DERBYSHIRE CARERS ASSOCIATION

Carers' Voice: High Peak Consultation Project

2023

Carers’ Voice: High Peak Consultation Project Report

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Background & Context

Who is a carer?

The NHS states that 'a carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid'.[1]

The broadness of this definition of care is important, because the care offered by someone who spends an hour a week shopping for their neighbour is as valid and worthy of support, as the person who provides life-supporting care around the clock, seven days a week. But its limitations must be recognised as well. The impact their caring role has on the carer will vary significantly between individuals and individual circumstances, but will inevitably be greater the more hours spent caring or the more intensive the time spent caring is, and sadly 'providing unpaid care is associated with negative impacts on carers' education, employment, household finances, health and wellbeing, and personal and social relationships'.[2]

The national picture

The pressure on carers is huge. NHS England is 'short of 12,000 hospital doctors and more than 50,000 nurses and midwives… the worst workforce crisis in NHS history',[3] and last winter the Guardian reported that 'as many as 500 people could be dying each week because of delays to emergency care'.[4] The picture in social care is equally 'dire'[5] with a vacancy rate nearly three times the national average[6] and Unison, the Public Care Union saying that 'Care workers are overworked, underpaid and struggling to plug the gaps in a sector desperately short of staff'.[7] It is inevitable that much of this shortfall in provision will fall on unpaid carers' shoulders, and The Directors of Adult Social Services 2023 Spring Survey stated that unpaid carer burnout was the primary reason given for a breakdown in unpaid carer arrangements'[8].

The Census tells us that there are 5 million unpaid carers in England and Wales, of whom 1.5 million are providing 50 or more hours care per week.[9] This

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[1] NHS, https://www.england.nhs.uk/commissioning/comm-carers/carers/

[2] https://post.parliament.uk/research-briefings/post-pn-0582/

[3] https://www.bbc.co.uk/news/health-62267282

[4] https://www.theguardian.com/society/2023/jan/01/up-to-500-deaths-a-week-due-to-ae-delays-says-senior-medic

[5] https://www.health.org.uk/news-and-comment/blogs/social-care-workforce-crisis

[6] https://www.health.org.uk/news-and-comment/blogs/social-care-workforce-crisis

[7] https://www.unison.org.uk/news/press-release/2023/06/the-social-care-crisis-is-worsening-by-the-minute-says-unison/

[8] https://www.adass.org.uk/adass-spring-survey-2023-final-report-and-press-release

[9] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021

amounts to 9% of the population providing some form of care, and thus makes the report that Carers Trust published in September 2023 particularly sobering. It's title: 'Unpaid Carers are not unsung heroes, we are forgotten, neglected and burnt out'[10] conveys just how much many are struggling, with carers' three highest needs stated as:

- Better support for the person or people they care for
- A break or respite
- More money to spend on what they need for their caring role[11]

That the primary concern for unpaid carers surveyed was securing 'better support for the person or people they care for' is perhaps unsurprising when that person is also a family member, friend or neighbour; and with 1.5 million carers providing over 50 hours of care a week[12], the Carers' Trust's report's second most stated need for 'a break or respite', is equally understandable.

'More money', the third most urgent need cited, is also unsurprising when 62% said that the current rate of Carers' Allowance, £76.75, was not 'enough to make a significant difference to their needs'.[13](It is worth reflecting that Carers' Allowance amounts to £2.19 per hour at most, against a national minimum wage of £10.42 (for those over 22 years of age)[14]).

As High Peak Carers are entitled to the same government benefits and support – or lack thereof – as the rest of the country, it is unsurprising that these concerns have also been expressed by High Peak carers. But as this report will seek to show, the peculiarities of geography, rurality and isolation conspire to make carers' needs for more money and better support from services (including the provision of better respite) particularly pressing in the High Peak, and make good communication essential.

The situation in Derbyshire

To establish the situation for carers in Derbyshire, we can turn to Derbyshire County Council's 2021/22 Carer Survey[15]. As with the Census, this document is

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[10] Pg. 1, https://carers.org/downloads/adult-carer-survey-report-2023--full-uk-report-(english).pdf

[11] Pg. 6, https://carers.org/downloads/adult-carer-survey-report-2023--full-uk-report-(english).pdf

[12] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037

[13] Pg. 7, https://carers.org/downloads/adult-carer-survey-report-2023--full-uk-report-(english).pdf

[14] https://www.gov.uk/national-minimum-wage-rates

[15]https://observatory.derbyshire.gov.uk/wp-content/uploads/reports/documents/health/specialist_reports_and_assessments/2022/SA

now several years old and so has its limitations in establishing the picture for carers at the current time, but nonetheless it serves as a useful comparator (not least because it is far more in depth)[16].

The most likely age to be a carer in Derbyshire is 55-64[17] which reflects the national picture. The key issues reported to Derbyshire County Council's survey are also consistent with the national feedback: 'tiredness, stress, depression, disturbed sleep and irritation'.[18]

Quality of Life scores for carers in Derbyshire are below the national average, and declining.[19] This is concerning not only for the carer, but their cared-for, as well as wider family and friends.

The fact that carers in Derbyshire are likely to be older adults and 41% of carers nationally didn't have a break from caring in 2022[20] may partially explain why nearly 70% of carers in the county have their own health issues[21], especially when one considers that the oldest carer to respond to the study was 94[22].

The situation in High Peak

High Peak is primarily rural, with a population density amongst the lowest 20% in England (only an average 1.2 people per football pitch-sized piece of land)[23] and 31.7% of people living in one person households[24], thus the risk of carer isolation and loneliness within High Peak is significant.

CE_2021_22_Main_Findings_Report_v6.pdf

[16] For example, 47% of respondents to the DCC survey reported caring for more than 100 hours per week, whilst the Census only asked if people cared for more than 50 hours per week.

[17] Pg. ii, https://observatory.derbyshire.gov.uk/wp-content/uploads/reports/documents/health/specialist_reports_and_assessments/2022/SACE_2021_22_Main_Findings_Report_v6.pdf

[18] Pg. ii, https://observatory.derbyshire.gov.uk/wp-content/uploads/reports/documents/health/specialist_reports_and_assessments/2022/SACE_2021_22_Main_Findings_Report_v6.pdf

[19] Pg. 11, https://observatory.derbyshire.gov.uk/wp-content/uploads/reports/documents/health/specialist_reports_and_assessments/2022/SACE_2021_22_Main_Findings_Report_v6.pdf

[20] https://www.carersuk.org/media/vgrlxkcs/soc22_final_web.pdf

[21] Pg. ii, https://observatory.derbyshire.gov.uk/wp-content/uploads/reports/documents/health/specialist_reports_and_assessments/2022/SACE_2021_22_Main_Findings_Report_v6.pdf

[22] https://observatory.derbyshire.gov.uk/wp-content/uploads/reports/documents/health/specialist_reports_and_assessments/2022/SACE_2021_22_Main_Findings_Report_v6.pdf
https://derbyshirecarers.co.uk/blog/survey-of-adult-carers-2021-22-main-findings

[23] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

[24] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

It is an area of significant social inequality - as the High Peak Alliance reflects: 'Overall, High Peak district is less deprived compared to the average for England, ranking 192 out of 326 English local authority areas (1 is the most deprived). However… [there are] small pockets of rural deprivation… There are 3 areas that fall within the top 20% of the most deprived in England. Notably the area surrounding Glossop, one of the most deprived areas in the entire county.'[25]

High Peak has a population of 90,900[26], so judging by the national average, there are likely to be approximately 8,181 carers in the area (of whom 1170 are registered with Derbyshire Carers Association[27]).

The population is overwhelming white British,[28] and it is ageing. The average median age is now 46 years; three years higher than at the 2011 census, five years higher than the rest of Derbyshire, and six years higher than the 2021 national average.[29] This is significant because the NHS identifies advancing age as one of the most likely factors in people needing care[30].

Between 2011 and 2021 the number of 65 to 74 year olds in High Peak rose by 28.4%, those aged 75-84 by 1.8% and those over 85 by 0.2%[31]. Given that the national census identified that 'at ages 65 to 69 years, 19% of people needed help [with at least one aspect of daily living]' and 'at ages 80 years and over 43% of people needed help'[32] one might expect the care burden in High Peak to be particularly high - especially as the population numbers also rose in the groups most likely to provide care (50-69 years)[33] and the 2011 census predicted that the number of carers nationally would double within 30 years[34].

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[25] https://joinedupcarederbyshire.co.uk/about-us/our-places/high-peak/

[26] https://www.ons.gov.uk/visualisations/censuspopulationchange/E07000037/

[27] Figure correct as of October 2023.

[28] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/(97% of survey respondents defined their ethnicity as 'white' and 95.9% said that they were born in Britain).

[29] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

[30] https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2021-part-2/social-care#care-needs-of-adults-aged-65-and-over

[31] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

[32] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/demandforadultsocialcareacrosscountiesandunitaryauthoritiesinengland/2018-12-18

[33] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15 - the age brackets answered by the census do not perfectly tally to those used to measure likelihood of providing care, but both possible age groups on the census: 50-64 and 65-74, did rise.

[34] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15#key-points

However, according to the 2021 census, the number of people in High Peak providing up to 19 hours of care per week actually saw a significant fall from 8% in 2011 to 4.8% in 2021, the number of carers proving 20-49 hours care per week saw only a small increase from 1.4% to 1.6% of the population, and the number providing 50 or more hours of unpaid care per week remained stable at 2.4% of the population[35].

We must be cautious about reading too much into the recorded decrease in the number of people providing less than twenty hours of care per week. The census itself notes that travel restrictions and the need to 'bubble', coupled with a change to the wording of their questions, may have led to underreporting in 2021.[36] Nonetheless, it is perhaps statistically significant that High Peak had the joint third largest fall across the region in the number of people providing this type of care, when all areas would have been affected by pandemic restriction[37].

The size of this fall in lower levels of care bears further investigation. The census speculates that one factor may have been the impact of the pandemic[38], but this does not seem to tally with the fact that the population in High Peak remained stable.

This mismatch highlights the lack of real knowledge about carers in the area and the need for a project such as the Carers' Voice consultation, because without it we cannot accurately tailor support to conditions affecting carers and their cared-for (especially given that the majority of carers in High Peak are still unknown to Derbyshire Carers Association).[39]

Those carers who are accessing support from Derbyshire Carers Association appear to reflect the ageing population in High Peak. Though there are 372 registered carers aged between 50 & 64 - the national average - the second most numerous group of carers are aged over 75 (315)[40]. If age is the most likely factor in needing care, we must consider how many of the carers in High Peak are likely to be in need of additional support themselves, and how this might affect the support that services need to offer them.

We must also consider the conditions that they are supporting, with the three most common categories of health need being: Dementia (229), long term

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[35] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

[36] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/methodologies/healthdisabilityandunpaidcarequalityinformationforcensus2021

[37] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

[38] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

[39] As of October 2023, 1170 High Peak Carers were registered with Derbyshire Carers Association out of an approximate carer population of 8,181

[40] Figures correct as of October 2023.

health condition (221) and physical disability (93) - all seemingly in keeping with the fact that High Peak has an older population.[41] However, it is possible that Dementia is not the most common cause of someone needing care, but simply that it is the carers supporting this condition that Derbyshire Carers Association has had the most success in reaching.

Introduction

Taking into account the situation facing carers nationally, the areas of concern highlighted by Derbyshire County Council's survey of carers in 2021, the particular demographic, social and logistical challenges posed by the High Peak area, and the limits on our existing knowledge of the carer population, this consultation project was launched to try and map the experience of carers in the High Peak.

Keen that this project represent carers' experiences as accurately, sensitively and openly as possible, the envisioned output of this project was a co-produced report between Derbyshire Carers Association and the carers themselves. The aims of the project were:

"To document the current experiences of carers in High Peak, as well as providing 'best practice' recommendations for the future based on insight we gain from the carers we speak to."

