the opportunity to receive information, advice and support from the commissioned provider.

Young Carers

It is our intention to have a Young Carers Champion in every school across Stoke-on-Trent. Following the recent changes in the school census which now requires all Young Carers to be recorded, our inhouse Young Carers Team will continue to strengthen the links with Young Carer Champions and share information where possible to ensure that Young Carers are getting the best support from their school.

Digital Inclusion

We are always looking to develop innovative digital solutions as we adapt to the technological advances in society, but we appreciate that some Carers may not want to or be able to access technology devices. In these situations, we would encourage them to use the community lounges, family hubs, libraries and carer support groups, where there is always staff and volunteers able and willing to provide information, advice and support. There is also a dedicated telephone line for our commissioned provider which is open 7 days per week.

The Carers Partnership Board would welcome Healthwatch Stoke to present this report at the next meeting. The findings from this report as well as data from the national carers survey that has been distributed in the past few weeks will inform the Carers Partnership in how we continue to shape and improve the support offer for unpaid Carers. If anyone is interested in being involved in the Carers Partnership Board, please email CarersPartnershipBoard@stoke.gov.uk.

Thank You

We are grateful to everyone who helped shape this document by sharing their stories, thoughts, and reflections.

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The contract to provide the Healthwatch Stoke-on-Trent service is held by
Engaging Communities Solutions C.I.C.

Blakenall Village Centre, 79 Thames Rd, Walsall, WS3 1LZ.

Tel: 0800 470 1518 | Email: contactus@weareecs.co.uk



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healthwatch Stoke on Trent


Healthwatch Stoke-on-Trent
Commerce House
Festival Park
Stoke-on-Trent
ST1 5BE

www.healthwatchstokeontrent.co.uk

t: 03303 130 248

e: info@healthwatchstoke.co.uk

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