The specific areas of coverage for the project were:

- Improve early identification of carers
- Preserve and enhance carers' physical and mental wellbeing
- Involve carers as experts
- Improve support through transition
- Improve identification and support for Young Carers
- Reduce, prevent or delay the need for statutory or health interventions
- Improve connections for carers and their families and reduce isolation

Methodology of consultation

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[41] Figures correct as of October 2023

This consultation is about carers, it belongs to them, and as such we have endeavoured to conduct this study in the way most accessible and most helpful to our carer participants.

The initial proposal outlined a 'model with a similar initial setup to Carers Space Notts (Nottinghamshire's online platform for carers and professionals)[42] and as such our intention was to host panels on key issues of concern to carers via Teams, as this would allow the broadest possible spectrum of carers to delve into areas of particular concern to them.

However, early conversations with carers made clear that to use computer-based fora would significantly narrow the pool of carers either willing or able to participate as many carers who were keen to engage would only do so if they did not have to do so via computer; either because they lacked the technological skills or means of access for an online based approach, or because they had the requisite computer skills, but resented the perceived retreat behind the computer screen of support services.

Therefore, we adopted a programme of one-to-one interviews (in person or via phone, as the carer preferred) and attended local support groups – both those run by Derbyshire Carers Association and external groups – in order to provide low-tech listening spaces for carers to share their feedback (because it cannot be right to approach a consultation on what issues and challenges carers are facing by perpetuating one of their most frequently cited frustrations with support services). Carers' feedback also prompted partnerships with Rural Action Derbyshire and the University of Sheffield to look more closely at how comfortable carers were using computers and the impact of digitalisation on carers.

The aim was always to maintain a very open conversation, to allow carers to speak as freely as possible about the topics that they most wished to address, whilst still seeking to answer five main questions:

- What impact does caring have on your life?
- What are your current concerns as a carer?
- Where do you feel well supported by existing services?
- Where do you feel services have let you down, or failed to offer sufficient support?
- What could be improved, changed or added to existing provision in

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[42] https://www.carersspacenotts.com/

order to provide more support to you and your cared-for in the future?

The consultation has been publicised through diverse means to ensure that it reached as wide a group as possible, including via Derbyshire Carers' Associations' own website, social media channels, and newsletter; as well as word of mouth from the High Peak Carer Support Workers and through the media channels of partner organisations.

Through these means, we have found a core group of 19 carers who have not only given regular feedback on their own experiences as a carer in High Peak, but also acted a sounding board for the changes that Derbyshire Carers Association have enacted or are planning to enact – to ensure that this consultation and its findings have been truly co-produced. A further 25 adult carers have given one off interviews or feedback, as well as 6 young carers. Finally carers' opinions have been canvassed through attendance at 26 meetings of carer groups and drop-ins (run both within DCA and externally, and with an average attendance of between 2 and 12 carers), as well as 5 large scale events to which carers were invited.

For all the benefits of one-to-one interviews and in-person listening sessions, we were aware that the number of carers that could be reached through these means would always be limited – primarily due to the time it would take. In order to reach the broadest group of carers possible we also devised two questionnaires, one for adult carers and one for young carers.

The questionnaires were released to carers in July in paper format and circulated directly to carers at the Information Roadshows and Young Carer Events, as well as through existing support groups and indirectly through partner organisations. They were then released online in October, and were publicised both through Derbyshire Carers Association's own media channels, as well as partner organisations. Both formats closed on the 30th of November. There were 117 respondents (110 adult carers and 7 young carers).

All the questions were proposed or inspired by carers in order to try and make sure that we were addressing the topics of prime concern to carers; that we were asking the "right questions" – those most relevant to carers' experiences in the High Peak.

Some questions were almost directly transposed into the final questionnaire, such as: 'What is the most difficult aspect of being a carer?' which became: 'What do you find most challenging about being a carer?'; whilst elsewhere we tried to preserve the spirit of the question while making it more broadly applicable. For example, 'What happens in the crisis?', 'What happens if I need to get physical care three times a day?' and 'Will they have to sell their house etc. [either to fund care, or because they cannot manage the physical upkeep of it]?' became 'Do you worry about your ability to continue caring in the future?' and 'Do you have a plan in place for what happens to the person you look after if you become unable to support them?'.

Several carers provided topics that they thought the questionnaire should address (rather than individual questions) such as: 'Carer finances, and the difficulty of completing benefit forms' which became the questions 'Do you worry about money?' and 'If you have completed any benefit forms on behalf of yourself, or the person you care for, did you find them easy to understand and complete?'.

We also endeavoured to respect carers' advice about how to ask questions (in order to make the questionnaire easy to understand and complete) by keeping questions simple, avoiding jargon and avoiding acronyms.

Before publication, a draft of the questionnaire was sent to Dr Baraniak at the University of Derby for her guidance.

By asking other support services to distribute the survey across their media channels, we have been able to reach carers not currently known to Derbyshire Carers Association – and make sure that their experiences are included too - since we need to know if there are specific reasons why certain carers or groups of carers are not reaching out for support.

Partnership working has also given us an opportunity to start responding to carers' feedback that there needs to be greater communication between agencies – something that we have then built on through the Information Roadshows. Carers have said, so we have done.

We have also discovered that the edited version of the questionnaire has been invaluable for garnering the opinions of young carers, as they have found the set questions less confrontational than an open discussion.

It is not just the consultation that has been co-produced, but this report itself. Examples have been anonymised, but they have all come directly from carers, and the core group of regularly participating carers have all been given the opportunity to read this report and offer their feedback, before publication. These are their experiences; this is their voice.

Difficulties/barriers to engaging carers

Many of the barriers to encouraging carer participation will be discussed in greater detail later in this report, as they can be a direct result of the intensity of caring burden or a lack of service support for a carer. Carers who are fatigued and stressed by their caring role may not be willing, or able, to take the time to engage in a consultation project – and indeed three carers had to withdraw before the end of the consultation due to an increase in the intensity of their caring role.

However, this project has also demonstrated that carers with a limited caring responsibility who feel they are managing that role well, are also less likely to participate, as it may not be worth their time or they may not feel that they have enough to say - this may account for why the percentage of participating carers caring for over 50 hours per week is correspondingly higher than in the census data.

And thus, when analysing the feedback received we must remain cognisant that it may not represent either of these extremes, and this is where it can be so useful to ground participating carers' feedback in the CarersUK 'State of Caring 2023' report, which says that: 'more than three quarters of all carers (79%) feel stressed or anxious, half (49%) feel depressed, and half (50%) feel lonely'. [43]. Many of the problems reported to the consultation in High Peak are not unique to the area, even if some are exacerbated by the peculiarities of geography and population distribution.

Limitations of project

Although the intention of this project must be to catalogue the experiences of carers in High Peak as faithfully as possible, we must be aware of the limitations of our information gathering and methodology. Co-production is inherently problematic as it relies on an organisation parsing and prioritising the feedback of multiple service users, and the organisation's representative will bring to bear their own implicit biases, as well as that individual's industry knowledge of resourcing and procedural requirements.

This 'inside' knowledge will obviously not be available to carers, and may mean that the organisation appears not to have responded to some of the feedback shared. This is a major issue when many carers are already so disillusioned that they doubt that any change can come from projects such as this.

As service providers, too, we must make sure that we do not add undue weight or bias to the stated aim of this project, to 'reduce, prevent or delay the need for statutory or health interventions' simply because reduced interventions – and therefore shorter waiting lists for needed interventions – are seen as a positive marker of performance for services.

Likewise, every carer is an individual, every set of circumstances is unique. So we can only state with absolute certainty that the feedback provided by participating carers is applicable to their own unique circumstances - there

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[43] https://www.carersuk.org/reports/state-of-caring-survey-2023-the-impact-of-caring-on-health/

can never be a guarantee that the feedback provided to this consultation is representative of the area.

This does not mean, however, that we should shy away from a co-production model – quite the reverse. Carers live every day with the realities of an NHS in crisis[44], a social care crisis[45], and experience first-hand the limits of welfare provision. Most are highly realistic about what can be achieved, but they need to be listened to. Not just because they have the right to be heard, but because – as discussed later in this report – the impact of services ignoring carers' input can be severe. If each participating carer brings only their own lived experience to this report, it cannot be overstated that their feedback represents the struggle, hardship, endeavour - and often love - of real people, in real caring situations within the High Peak.

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[44] https://www.kingsfund.org.uk/publications/nhs-crisis-evaluating-radical-alternatives

[45] https://www.kingsfund.org.uk/blog/2023/04/reform-adult-social-care-vanishing-over-horizon

Carers Feedback – Challenges & Problems

A complex picture

Unpaid carers save the country an estimated £162 billion per year (the equivalent of a second NHS budget)[46] and so it is in society's interests to look after and support them, and yet carers in the High Peak believe that 'caring is underfunded, under supported and undervalued, so it is no surprise that support is inadequate'.

Not all High Peak carers feel let down by the support they receive, but unfortunately the vast majority of respondents do.

With 84% of surveyed carers happy to continue caring, it is worth stressing that the majority of carers are not asking services to relieve them of their caring role, but to give them the tools in order to do it well. They want the necessary information and support to enable them to help their loved ones well (and protect their own mental and physical health whilst doing so); they want to 'know that I am doing everything that I can possibly do for [my cared-for] & I… to make this road a little easier'.

Before delving into the particular issues that carers have raised concerns about, it is worth considering the cumulative nature of the challenges that many carers endure. One couple spoken to (who provide mutual support) raised 33 points of concern about the challenges that people in the High Peak face accessing health and community support; against just eight areas where they felt well supported or that services had helped them – four of which the couple had had to privately fund and arrange themselves.

The consequences of carers' understandable disillusionment are serious, with multiple carers admitting that they 'hate hospitals' and actively avoid their own doctor's appointments – making it very difficult to care for their own health.

Although carers have been keen to contribute to this project, many believe that carers are never really listened to and therefore 'they [service providers] aren't going to do anything'. The sense that 'everything is harder' now and that there has never been less support available for carers is pervasive, with many questioning what this report can achieve and saying that accessing support for either themselves or the family or friend they are supporting is like 'swimming through custard… everything you have fight for'.

Different carers have highlighted different areas where they have most struggled; each situation is unique. But certain themes remain consistent, and almost all the carers spoken to believe that accessing support is incredibly

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[46] https://www.carersuk.org/press-releases/unpaid-care-in-england-and-wales-valued-at-445-million-per-day/

challenging, that communication between services is limited, and that service users are suffering as a result.

The impact of the current ‘fight’ for recognition and support cannot be overestimated when many carers are already time poor and performing challenging complex care for which they may have no training. When coupled with the feelings of ‘loneliness’ and ‘isolation’ that many carers report, it is unsurprising that 72% of survey respondents said that caring has had a negative impact on their mental health, with many of the carers citing more and better respite as the thing that they most need.

Services

‘The very, very original problem, [is that] none of the individual agencies speak to one another and it’s just a massive pain’. This sentiment is widely held amongst carers. Although they have offered detailed feedback on specific services - as discussed below - if there is a single theme that all services could act on from carers’ feedback it is the need to improve communication both between ourselves and with the community we serve (including carers and the family and friends they support). Carers across the board have stressed that ‘when you start off as a carer you don’t have a clue’ and more needs to be done to publicise the available support to them.

Resources are limited, but by ensuring that we communicate clearly we can all best utilise the resources we have, and ensure that we are providing support to the best of our ability.

Respite

Brenda and Holly care for Bernard, a family member with dementia. When we first spoke they were determined to keep Bernard at home, believing that this was in his best interests and what he deserved.

However, Brenda and Holly required a rolling package of residential respite to be able to manage this. No such respite could be found. Nearby residential homes had spaces, but only for permanent residents.

Unfortunately, without this respite and with a deterioration in the health of both the cared-for and one of the carers, the decision had to be made to move Bernard into permanent residential care.

Respite falls into two main categories, day respite and overnight respite. Carers have reported issues with both, and the above exemplifies so clearly the potential consequences of not providing sufficient breaks, and explains the frustration that participating carers have cited with existing respite provision.

Carers have found that there is a shortage of suitable placements in the High Peak for a variety of conditions including physical disability, dementia and learning disabilities – with some carers being unable to source respite places within their allocated social care budget.

Carers are angry that they often have to make a financial contribution to respite care when no employee would be expected to pay for their own holiday entitlement, and have raised concerns about the shortage and calibre of care and nursing homes in the High Peak.

Some carers have reported failings in care at the care homes which they have entrusted with their family or friend’s wellbeing, and have said that they can be so anxious about whether their loved-one’s needs are being met that they are unable to ‘enjoy the break’.

There is a sense, amongst carers interviewed, that the High Peak is particularly lacking in respite, with several saying that they have had to make compromises about what sort of care would suit the cared-for best as there simply are no places available in their preferred setting.

Others have expressed frustration about not being able to utilise a much needed break as they would wish because they have not been given enough notice as to when respite would be available. Carers need respite, but they also need clear and timely communication as to when they will get it:

Even though they were granted respite, one carer had to cancel an operation for themselves because the respite that they had booked was not confirmed until three days before it was due (and after the deadline for confirming their operation) and the carer could not risk respite being refused and their loved-one being left unattended.

Carers need more respite. With 44% of respondent carers saying that they care for more than 100 hours a week, 24% of carers saying that they have been unable to access respite and 60% saying that they are reliant on family members, friends and neighbours to provide respite; this is a fact. It is also a fact that resources are limited. However, even where resourcing makes increased provision an impossibility, better communication over when respite will be available and for how long, would improve carers’ ability to utilise it.

GP Surgeries

Their relationship with the General Practice team is probably the single issue that carers have raised most frequently as having a significant impact on their experiences as a carer. Research shows that continuity of primary care over 15 years increases survival rates of complex conditions by 25%[47], and there is a strong sense that to the rural communities of High Peak the General Practice team is particularly essential, as they are the gatekeepers of onward support and so key to 'improv[ing] early identification of carers'[48]

A strong relationship with a GP doctor can have a hugely beneficial effect on carers' wellbeing and their cared-fors' access to support, with one carer praising their GP for writing a letter in support of the carer's expertise and right to be listened to by hospital staff making decisions about their cared-for.

A good relationship can even overcome some of the difficulties posed by the remoteness of the High Peak from specialist support, with one carer reporting gratefully that that their doctor 'broke all the rules' in order to get a specialist in from Derby to assess both their cared-for and themselves.

Carers have also praised certain aspects of the wider provision available through their General Practice team, in particular, the dementia home support workers and the GP based counselling-service.

However, the majority of carers have raised serious concerns about access to appointments and communication failures that centre on the GP practice, even saying that the current system is 'diabolical'.

Failures of communication with patients, hospitals, community services, and carers have had negative consequences for both carer and cared-for, including:

Hugo and Eve, who were left for six months, after Eve was given a diagnosis of early-onset dementia, without any onward signposting for support.

Tom who was unable to access medication after a hospital appointment as the prescription was sent to another county instead of their local GP.

And Suzanne, who was 'blasted' by her local chemist for trying to collect a prescription early, despite having been told to do so by her GP.

Given the impact that their relationship with their General Practice team is having on carers' experiences, Derbyshire Carers Association has appointed a GP Liaison Worker to support GP surgeries across the High Peak to think proactively about how they can support carers through the appointment of a

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[47] https://www.bmj.com/content/375/bmj.n2468#:~:text=In%202018%2C%20people%20who%20had,any)%20produce%20benefits%20this%20dramatic.

[48] One of the seven initial aims of this project.

Carers’ Champion and sign-up to the Carers’ Pledge. It is imperative that all members of the General Practice team are supportive of carers and those with long term health conditions – not just the doctors themselves.

As the first point of contact, the attitude of the receptionist is particularly key. If carers are not treated with compassion, respect and understanding at this first point of triage, they (and their cared-for) may never get to speak to a doctor.

The difference that it can make to carers when their status is acknowledged and supported is immense, as Rosie’s story demonstrates:

Rosie cares for multiple family members. At those GP surgeries where she is registered or known as a carer, Rosie has a ‘good’ relationship with doctors; but at her grandmother’s GP - where she is not known to be a carer - getting her grandmother an appointment can be ‘traumatic’ and she has found ‘the receptionist... turning me away without even asking if [the appointment] was [for] a vulnerable person’.

Carers themselves have offered concrete suggestions about what would help them to navigate appointments for themselves and their cared-for, namely:

- Regular check-ins on the carer’s health and wellbeing (especially their ability to continue caring).
- Flag the notes of those with long-term or complex health conditions, so that they may be prioritised for appointments
- Reduce waiting times for patients who wish to speak to their designated GP doctor as currently people have to choose between a swift appointment or ‘continuity of care’
- Shorter waiting times to speak to a receptionist and book an appointment, as carers are currently reporting waits over an hour for the phone to be answered
- Better onward sign posting from the General Practice team, because ‘where does it start when you are ill... at the doctor’s’ (including creating and using dedicated signposting checklists for complex conditions)
- A separate, quiet waiting room/area at the GP surgery for autistic people and those with sensory processing disorders
- Home visits from the General Practice team for those with sensory processing disorders that would make attending the surgery in person

difficult

- In-person appointments for those with complex health conditions or communication difficulties
- Double appointments when needed
- Be realistic about the accommodations that disabled patients need (e.g. allowing them enough time to reach the surgery for a same day appointment)
- Immediate referral to Living Well for all those diagnosed with dementia
- Out of hours and online services for those whose caring commitments mean that they cannot contact the practice during working hours (especially to deal with repeat prescriptions).
- Follow-up appointments/reviews for all those with dementia diagnoses, not *just* those on medication

Hospitals

If a caring journey does not start at the GP surgery, then for many it will start with a hospital diagnosis.

Carers have spoken about how difficult it can be to take on board all the necessary information during a difficult diagnosis and how beneficial it would be to have a specialist nurse there taking notes, or even someone available ‘just for a hug’. Whilst this may not always be possible, it emphasises carers’ need for personal, face-to-face support and contact with services.

Better communication between: different hospitals; different departments; hospital and community services; and carer, cared-for and hospital staff; would all improve carers’ wellbeing as carers currently report a ‘binary system’ of NHS provision in the High Peak – where one is either under hospital or community care – with carers serving as the only point of contact between different medical providers. Many feel the stress and responsibility this entails keenly, saying that there is no help ‘if I am not proactive’.

Carers have reported a lack of respect from professionals, with one carer saying that her husband’s care ‘wasn’t even discussed with me’; and another that his cared-for’s condition was worsened after medical professionals failed to consult him and therefore continued to pursue treatment after the cared-for had already reached sats that were normal for them.

Carers have demonstrated that as well as relieving carer-burden and improving outcomes for the cared-for, improved communication could avoid wasting limited resources:

If Suzanne had been given more than a few hours' notice of a cancelled appointment she would not have booked ambulance transport, thereby potentially freeing up an ambulance to transport another patient.

Hospital care, whilst undoubtedly vital in certain circumstances - and potentially life saving - also highlights the extraordinary levels of care that family carers may provide. One carer reported that their husband lost function during his hospital stay as staff did not support him to mobilise and attend to his own personal care – both things that the carer had been managing to do at home.

Another carer said that their cared-for was turned away by a hospital consultant as being 'too complex' for their facility, even though the carer – with no medical training – has to manage the cared-for's condition at home, on a daily basis.

Sadly carers have relayed a catalogue of failings in hospital care and unsafe practices around discharge, from multiple trusts - including being pressured to put their loved-one into care and being told that the hospital was 'not a rest home' when the carer said that they needed more time to safely adapt their home before the cared-for's return.

Whether this is because hospitals are showing a lack of compassion and respect for the challenges that patients and carers are facing, or simply due to a communication breakdown when information is relayed, it is clear that communication with carers must improve, and that communication must be a *two-way* dialogue in which hospitals listen and respond to carers' concerns.

Some hospitals' inability to adequately support disabled patients has been highlighted, with carers and cared-for complaining of:

- A lack of facilities for wheelchair users
- Inappropriate food being provided to those with swallowing difficulties
- Lack of support for patients who cannot feed themselves
- Insufficient provision being made to communicate with those with speech difficulties

Rather than coming up with a solution when challenged over failing to make *suitable provision to allow a wheelchair user to access urgent care, staff at one hospital declared that the wheelchair user was refusing treatment.*

It is arguably in hospital provision that the High Peak's isolated position is most keenly felt, not only because of the distances that carers may have to travel to access hospital care, but also because they may be accessing hospital care from multiple Trusts (and potentially from a different Trust to their community support provider) - with all the potential complications that may bring.

Carers see access to support as postcode lottery; with one carer (whose husband's dementia is treated at a Stockport hospital) saying that carers in Stockport get everything, and Derbyshire carers get nothing, and another that: 'people at the hospitals forget us in the High Peak, we are an oversight'.

Social Care

Carers supporting learning disabilities and dementia have expressed considerable frustration over their interactions with social care, saying that they have been treated with a lack of respect by social workers and have been excluded, unnecessarily and detrimentally, from conversations about their cared-for's needs.

Communication failures have even led to the complete breakdown of support as when:

Lara managed to convince her parents to accept professional carers' visits on the understanding that no reference was made to her father's dementia, as this would increase both parents' distress and reluctance to engage. However, documents explicitly stating his dementia were left lying around and found by the parents, who refused to engage further with services.

Other carers have reported longstanding lack of engagement from social care:

Nora is now in her thirties. She has complex learning difficulties, but has not had an assigned social worker since she was two, and as her mother put it: 'how can you make judgements about my daughter, when you've never even met her?'

This lack of engagement has been particularly felt by carers supporting those who are self-funding. Carers have repeatedly stressed that even though they may not be in need of financial support, guidance from social care about what support is available (and how to access it) would be invaluable.

Continuing Healthcare

When we first spoke, Suzanne had been waiting 18 weeks for the outcome of her husband's Continuing Healthcare application, and multiple carers have raised concern about the existing Continuing Healthcare provision, especially waiting times and decision making processes:

Damian remains very angry about his wife's Continuing Healthcare decision meeting several years after the event. He believes that the 'vile' way it was conducted had a direct impact on 'her mental health... her survivorship' and caused unnecessary stress to her in her final weeks.

Many carers – supporting those with complex health needs – had not even heard of Continuing Healthcare before we spoke, whilst others reported confusion over how to apply and which community service teams could support their application.

One carer was told by social care that they had 'no chance' of getting Continuing Healthcare – despite their statutory right to request an initial assessment - and when they were directed by Derbyshire Carers Association to approach their GP surgery, their doctor said that the community team would be in contact. No contact has been made.

The impact of such confusion and delay is profound, and yet again means that access to support depends largely on carers' ability both to investigate what is available and then advocate their loved one's case once they have done so.

Thus the impetus must again be on services to improve communication between ourselves and with carers. Not every Continuing Healthcare application can be successful, and there will be waiting times, but if these are successfully communicated, then the adverse impact can be lessened, and decisions made fairly:

Lauren has appealed her husband's Continuing Healthcare decision, but does not feel that she has been given all the information needed to do this successfully - firstly it was not made clear that decision makers would not have sight of documentation provided during her husband's original application, and then she was not advised that professionals could write in support of her husband's application ahead of his appeal.

Wheelchair service

Only two carers raised concerns about the wheelchair service, but in both cases the impact was serious, with one carer reporting that delays in the supply of a new wheelchair had left their cared-for unable to leave the house for six months, and another that the stress of getting their loved-one's wheelchair repaired had seriously adversely affected their mental health.

In both cases, carers were struggling to get a response from the service, and thus communication must be improved.

Community Mental Health Support

Carers expressed frustration and anger at waiting times for community mental health support for both adults and young people (especially for young adults who may age-out of children's services before they are seen, and then have to "start again" at the bottom of the adult's waiting list).

They are frustrated at the lack of communication both between different services and between services and carers, with one carer saying that there was no response from the community mental health service after his daughter was re-referred into them. Even if waiting times could not be shortened, a clear acknowledgement of the referral and clarity about how long the expected wait would be, would have helped this carer to manage in the interim.

Communication breakdown between support services and carers has had a particularly big impact during crisis interventions, with carers reporting that they have been excluded from decision making and made to 'feel small', when they have disagreed with agencies' advice.

Carers have also reported challenges related to the High Peak's liminal status, where it covers a number of different county borders. Indeed, one group of carers have become so frustrated with the lack of available support that they have set up their own support group for the people they care for. Yet this too exacerbates the stress felt by these carers, as they have to source funding for the group alongside their often expansive caring roles. Another source of concern was the level of out-of-hours support available - not only for the cared-for, but also for the carer themselves..

It is worth emphasising the range of carers which mental health provision will impact, as some cared-for with a different primary health need will also need mental health support. Carers have particularly flagged the difficulties in assessing the mental health of a non-verbal loved one and the additional barriers that neuro-divergent individuals may face in accessing support:

Reg is autistic. After difficulties at school, he was referred to a mental health drop-in. He found the environment challenging and did not feel able to attend the sessions alone. As it was not possible for him to attend with a carer, he stopped attending.

With 72% of surveyed carers reporting the negative impact of caring on their mental health, many carers will be accessing help for themselves, not just for their cared-for, and the carer's ability to access support may have a direct impact on their ability to continue caring. In turn, a downturn in a carer's ability to continue caring may lead to their cared-for needing earlier clinical intervention.

Given that 19% of carers surveyed worry about their ability to continue to care because of their own mental health, more support is needed. As more than one carer put it, ‘because I don’t want to kill myself, I don’t get support’.

Provision for Learning Disabilities

Many of the carers who are supporting someone with learning disabilities expressed concerns about the longevity of their caring role - indeed, many considered it a life-long commitment. They raised concerns about the impact of this longevity on their mental health, and worried about their ability to continue to provide care as they themselves grew older and potentially frailer. There is also a fear that although their support is vital for the welfare of their cared-for, services may underestimate the needs of their loved one, who therefore may fall through the gaps of provision when their carer is no longer able to advocate for them or provide the same level of support.

The sense of falling through the gaps of provision is pervasive amongst carers supporting someone with learning disabilities. Three particular areas highlighted were the difficulties of trying to access support for themselves as an adult carer of someone under 17; the struggle of trying to help their cared-for navigate from children’s to adult’s services; and the complexities of negotiating the move from day centre to community provision.

What is clear, is that good communication with services is crucial to the experiences of carers supporting those with learning disabilities, and how well they feel that they can cope:

Polly’s sister has learning disabilities. She has moved from day centre provision to community provision. With this move, her hours of support have been halved. The impact on both Polly and her sister’s wellbeing has been immense, but Polly does not feel that any explanation has been given for the reduction.

For carers like Polly, the single most helpful change to provision that could be made would be a continuation of community projects for adults with learning disabilities through the school holidays, as some of these close during those times. Likewise, sufficient staffing at agencies to ensure that illness and absence cover is in place for community carers is vital, as covering absences is currently falling on the family carer’s shoulders and is creating additional disruption for the service user.

National holidays acting as a particular point of crisis has been consistently reported amongst carers, with one carer recalling how difficult it was to get help when their partner, in palliative care, deteriorated at Christmas because ‘everyone’ was on holiday. However, the prevalence of this issue being flagged by carers supporting autistic individuals or those with learning disabilities demonstrates that more support is particularly needed for these carers at these times.

However, when this consultation has broached these issues with existing support agencies, we have been assured that there are services able to provide short term cover during project breaks. The issue appears to be, at least in part, that carers are not aware of the support available to them - something borne out by the consultation responses, with 65% of carers saying that they do not know what support is available to them, and 68% saying that they do not know what is available to the family or friend they support.

It is obviously not just carers who have been impacted by the reduction in day centre provision, but those who used to attend, some of whom are displaying ‘challenging behaviours because their whole lives have been turned upside down’.

This report therefore suggests that there needs to be an agreed blueprint for how changes in provision for learning disabilities are communicated, across services, and that - where possible - this needs to include an accessible format of communication for the cared-for.

There also needs to be reassurance offered to those whose learning disabilities are more profound, that provision will not be withdrawn for them. One carer said, that these individuals ‘can’t go into the community, because there are no services’, and so are reliant on day centre provision. However, as this provision has been scaled down, it now offers fewer opportunities to socialise and has less infrastructure to support it. When one carer challenged the reduced provision, they were simply advised ‘not to rock the boat’.

Professional Carers

Good support from professional carers can be invaluable, with three contributing carers singling the care agencies they used out for praise. However, there is a recruitment crisis in social care.

In a recent survey by the Care Quality Commission (CQC) 54% of adult social care providers said that ‘they were having challenges recruiting’, ‘31% said that they were having challenges in retaining [staff]’ and ‘26% said that staff shortages due to recruitment and retention issues were resulting in unused capacity'.[49]

Unpaid carers have stressed again and again to this consultation how the diminishing pool of available professional carers means that they are not able to hire the most appropriate care for their loved one (and the negative consequences this has for both themselves and the cared-for). They believe that lack of respect for the caring profession, and a consequently low wage, are the primary drivers behind low recruitment and high turnover, because 'people need a decent wage to do a decent job'.

The shortage of professional carers means that many unpaid carers have reported being unable to hire the gender or age of carer that would make the cared-for most comfortable, and the cared-for's consequent discomfort has led to behavioural challenges in some cases. They further report that high staff turnover leads to a 'lack of continuity of care' and can distress the cared-for when relief carers are 'not used to [their] ways'. Perpetual short staffing is also increasing the burden on family carers and is impacting on their ability to work, as they have to cover absences.

Carers definitely believe that the High Peak's rurality and remoteness from major population centres contributes to the shortage of available care staff, with one saying that they were advised to source carers from Sheffield (and pay their travel time), and another that "remoteness does lead to a reduction of service provision".

The impact of these staff shortages can be profound:

Joe was unable to be discharged from hospital for more than a month after he was deemed fit enough to leave, because professional carers could not be found to implement his discharge package. During his extended hospital stay he contracted three additional serious health conditions and was unable to start physio – which has had a lasting impact on his ability to mobilize. His extended stay also meant that that his acute hospital bed could not be utilized for another patient.

Availability of staff is not the only issue though, unpaid carers have also stressed that communication between care workers or between care agencies is often lacking. Carers have cited multiple occasions when failings in care have occurred due to lack of record keeping or clear communication on the part of professional carers, and have emphasised how this lack of communication increases pressure on the unpaid carer to act as advocate and co-ordinator for their cared-for, because 'it is unbelievable how much information doesn't get transferred [between services]… it's like a game of… whispers'.

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[49] https://www.cqc.org.uk/publications/major-report/state-care/2022-2023/workforce

Analysis

The sheer number of areas in which carers feel unsupported, or that support could improve can feel overwhelming. Many carers feel overwhelmed. However, as services we should see this as a positive opportunity to change and adapt the support we offer in response to what carers are telling us.

Carers have offered concrete examples of the changes in provision that would be most useful to them, and some of these changes are relatively small, for the scale of the impact they could have.

Carers who have been kind enough to give up their time to this project have done so with a real sense of duty to the next generation of carers –feeling that even if ‘it is too late for us’, they want things to be better for others, and so, as services, we must be seen to respond. In doing so we could actively address the seven original goals of this project.

We must also not lose sight of the fact that carers have shared positive stories of where support has been successful (as will be discussed in more detail in the ‘What is working well’ section below).

The picture is concerning, but it is not universally bleak, and in our final conversation for this consultation one carer was particularly keen to highlight the positives, to make sure that this report reflected the fact that ‘it’s not all bad’.

Carer Wellbeing

With 44% percent of adult respondents to this consultation caring for over 100 hours per week and 72% of them saying that caring has worsened their mental health, and 33% of young carer respondents caring for over 100 hours a week and 50% of them saying that caring has worsened their mental health, the toll that caring can take is undeniable. Yet many feel their wellbeing is rarely considered.

Although, the carer and cared-for ‘come as a package’ and the wellbeing of one inevitably affects the wellbeing of the other; carers often feel ‘invisible’. One carer reported that as part of her husband’s hospital discharge package she was questioned about how she was, whether was coping well? Despite saying that no, she was not coping well, the carer was offered no additional support – making her angrier than if staff hadn’t bothered to ask at all.

It is good that hospital staff were including the carer in their discussion, but here again, it is not enough simply to listen to carers, services must act and be seen to act. We cannot shy away from the most difficult of questions: why are we consulting carers if we are unable to respond to their concerns?

It is probably impossible to divorce stress and anxiety from a role that can involve being on-call 24 hours per day, even were that task not as emotionally involved as supporting a loved-one. However, carer wellbeing deserves serious attention. Participating carers have spoken at length about their own isolation, guilt and sadness.

Some carers fear for the future, asking: ‘Who is going to look after me?’ Whilst others say that ‘sometimes I just feel like I'm the worst person in the world’ for finding it difficult to cope and judge their own lapses in patience and compassion, saying of themselves: ‘You are not a very nice person’.

Carer isolation is not limited to people supporting any one condition or who are caring for more than a given number of hours per week and tackling it does not have any simple answers. Carers whose responsibilities allow them to socialise outside of their role, speak about watching the clock, and worrying whether or not they will make it home on time. Even those with a strong network of family or friends around them have spoken about the loneliness of their experience:

Lauren’s husband is in palliative care. Several of her friends have sympathised with the strain of caring for him by comparing Lauren’s role to them looking after their parents. But as Lauren points out, the comparison, whilst undoubtedly well intentioned, is lacking because this is not her parent, but her partner.

Fiona and her husband speak to their children regularly. The family is very close. But Fiona remains aware that her husband would not want personal aspects of his care discussed with them, and that her children may not feel comfortable knowing such details about their father.

Carer isolation can span all ages, and is a particularly devastating issue when considering young carers, one of whom said that their caring role means that they have never learned to socialise with their peers; and another, that opportunities to socialise alongside the family member they support was the single biggest thing that would make a difference to their ability to cope.

Isolation has also been repeatedly flagged by male carers. Although approximately 40% of carers are male,[50] they make up only 30% of carers in High Peak currently accessing support from Derbyshire Carers Association[51].

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[50] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/census2021#:~:text=In%20England%20and%20Wales%20there,over%2C%20age%2Dstandardised).

[51] Correct as of October 2023

There is a sense that existing support groups may feel less welcoming to male carers or that if they are less demonstrative family and friends may not realise that they need additional support or companionship. The feeling of being overlooked is prevalent, with one carer saying: ‘If I was a female, I would get more help. Because I am a male on my own, I just get left… men can be vulnerable too’.

Carers UK report that eight out of ten carers are lonely,[52] so isolation and loneliness are certainly not unique to the High Peak, but the rurality of the region can certainly exacerbate the problem, and carers have spoken about being unable to engage with support groups because they worry about how quickly they could get back to their cared-for in an emergency. Thus demonstrating some of the particular challenges of the area and the value of detailed local study and a tailored response at a regional level.

Distance

The impact of the geography of the High Peak on carers is something that services have consistently failed to understand and respect. Although carers may value the ‘good community around High Peak’ its rurality presents challenges:

John, who does not drive, was expected to take his son on a six hour round trip via bus in order to access a necessary hospital medication review, when long trips via public transport are so stressful to his son that they can cause violent meltdowns.

One carer, in her eighties, drives a three hour round trip to visit her husband in his care home multiple times a week, and says that doctors making the decision to place him in that home did not even ask if she was capable of driving those distances before authorising the placement. Aside from the significant cost in petrol, as her husband’s only regular visitor she worries greatly about the impact on his wellbeing if she becomes unable to manage the trip, saying ‘if I couldn't drive, he would have no visitors’.

It is not just literal distance that impacts on carers in the High Peak, but the scarcity of public transport, with one carer walking five miles in each direction to reach his cared-for, because he cannot drive. Two other carers expressed their anxiety about what happens if their old cars stop working, and the financial cost of repairing them – with one citing it as their most pressing concern, because they and their cared-for, are completely reliant upon their cars.

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[52] https://www.carersuk.org/news/10-facts-about-loneliness-and-caring-in-the-uk-for-loneliness-awareness-week/

The necessity of being able to drive is widely reported amongst carers interviewed, with those who do not drive saying it is one of the biggest barriers to them accessing support, not only for themselves, but for their loved ones. We should therefore be particularly mindful of the risk of isolation to young carers and the 24% of carers who report that they themselves are disabled.

Rurality also limits the services available to carers. In a bustling city a strained relationship with a given service provider would be of little issue, as you could simply patronise an alternative, but for many in the High Peak, that is simply not possible. There may only be a single chemist or doctor's surgery covering a given area, and as such it is beholden on service providers to maintain good supportive relationships with carers wherever possible.

The High Peak's rurality can also have a significant financial impact on carers, with one carer reporting that a return taxi fare to the hospital costs them £70. They cannot use the train because their local station does not have a wheelchair lift, and they were recently unable to drive due to their own health needs. In an emergency, the distances that many people live from their local hospital can become truly concerning, with the same carer reporting that ambulance wait times were in excess of three hours before Covid, and are now worse. Once an ambulance arrives it is an hour to an hour and a half's journey to the hospital.

It is not only distances that carers are expected to travel within High Peak that are concerning, but the High Peak's remote position on the Derbyshire border. Carers have spoken about feeling 'forgotten' in the High Peak, and their frustration about the fact that support is often focused on denser population centres like Chesterfield and Derby.

Solving this lack of access to support is tricky however, as it is an unfortunate reality that resources will always be finite, and it is logical for support services to concentrate their efforts where they may be able to reach the greatest amount of carers. However, carers participating in the project have been clear that the current tendency to turn to computers to bridge the geographical gap needs rethinking.

Several carers who wished to participate in this project were clear that they would only do so, if they did not have to resort to computers, and whilst attending in-person support and information events can prove immensely challenging to carers supporting those who cannot be left unattended, carers have been clear 'signposting towards the... website' or being offered a remote appointment rarely solves this issue.

Occasionally however, the High Peak's remote and convoluted transport system can offer carers support:

Gwen reported how the local village bus has its own community, with the same people riding the same route on a daily basis and therefore all getting to know one another for a chat.

It is also important to remember that carers are individuals, and a single solution will not work for all. Carers agree that there needs to be clearer signposting towards support services, earlier on the caring journey, but how to achieve this is less clear. Many have maintained that in person signposting ‘with the right sort of person’, would be the preferred way to achieve this, but resourcing this is often impractical. Others have praised the idea of a signposting booklet – something that carers can reflect on after the shock of a diagnosis - whilst others have exclaimed: ‘not another leaflet!?’ and have worried about the environmental impact of paper distributions. Many carers interviewed have spoken positively of text message communication – and its effectiveness is demonstrated by the use of text message by the GP surgeries – but although phones remained a popular method of communication amongst surveyed carers, they preferred phone calls (14%) and Whatsapp (5%).

The differing feedback reinforces the fact that carers cannot be treated as a single homogenous entity for which a single method of communication will work, a multifaceted approach is needed.

Technology

Technology is becoming an ever greater and more essential part of all our lives, and the benefits can be great:

Rosie has multiple caring responsibilities – including for her grandmother – and when she is not on site has been able to use a remotely connected camera to check that her grandmother is safe and well.

Yet, only 49% of carers surveyed are happy for ‘information about support services to be communicated by email’. As mentioned above, several carers participating in this study have made clear their antipathy for the medium, saying that they ‘hate computers’ and are ‘frightened’ of being scammed. They resent feeling that services ‘don’t want to talk to you [but think you should] get online’.

When considering the benefits of technology in providing support to carers, it is perhaps important to reconsider accepted truths like “technology makes things easier”.

Whilst it is undoubtedly true that holding a meeting via Teams can be easier and less time consuming for all participants than travelling to a distant location to meet in person or holding a telephone conference where you cannot see the other person's face or reaction, technology for carers can be more of a double edged sword. Consider the frustration of trying to interact with a loved one via Zoom when they cannot talk, or the pressure of trying to convey to a remote doctor the changes in a loved one with learning disabilities or mental health issues (all scenarios which carers have relayed to explain their disdain for computers).

This is not to suggest that technology does not have a place in supporting carers and cannot be something of great benefit, but simply to highlight that we need to consider its limitations and how better to support its usage when it is used.

It is that clear that there must be provision for carers who are not digitally confident or who are digitally fatigued:

John does not own a computer, nor does he have access to one. All correspondence must be by post.

Hugo is digitally confident, but has spoken of his frustration at being directed towards 'yet another website' to find out about his wife's condition.

Carers have indicated that they would be receptive to digital training sessions, but these must be social events as well, and so Derbyshire Carers' Association partnered with The Peer Leadership Development Programme, Rural Action Derbyshire and PC Refurb to offer a communal, supported, taster session of the Peer Leadership Development Programme to carers at the Buxton Information Roadshow.

There is also a generational reluctance to consider. The needs of older carers are particularly urgent to consider given the ageing population in High Peak[53] and Derbyshire Carers Association is striving to respond to this identified need through:

- Digital Inclusion Awareness Training for all support workers (including volunteers).

- Trained digital champions within teams to ensure carers have access to the correct training, technology and guidance to access online support.

- Adding a question to the Carers' Assessment to ensure we understand carers' digital skills, confidence and the barriers around using technology (so as to ensure that all carers have access to the correct support).

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[53] https://www.ons.gov.uk/visualisations/censusareachanges/E07000037/

- Offering carers the opportunity for additional support to attend Derbyshire Carers Association's online groups and activities.

- Responding to carers' desire for training sessions to be social activities, by offering some digital training alongside other activities

Finances

70% of surveyed carers worry about money,[54] which is perhaps unsurprising when a full time carer receives just £76.75 per week on Carer's Allowance[55].

Some carers are unable to claim even this, as they are in receipt of a full State Pension or earn over the income threshold[56]. Carers feel that this is deeply unfair, as regardless of their age or other income, they are still caring. Pensionable carers are particularly angry that they are being penalised when they when they have 'paid a full stamp [throughout their] whole working life'.

That the completion of benefit applications is so complex is a further source of anxiety and frustration for carers, with one carer succinctly saying: 'UGH!' when asked about benefit forms.

58% of those surveyed did not find benefit forms 'easy to understand and complete' which is particularly concerning when carers report that they 'lack the mental energy' or are 'too busy' to apply for all they are entitled to, or even to find out what that is. Many of those interviewed feel that access to benefits is determined by how well a carer can advocate their position, or how well their loved one fits into predetermined boxes, rather than the level of care they provide or their loved one's level of need.

The carer and cared-for cannot be treated as individual units, the wellbeing of one is likely to affect the wellbeing of the other, and this includes financially:

One carer in particular, knows that her cared-for rely on her income to be able to afford the household bills. The carer's anxiety about how the cared-for will manage financially without her adds to her anxiety about the fact that her cared-for will likely outlive her.

Obtaining financial support for the family member or friend they support can

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[54] With 40% responding that 'yes' they worry about money, and 30% that they 'sometimes' do.
[55] https://www.gov.uk/carers-allowance
[56] https://www.gov.uk/carers-allowance/eligibility

also be the carer's responsibility, and carers have raised concerns about the narrowness of the eligibility criteria for the Personal Independence Payment (PIP), Attendance Allowance and Continuing Healthcare, saying that forms are often inappropriate for mental health sufferers, autistic people and those with learning disabilities as questions like: 'Can you walk 20 yards?' may not apply, or the answer may vary greatly depending on the time, the day, or stage of the condition.

Even those with physical health needs can be caught out by the questions asked in order to determine a level of need:

Despite being advised that he may be eligible by health professionals who know him, Glenda remains convinced that her husband's Continuing Healthcare application would be rejected because when asked the question: can he feed himself she would have to say 'yes', even though it is only with her having done all of the preparation and prompting.

The appeals process can be equally opaque, and highlights how hit and miss support for carers can be:

One carer, who successfully appealed when his Attendance Allowance was rejected, said that he only knew to do so – let alone what to say – because of his involvement with the local hospice. If he had not been known to this service he would still be without this source of income.

Aside from the impact on carers of navigating the complexities of the benefit system and dealing with a loss of income if they have to give up work, some carers have reported that caring actually costs them money, as they are expected to cover professional carers' meals and mileage (even when the care is funded), pay for additional hours from care-agencies in order to attend medical appointments for themselves, or purchase specialist kit in order for their loved-ones to access community services (like physiotherapy).

The Carers Trust report 'Pushed to the edge' demonstrates that financial anxiety amongst carers is nationwide.[57] Indeed CarersUK recently submitted an open letter, ahead of the Chancellor's Autumn budget, highlighting the need of carers nationwide for additional financial support.[58]

But living in the High Peak can certainly add to the financial challenge of caring not only through the transport costs discussed above, but also because the proposed changes to Continuing Care Charging will significantly increase the contributions that some carers will be expected to pay towards

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[57] pg. 26 & 27, https://carers.org/downloads/resources-pdfs/pushed-to-the-edge.pdf

[58] https://www.carersuk.org/media/omlpxmf1/carer-poverty-coalition-open-letter-to-the-chancellor-november-2023-final-with-signatures.pdf

professional support.

Completing the Continuing Care Charging Proposal forms has added to many carers' anxiety and has been *the* key topic of conversation at multiple support groups across the High Peak this year; with one carer saying that these forms were 'the straw that broke the camel's back'.

A loved one who does not accept their support needs

Sourcing support can become even more complicated when the cared-for does not accept their need for support, and is the single biggest reason cited by respondents to our questionnaire as to why they were unable to access support:

Debra cares for her partner, who has dementia and mobility issues. She utilises a sitting service for a few hours a week in order to be able to go out with friends. Thankfully, her partner 'hit it off' with the sitter, and so this arrangement is working well, but her partner's insistence that he would be safe to be left unattended is a source of anxiety for Debra.

The situation also causes her partner considerable upset, because, as he said: "I hope I've never stopped you doing something you want to do".

Indeed, one of the most sensitive challenges that carers have spoken about facing is when the loved-one whom they support does not accept their care needs - whether that is the diagnosis they have, or merely the extent to which it has debilitated them. Carers have given multiple examples of trying to offer their loved ones covert care, and reflected on the additional challenges that this can pose to accessing support – with one carer who was sent the Community Care Charging Proposals having to hide them in a wardrobe in order to avoid distressing the family member they were supporting.

Another carer highlighted how a loved-one's refusal to accept their own care needs can delay the carer recognising their own caregiving role. The delay in carers recognising their own status is well documented[59] - and a known barrier to reaching out for support - but how much harder must it be to identify yourself as a carer, if your friend or family member does not acknowledge their care needs? How can you possibly be a carer if the person you support does not need care?

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[59] https://www.england.nhs.uk/commissioning/comm-carers/carers/#:~:text=A%20carer%20is%20anyone%2C%20including,care%20they%20give%20is%20unpaid
https://www.carersuk.org/policy-and-research/our-areas-of-policy-work/identification/#:~:text=Many%20carers%20simply%20do%20not,recognise%20themselves%20as%20a%20carer.

It is ironic therefore, that the carer's burden is likely to increase if their cared-for refuses to engage with their diagnosis. Carers have reported going to great lengths to provide covert care that preserves the cared-for's independence and dignity; including sneaking in whilst the cared-for is out to wash and replace soiled furnishings and priming neighbours to direct the cared-for home if they get lost whilst out walking.

Loved ones who refuse to engage with services has been most commonly reported by those supporting an autistic person or someone with dementia or mental health challenges, and can have serious consequences:

Jean supports two family members - her daughter, who has learning difficulties, and her son, who is autistic. When her daughter had a fit and landed on Jean's toe, breaking it, Jean had to set it herself, as her son was unable to phone for help and she could not leave her daughter unattended.

Jean knows that her son struggles to talk to people, but because he has capacity and refuses to engage, she cannot get him any support with this.

Clearly services cannot, and should not, force people to engage or to accept a diagnosis, but we can be mindful of the impact that a bad experience can have and our responsibility to do all in our power to encourage people to reach out for support.

Sarah refuses to visit the GP unless it is 'life or death' after being shown a lack of compassion and understanding, including being incorrectly challenged on why someone of her age required a Covid vaccination, and seeing a GP checking his watch and asking: 'You're not expecting me to solve a long term condition in 10 minutes?' whilst being told her patient history.

George's daughter struggles with her mental health. He encouraged her to reach out for community support, but she was only offered assistance to visit a local café, which was neither appropriate to her needs or within her budget.

A bad impression can have lasting consequences, and services must be mindful of the language that we use. It can be useful shorthand to refer to people as carer and cared-for, but is that an appropriate definition or division? What about the family where multiple members are disabled or have care needs and offer mutual support where they are able? What about the familial relationships that often underpin caring relationships? As one carer put it: 'I love looking after her, she's my daughter' – the relevant relationship here is that of parent and child, not of carer and cared-for.

We must similarly careful of assuming what constitutes "care". Whilst it is absolutely right that Derbyshire Carers Association is willing to recognise that the person who shops for their neighbour is every bit as much a carer as those who provide round the clock care for immediate family – and every bit as deserving of support – nonetheless we must acknowledge that "care" does not have a universal definition, and we must be respectful of the distinctions that individuals draw:

Brenda's husband has dementia. As his registered carer, Brenda laid his clothes out every morning. He would not have been able to dress himself without her doing this. But she did not lay out his clothes because she was his carer, she did it because she saw it as one of her responsibilities as his wife, and so, has done it for the entirety of their marriage.

For Brenda and her husband this act may *demonstrate* love and care, but it is not performed *in order* to provide care, and services must be respectful of how those involved perceive the situation (otherwise we risk making people less willing to engage with services – with all of the potential consequences).[60]

When difficult conversations need to be had, this should be done with respect and we, as services, must be careful of the assumptions we make:

David had to have an operation. When he had to return to the hospital for post-operative checks, his wife was advised that he could not attend unaccompanied. His wife explained that this was impossible as both she and her husband are wheelchair users and had no method of reaching the hospital together.

David's wife was made to feel guilty for being physically unable to meet her husband's support needs, but no alternative transport arrangements were offered, it was just reiterated that David could not attend alone. (This is particularly ironic given that David is the registered carer for his wife).

Respect for carers

Only 33% of carers surveyed consistently 'feel adequately consulted, and that [their] opinion is respected, when professionals are making decisions about [their] friend/family-member's care', yet carers are often the people who know their cared-for best. Whilst carers may lack medical qualifications, their intimate knowledge of the individual they support and their particular needs means that they can be best placed to know what is normal for that individual, and the consequences of not listening to their input can dire:

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[60] Derbyshire Carers' Association's other research project into community inclusion demonstrates how alienating many communities may find the term carer, and the mistrust of services that the word may cause when people see themselves as simply performing the duty of a spouse or child to a loved-one. The report into community inclusion is due to be published in the first quarter of 2024.

Nora was given two unnecessary operations because hospital staff did not listen to her mother, who told them that she believed her symptoms were a result of a reaction to her medication.

It is not just regarding their loved one's care that carers' status needs to be respected, but when carers are sourcing treatment for themselves:

When one carer asked her consultant if she could be first on the list for a minor operation – so as to minimise the time during which her cared-for was left unattended – she was dismissed and told that 'everyone' has a reason to want to be first.

For young carers, it is not just in the medical setting where this respect of their status is so crucial, but also at school. Young carers reported very mixed experiences with their schools, with one young carer saying support from school was amongst the most positive aspects of being a young carer, another that their school had been 'useless' and failed to understand why they struggled to arrive on time in the mornings. Again, the consequences of lost trust were shown when one young carer said that counselling through school would be the single change would make the biggest difference to their ability to care in the future, but due to the school's 'previous reactions' when asked for support, they doubted that the school would provide this.

Thus services must respect carers' status in order to preserve trust, maintain engagement and improve outcomes for both carer and cared-for. Staff awareness and training is crucial, but good communication is even more fundamental, and can start with something as simple as 'including the carer in the conversation'.

'What happens in the crisis?'

It is in the context of widespread stress and anxiety that the issue of 'what happens in the crisis'? (I.e. what happens to me and to my cared-for if circumstances mean that I can no longer support them in our own home?) must be considered. 83% of carers surveyed worry about their ability to continue caring in the future, and this is the single biggest anxiety expressed by many of the carers interviewed.

For some that crisis may come from being left to deal with complex medical needs without sufficient support, but for others, that crisis may come because a deterioration in their own health or that of the cared-for means that they can no longer perform the more basic tasks that surround their caring role.

What that deterioration may look like will be different for every family, but the following examples may highlight the breadth of perspective that support services need to have, because for many it may not be a strictly medical crisis:

Sharon cares for her husband, however her back problems mean that she struggles to put away their food shopping.

Suzanne 'struggles remembering what I've been taught because I'm stressed, permanently' .

In his mid-eighties, with a serious health condition himself, Damian worries about being able to maintain the garden and how he would change a lightbulb if one blew. He emphasises that people need 'care with a big C' (i.e. a comprehensive package of support from services, not an exclusive focus on medical issues).

To address these concerns, Derbyshire Carers Association have partnered with Time Swap to give carers a cost free route to voluntary assistance with their home and garden if needed, and are producing a Welcome Booklet which will include necessary information for all carers, to ensure that carers know where to turn for additional support *before* a crisis occurs.

Services cannot necessarily prevent a crisis from happening, but by communicating clearly to carers the available avenues of support we can help ensure that they have the necessary tools to respond to it.

What happens next?

One carer said that she was 'sick to the back teeth of never getting anywhere in my own life', and this sense of frustration at a lack of time and energy to look after themselves is widespread.

Damian used to wake up two hours early, just so that he could have a little time to himself in the mornings to read the paper before his caring role commenced.

John says 'I don't eat', 'I don't sleep' because of the demands of his caring role.

However, we must also consider what happens after a caring role comes to an end. The moment at which someone becomes a former carer can be highly subjective; is it when a loved one moves into residential care, or when they die, or when the carer has finished grieving?

Officially, all of these people would be classed as former carers, but the extent to which many people still identify as carers following a bereavement is attested to by their desire to continue attending support groups, and their willingness to contribute to this project; stating that they want to protect the next generation of carers from suffering as they did, because they had ‘no one to talk to… no help…nothing, nothing, just left on my own… [and] it’s just as bad now.’

The idea that someone is no longer a carer simply because their loved one has moved into residential care is particularly problematic:

June not only spends hours every week visiting her husband, she also irons his clothes, takes him out to lunch and tries to monitor his medication. Most of all she worries about his welfare and wellbeing.
She is still caring.

For some carers, the question is not what happens next for me, but what happens next for my cared-for? As they anticipate their loved ones outliving them or outliving their ability to support them. Here too information – *before* the crisis point – is vital.

Improved support through transition was one of the key aims of the original proposal for this consultation and carers have made several suggestions about what would help them navigate these difficult changes, including:

- Support to have ‘difficult conversations’ with loved-ones as they approach end of life to ensure that they have made all the preparations that they wish to.
- Information about where to turn for support *before* a deterioration or crisis happens.
- More tapered support for bereaved carers.
- Asking services to reconsider whether the definition ‘former carer’. applies to those with loved ones in residential care when the family member retains all of the stress of managing their affairs.
- Advice on how best to manage the finances and assets of loved ones in residential care.
- More information on what support is available for former carers.

Derbyshire Carers Association has sought to respond to these requests by:

- Publicising the fact that support remains available to all carers for a year following a bereavement and carers remain welcome at support groups.

- Partnering with Blythe House and the Bereavement Service to offer more support to bereaved carers.

- Launching a Welcome Booklet (with necessary information for all carers) as well as offering targeted information sessions for carers which will address a variety of topics including 'difficult conversations', disease progression, bereavement and future planning.

Analysis

Despite all of the stressors discussed above, 84% of adult carers[61] and 100% of young carers[62] surveyed say that they are happy to continue caring. The vast majority of carers are not asking to stop caring, they are simply asking for the tools and support to be able to do it well, and minimise the toll on their own wellbeing.

Not all of the stresses of caring are solvable for every carer; we must accept this reality, and this consultation makes apparent that the rurality of the High Peak can make carers particularly vulnerable to 'loneliness' and isolation. However, with 65% of carers saying that they do not feel well informed about what support is available to them and 68% that they do not feel well informed about what support is available to the friends and family they care for, services must do more to ensure that carers are aware of the help available to them.

We must also listen to carers' concrete suggestions on how services could support their wellbeing through:

- Providing more information about likely disease progression (especially for dementia).

- Offering better signposting to support ahead of a crisis.

- Offering carers more opportunities to speak to support services in person.

- Offering more support to former carers (and reassessing what a 'former' carer is).

- Showing respect to carers, through understanding and acknowledgement of their role.

- Understanding that people aren't *just* carers, they are daughters, wives,

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[61] 41% of respondents said yes; 43% said yes, with the right support
[62] 60% of respondents said yes; 40% said yes, with the right support

husbands, sons. They have their own set of characteristics, disabilities, health needs etc.

- Offering support groups and socialising opportunities tailored to the *interests* of both carer and cared-for (not simply grouping people together because they happen to have the same diagnosis).

- Acknowledging the symbiosis of the carer/cared-for relationship i.e. what helps one, helps the other - by looking after the carer, you are looking after the cared for.

- Offering a responsive service that listens to carers' feedback.

And, above all:

- Communicating clearly with carers, involving them in decisions and explaining processes. (Whilst avoiding the use of complex terminology, acronyms, or rebranding of services).

Carer Feedback – What is Going Well

Carers

It feels unfair to place unpaid carers themselves under the heading 'what is working well' when 44% of respondent carers report that they are caring for over 100 hours a week; 72% that caring has negatively affected their mental health, and 82% that it has negatively affected their physical health. However, despite the enormous challenges that many face, carers – by definition – continue to care.

In fact, many do not only care. They 'fight'. They fight for access to support for themselves and their loved-ones. They fight to be listened to. They fight to be respected. The impact of this 'fight' cannot be overestimated, with one father reporting that when supporting a child with complex mental health needs, 'one parent just about survives, the other doesn't'.

With the potential cost of caring – both literal and emotional – so high,[63] and many balancing caring responsibilities alongside work, their own health needs, or other family commitments, the fact that two thirds of the population will offer unpaid care during their lifetime[64] is extraordinary. What is even more worthy of comment, is that most wish to do so; when as one young carer put it: there is 'no character building [in caring]. Just misery'.

Derbyshire Carers Association

Carers have been glowing in their praise of the support facilitated by Derbyshire Carers Association so far saying: 'I've nothing but compliments for you all'.

Carers speak especially highly of the local support workers, who are 'absolute stars', 'so, so useful' and 'so kind'. They have made particular mention of how much personal budgets and emergency grants have 'helped' and of how useful support groups are in allowing carers to learn from others in similar circumstances as well as for 'making friends' and helping carers to feel that 'I am not on my own'. Young carers have even said that Young Carers' Events are one of the greatest positives of caring.

However, despite the above we should be conscious of the limits of support that Derbyshire Carers Association currently offers. Although several former carers currently attend support groups – and have a wealth of experience to offer – there is no official provision for them after the first year following a

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[63] As one carer put it, caring is: 'doing a job every week that you're not paid for, not trained for. I know it's your family, but you're saving them [the government, NHS and ASC] a £1000 a week'

[64] https://www.independent.co.uk/life-style/women-carers-sick-disabled-old-relative-caring-report-a9211966.html

bereavement or changed circumstances. Therefore, former carers have expressed anxiety about their welcome at such groups; their *right* to attend.

Likewise, Derbyshire Carers Association cannot currently offer formal support to adult carers of those under 17, which leads to the frustrating need to tell some carers that we can offer support in “so many months’ time”, or that we can offer support for one caring responsibility, but not for another. Whilst there will always be a need to categorise people in order to allocate limited resources, we must acknowledge those who fall through the gaps – what use is it to the parent-carer in need of support *now* to say that your child is not old enough to warrant our involvement?

Most fundamentally we must acknowledge those carers who have never even heard of Derbyshire Carers Association. Approximately, 14% of carers in High Peak are known to Derbyshire Carers Association. Some of the remaining 86% will no doubt receive support from other organisations, whilst others will have no need or no desire to engage with our services, but one must assume that a significant proportion will simply not know that support is available. (Especially when 65% of respondents to this consultation say that they do not know what support is available to them).

Indeed, a lack of knowledge about support is one of carers’ most frequently cited complaints, with one saying that she gave up work to look after her child with additional needs because ‘I didn’t realise at the time that I could have got help.’

The most common length of time for carers to have been caring before registering with Derbyshire Carers Association is more than 10 years[65]. So it appears that a fundamental issue may also be how long it may take someone to identify with the word ‘carer’, let alone see fit to reach out to a carers’ association. At what point is an individual going to decide that they have moved beyond being simply a husband helping out his wife, and into an official caring role? And yet, despite its problems, the term ‘carer’ is important as carers have rights enshrined in law[66]. Caring is what Derbyshire Carers Association’s service users are doing, we cannot avoid the use of the term, but we should not reduce people to being *merely* a carer either.

Therefore, we must consider not only how to make the term more accepted, but how to publicise to communities what carers are and what support Derbyshire Carers Association can offer.

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[65] It is worth stating however that the majority of carers have not declared how long they have been caring for, so these statics must be treated with caution.

[66] https://www.carersuk.org/help-and-advice/practical-support/what-are-your-rights-as-a-carer

GP surgeries have consistently emerged as most carers' primary point of contact with health and support services in the High Peak, and an automatic referral process from the GP would certainly serve to ensure that more carers were known to Derbyshire Carers Association (given that as one carer pointed out more than 92% of the population are registered with a GP surgery[67]). If this was coupled with all those attending review appointments for long term health conditions being required to nominate a carer then registrations could drastically increase. However, we must take a moment to consider both the potential impact on the cared-for of having to publicly declare their need for care, as well as whether this rise in numbers could actually be underpinned by increased support for carers in High Peak, given the realities of resourcing constraints.

We must, as a service, walk a balancing act between ensuring that support is available to those in need and not promising more than can be delivered. Increasing numbers of carer registrations would do little without the resourcing to back it up however – a service with more registered carers that takes longer to respond to those in need helps no one. Especially given that there is already frustration with the limits of what DCA can offer.

As one carer put it, '[the support worker] rings me every week, but what does that do?' – we can offer a listening ear, we can perform a Carer's Assessment, but we cannot provide respite if that is found lacking and we can only offer funding within tight constraints to a carer in need. That is not to negate the importance of a service for carers, but simply to acknowledge the limitations of support that are currently available.

However, this consultation project has served not only to highlight the challenges that carers are facing, but also to increase the remit of support that Derbyshire Carers Association can offer. Where carers have raised concerns about the support that they and/or their loved ones have received from health and social care, their feedback has been anonymised and referred into Healthwatch. Thus providing not only an additional avenue for carers' voices to be heard, but also starting to address the frequently cited concern that services do not talk to one another.

In conducting this consultation we have also sought to apply some of the learning that it has revealed, including about communication. We have sought to utilise available resources in the ways most helpful to carers, by addressing the issues of prime concern to them and re-thinking and re-

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[67] https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis#:~:text=September%202015%20to%20October%202023,-0%2010%2C000%208%2C000&text=Whilst%20the%20GP%20workforce%20is,with%20GP%20practices%20in%20England.

targeting our comms strategy.

One carer highlighted that events in High Peak are currently primarily publicised online and via email, so carers who do not use these mediums do not find out about them except by word of mouth at their local support group, therefore those whose support group falls later in the month often find that places are already booked up. Several other carers have volunteered that they would find publicity by text more accessible and effective. So when we were publicising the Information Roadshows we made sure to distribute flyers around the local area and strengthen our partnerships with local GP surgeries who already have existing text message networks, in order to make sure that we were reaching less tech-confident carers as well.

Finally, DCA must acknowledge that the sense of the High Peak being the 'forgotten' or 'the back and beyond of forever' extends to its own service, as well as wider support provision. We have sought to address this by not only strengthening the links between our High Peak and Ripley offices, but by publicising that we have done so through our newsletter – so that we can be *seen and known* to be responding to carers' concerns.

There is more to do. Support for carers in High Peak can and must continue to improve through better partnership working, continued consultation to ensure that we are utilising limited resources as effectively as possible, and perhaps most essentially review of our existing communication methods to expand our reach to more than 14% of the carer population. But hopefully this report demonstrates that carers are being listened to and their feedback is being enacted, as no one is better placed than them to tell services what is working and what is not.

The support of family and friends

Several carers have talked about how imperative a strong network of support from family and friends has been to their ability to cope with their caring responsibilities, whether that is as a listening ear, a source of advice, or a relief carer.

All too often however, it is apparent that family and friends are not a welcome source of additional support, but rather an essential back stop to replace an absence of professional support. This cannot be right. Not only does it place additional pressure on familial relationships if family are 'not the best at helping', but what about carers who have no family to turn to or who feel that the nature of their caring role is too personal to pass onto loved ones?

Frances cares for her husband, Henry, but recently had to have a knee operation herself. She and Henry coped because they have a 'little nucleus [of family] who made sure that [Henry] was ok, and that [Frances] could hobble *about ok'. Otherwise, Frances would have had to hire in professional support and as such, she said 'that link to [professional] help is absolutely essential' for carers who do not have family support.*

Carers have repeatedly said that clearer signposting to available support earlier on their caring journey is one of things that would be most helpful to them, so that in the event of a deterioration in the health of either themselves or their loved one they already know where to turn for additional support.

To this end, Derbyshire Carers Association hosted three Information Roadshow events between July and October 2023. Services were invited to different locations across the High Peak to run information stands and answer carers' questions. Thereby attempting to give carers the opportunity that they had asked for to find out about support, in person, without having to travel too far (as well, hopefully, as providing an opportunity for services to network and strengthen communication between themselves).

The Roadshows were well received, with carers saying that they were 'fab', 'fantastic', 'very informative' and 'very useful', and even asking for them to become 'permanent events'. Therefore we intend not only to bring the Roadshows back to the High Peak in 2024 but to expand them across Derbyshire.

However, recognising that although the desire to be able to speak to services in person is strong for many, not all will find it possible or convenient to attend such events, Derbyshire Carers' Association is also looking to strengthen our signposting, linking directly from our website to identified areas of priority support – such as information on support for former carers. And also aiming to produce a Welcome Booklet in 2024 to be presented to all newly registered carers with crucial information about available support. (Services are warmly invited to volunteer for inclusion in this, and we hope that it will contribute to an increasingly joined up offer of professional support).

Carers have highlighted that current support offerings can rely too heavily on them having family back-up available, with one contributing carer questioning what would be the point of him completing an Emergency Card application form when there is no one – friend or family – whom he could nominate to be contacted in the event of an emergency.

It is not just in an emergency that services must be wary of relying too heavily on family back-up:

June reports that the majority of her husband's children have only visited once since his move into residential care.

The day to day realities of caring are rarely evenly divided between family members, and some carers may even need to assume additional responsibilities to the wider family alongside their primary caring role. Therefore, as services, we need to ensure that support is adapted to individual circumstances.

To this end, carers have said that information sessions around how to discuss difficult topics as a family would be of use. As Frances put it: 'the more open one can be - which I know is not for everyone - then we know where we are going, it's not such a shock [if the cared-for deteriorates]', however, this can be difficult when she knows that certain topics are likely to cause upset.

The consequences of not feeling able to have difficult conversations can be very severe. Gwen did not feel able to approach her partner about what would happen after his death and as such he was not well enough to make the changes to his will that he wished – which has had a long lasting impact on the surviving family.

To this end, Derbyshire Carers Association are looking to put together information sessions for carers – with topics nominated through this consultation and our new Carers' Voice Panel – one of which will focus on how to have the difficult conversations with loved ones.

Local, specialist support services

Blythe House, the SALT service, the Dementia Palliative Care Team, the Dementia Home Support Workers, Leukaemia Cares, the Jubilee Centre, Peak Pharmacy (Chinley) and Haywood Pharmacy all feature amongst the local specialist support services praised by carers as 'brilliant' for the assistance they can offer, not only in their own area of expertise, but as a link into other services. With carers saying that the support of the *right* support service can help them to live 'healthily and happily'.

However, the praise for specialist services is not universal, with carers reporting that some lack 'empathy and interfacing'. The issue of carers not knowing what support is available to them also looms large, with carers asking: what if I had not found about *x*? And, how would I have found out about *z* without *y*?

One must also consider the carers who do not meet the threshold of support for a specialist service, such as Kiera, who has been told - after a two year waiting period – that community mental health services cannot help her young son, without any explanation being given as to why.

Small changes

The scale of the task to improve carer support can seem daunting, and yet time and again there have been examples of a single individual garnering praise from carers; be that the 'fantastic' home support worker within a local clinic, the consultant who took the time to have a 'very useful' in depth conversation with a carer or the GP doctor who 'broke all the rules' to source specialist support.

We must never lose sight of the impact of the individual, and that must apply to professionals as much as to carers. We each, as individuals, can strive to make a difference to individual carers – especially when we work together.

By listening to carers and strengthening the communication between services, we can make small thoughtful adjustments, without cost, that can make a real difference. As when Derbyshire Carers Association listened to the feedback from carers supporting loved ones with dementia in the Glossop area that they were unable to attend the existing carer support group because it clashed with a group for the friends and family they supported. Changing the day on which the support group was held, increased attendance by six people in the first month.

Taking the time to consider how we communicate is equally valuable. How a question is asked, how a document is worded, or our attitude in speaking to a carer makes a real difference to their willingness to engage, and sometimes their whole outlook.

Services must never lose sight of the fact that though caring can be a difficult and demanding task and is worthy of respect, people are not *just* carers, they are family and friends as well. One carer reported that her entire outlook changed from despair to hope on the basis of a single appointment where staff respected her and her husband's relationship – independent of her caring role.

Conclusion

Outcomes of this consultation

Carers' feedback has informed the methodology not only of the consultation, but of this report. Carers' instructions to avoid jargon and acronyms are as applicable here as in the formulation of the questionnaire, and the core panel of contributing carers have all been offered the opportunity to read a draft copy of the report ahead of publication and their feedback has been incorporated wherever possible.

We have devised a table to clearly demonstrate not only where Derbyshire Carers Association has already acted on carers' feedback, but also how we will strive to incorporate this consultation's findings into future service provision[68]. Thereby demonstrating that even after the end of this consultation, Derbyshire Carers Association wants to remain a listening service – guided by what carers want and need.

In keeping with the fundamental principle of this project, to act as a platform for carers and give them a voice, when carers have raised complaints or concerns outside of Derbyshire Carers Association's own remit we have partnered with Healthwatch to try and ensure that carers' feedback can be fully addressed. Even when resourcing constraints mean that action cannot easily be undertaken to address the failings that carers see in the current support, we have sought to catalogue the broad themes of their concerns in this report - carers deserve to have their desires, concerns and best-practice goals acknowledged, even when, in some instances, meeting them would require wholesale, societal change. It is beholden upon us, as services, not only to listen, but to be *seen* to listen, *seen* to acknowledge, and to respond appropriately - especially as 'nothing will change' has been one of the most frequently cited caveats to carers wanting to participate in this project.

We identified early in this consultation that technology usage was a potential blocker to engagement with the project, and was a wider issue for the carer population in the High Peak. Derbyshire Carers Association flagged this to Rural Action Derbyshire, who conducted a survey of carers known to Derbyshire Carers Association on their ability to access the internet and engage with technology.

Their survey found that 63% of carers could use the internet without help and 97% had internet access at home. Given the discrepancies between the number of carers with access to technology, and those willing to use it for engagement with this project, Derbyshire Carers Association and Rural Action Derbyshire will meet in 2024 to discuss these results in more detail, and

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[68] Please see Appendix E

identify any required actions or workstreams.

Recommendations

This report was commissioned to represent the voices of carers in the High Peak, and the above sections identify the project's findings.

The project's other remit was to specifically address a number of key areas identified and to suggest improvements. Therefore, drawing on the evidence already cited from carer testimonials and survey responses, this report makes the following recommendations:

Improve early identification of carers

General Practice teams have a key role to play in carer identification and experience, and all GP surgeries should consider:

- Carer awareness training for all staff
- Regular check-ins on the carer's health and wellbeing (especially their ability to continue to caring).
- Flag the notes of those with long-term or complex health conditions, so that they may be prioritised for appointments
- Reduce waiting times for patients who wish to speak to their designated GP doctor as currently people have to choose either a swift appointment or 'continuity of care'
- Shorter waiting times to speak to a receptionist and book an appointment, as carers are currently reporting waits over an hour for the phone to be answered
- Better onward sign posting from the General Practice team
- Immediate referral to Living Well for all those diagnosed with dementia
- Supply more information about likely disease progression to carers earlier on the caring journey
- Earlier signposting towards support services

Where practicable, surgeries should also consider:

- A separate, quiet waiting room/area at the GP for autistic people and those with sensory processing disorders
- Home visits from the GP for those with sensory processing disorders that would make attending the surgery in person difficult
- In-person appointments for those with complex health conditions or communication difficulties
- Offer double appointments where needed.
- Be realistic about the accommodations that disabled patients need (e.g. allowing them enough time to reach the surgery for a same day appointment)
- Out of hours and online services for queries/issues with repeat prescriptions, for those whose caring commitments mean that they cannot contact the practice during working hours.
- More in-person support, especially at the point of diagnosis.
- Follow-up appointments/reviews for all those with a dementia diagnosis, not *just* those on medication

Service providers should also work together to:

- Create a comprehensive checklist of the available support services for conditions which require care, supply it to GP surgeries and other points of primary care, and work together to ensure that care providers have access to it and that they are using it for onward signposting

Preserve and enhance carers' physical and mental wellbeing

The single thing that would most improve carers' physical and mental wellbeing is undeniably more money - not just for their own use to buy in support and respite as needed, but more money invested in the existing support services. However, even where no additional resources are available, ensuring that we, as services, are working as effectively and collaboratively as possible can have a major impact on carers' wellbeing (and indeed their ability to continue caring). Clear communication is at the heart of this.

As services, we should all:

- Communicate clearly with carers

- When there is a delay in access to a service explain why and how long the wait will be. If someone is not eligible for support explain clearly why and (where possible) signpost onto alternative avenues of support.

- Avoid the use of complex terminology

- Avoid acronyms

- Avoid rebranding services

- Communicate effectively with other services – so that the carer is not the single lynch pin holding support together and so that we can offer the joined up care to which services aspire.

- Improve collaboration and communication between the High Peak and the rest of Derbyshire - so that county-wide services are not only providing a cross-Derbyshire service but are *seen* to be doing so; thus demonstrating that the High Peak is not 'forgotten'.

- Recognise that failure to coordinate and collaborate may lead to collapse of care

- Think about methods of communication – Is face to face possible? Are all my service users online? Do I need to print 'yet another' leaflet? Can I streamline communication into a single document or source? Would a specialist coffee morning offer an opportunity to target multiple carers supporting the same condition at once?

- Avoid making assumptions – carers do not look like one thing, or have one set of characteristics or needs. They may have disabilities or health needs of their own that make support even more imperative.

- Respect carers, both for the complexity and challenge of the role they are performing and their expertise in their cared-for's unique situation and symptoms.

- Work smarter – where additional resources are not available, we must all strive to maximise the impact of what support we can offer.

- Provide support for all carers and cared-for over national holidays like Christmas and Easter

- Provide support in school holidays for carers of adults with learning disabilities

- Ensure that all carers are aware of holiday provision and how to access it.

- Work towards care-friendly communities, supported by Carers' Champions

- Carers have also offered the following specific suggestions as to what would improve their wellbeing:

  - Accessible support groups for carers who are neuro-divergent

  - In-person support for male carers

  - More interest-based, accessible activities for the cared-for

  - Shorter travelling distances to access support (ideally within 15 minutes)

Involve carers as experts

- Derbyshire Carers Association is instituting a Carers' Voice co-production panel with which to prioritise, plan and redesign future provision for carers across Derbyshire, as well as rolling out the Carers' Voice consultation model to other parts of Derbyshire.

- It is hoped that the panel will act as a force multiplier for services that take part. Therefore, the more services involve themselves in the Carers' Voice panel, the more effective the panel will be, and the greater the benefits will be for both services and service users.

- Derbyshire Carers Association adopted a 'You Said: We Did' model, and our key panel of carers were not just given a single interview, but bi-monthly contact where they were updated as to what actions had been taken on their previous feedback, asked whether they were happy with those actions, and whether there was any additional feedback which they wished to add.

- We have also incorporated a plan of 'You Said: We Will' to signify that the conclusion of this project is not the end of Derbyshire Carers Association's attempt to refine the support that we can offer in High Peak.

- Information Sessions for carer transition are being planned for 2024, and some of these will be facilitated by carers and experts-by-experience.

Improve support through transition

- Derbyshire Carers Association have hosted three Information Roadshows as part of this consultation and intend to continue and expand the Roadshow programme in 2024

- From April 2024 Derbyshire Carers Association will offer an all age service (rather than offer separate young carer and adult services) in order to strengthen support for the whole family, especially young carers who are transitioning to adult carers.

- From April 2024 Derbyshire Carers Association will also provide focused support for parent carers whose child is moving from children's services to adult services.

- A series of Information Sessions are being scheduled for carers, and are designed to help carers prepare for ‘what happens next’.

- Services are invited to volunteer to participate in the Roadshows or to run targeted information sessions on their own specialism.

- Services should look to identify more clearly-delineated support for former carers.

- Where services are being cut, reduced or changed, such as in day centre provision for those with learning disabilities, provide clear communication to carers explaining why this is happening, the timescales in which this will happen, and the alternative/support structures in place to enable them to cope.

- Create a specific, accessible communication for the cared-for affected by the changes that takes into account their condition and explains what is happening to support them and their carers with the transition.

Improve identification and support for young carers

- Young people can find it harder to self-identify as a carer. Therefore early identification and support from medical professionals is key to identify young carers (as per the recommendations above)

- Services should look to work with schools to provide guidance on how they can best support young carers.

- Services should look to provide specific, parallel socialisation opportunities for young carers and their cared-for as this was the biggest factor cited in affecting the health and wellbeing of young carers. (Derbyshire Carers Association intend to a co-produce an activity and learning model for young carers).

Reduce, prevent or delay the need for statutory or health interventions

Support services, General Practice teams, Hospitals and other NHS/Care services need to:

- Provide two stages of support:
    - Make sure that carers are as 'well informed as possible' from the point of diagnosis
    - Provide ongoing support to carers in the form of support groups, respite, and regular updates (notifying carers of advances in treatments etc.).

- Recognise that the needs of the carer and cared-for are inextricably linked, and that therefore any support given to one must be reflected in the support to the other, including the respect with which they are treated.

- Derbyshire Carers Association will contribute to these two recommendations with its new Welcome Booklet. We hope that this booklet will be as comprehensive as possible, and therefore services are invited to volunteer for inclusion in the booklet.

Improve connections for carers and their families and reduce isolation.

- Services need to offer a broad range of ways for carers and their families to engage and socialise in order to cater for the widest possible group of carers

- Services need to reconsider how to effectively publicise activities for carers, ensuring they have multiple different channels for communication, including some offline channels.

- Services need to consider both the distances that they are expecting carers to travel, and whether a venue is accessible to carers who cannot drive.

- Services must provide stimulating social opportunities for the cared-for as well as the carer, which are interest-based rather than condition-based.

- Derbyshire Carers Association will be targeting their events in 2024 in High Peak on the basis of the interests and preferences expressed to this consultation

Acknowledgements

This report owes everything, first and foremost, to the carers who have shared their stories, feedback and candid comments. Without them, this report would not be possible, and we hope it adequately reflects their experiences.

Derbyshire Carers Association would also like to place on record its thanks to the following organisations for their support in this project:

- High Peak Place Alliance
- High Peak CVS (Council for Voluntary Service)
- Time Swap
- Older Adults Community Mental Health Team
- Transforming Care Team
- The Continence Service
- Blythe House
- Citizens Advice Bureau
- Community Connectors
- High Peak Bereavement Service
- Derbyshire Dementia Support Services & Alzheimer’s Society
- Healthwatch
- Live Life Better
- Zink (including The Neuro Divergence Hub)
- Dementia Palliative Care
- Derbyshire Fire & Rescue
- AbilityNet
- The Bureau

- Living Well Collaborative
- Carelink
- Mentell
- The Adult Education Service
- Mental Health Together
- University of Derby
- University of Sheffield
- Rural Action Derbyshire
- The Peer Leadership Programme
- PC Refurb

DERBYSHIRE CARERS ASSOCIATION

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DERBYSHIRE County Council

NHS
Derby and Derbyshire
Clinical Commissioning Group

A Network Partner of
CARERS TRUST

Appendices

Appendix A – High Peak Adults Carer Questionnaire

High Peak Consultation Questionnaire

Derbyshire Carers Association is running a Consultation Project across the High Peak until the end of 2023. The High Peak Consultation Project has two main aims: firstly to listen to and record the experiences of carers in High Peak, and secondly to make 'best practice' recommendations for future service provision, based on carers' feedback.

The questions below have been informed and inspired by interviews with carers.

It would be very much appreciated if you could take a few moments to answer the survey, as the more carers who respond, the more accurately Derbyshire Carers Association can respond to any concerns or feedback that you have.

Answers may be quoted in the Consultation Project's final report, but any identifying features will be removed, and all answers are anonymous.

If you would like to get more involved with the Consultation Project, then please ring Emma Beestone on 07816 283550 or email emma.beestone@derbyshirecarers.co.uk

Thank you.

1. Who do you care for (please tick all that apply)?

a) Spouse
b) Parent
c) Child
d) Other family member (Please specify ______________)
e) Friend
f) Neighbour
g) Other (Please specify ________________)

2. Why does the person (or people) you care for, need your support? (Please select all that apply, in order of importance)

a) Physical health condition
a) Mental health condition
b) Sensory impairment
c) Learning disability
d) Autism
e) Dependence on alcohol or drugs
f) Other

3. How many years have you been caring for?

____

4. How many hours a week do you provide care/support?

a) 0-9 hours
b) 10-19 hours
c) 20-34 hours

d) 35-49 hours
e) 50-100 hours
f) More than 100 hours

5. How well do you feel that you are coping with your caring responsibilities?

a) Very well
b) Fairly well
c) Coping some of the time
d) Not very well
e) Not at all

(If you answered c,d or e to the above question, then please do ring Derbyshire Carers Association on 01773 833833 if you would like additional support or to talk through any concerns. The phone line is manned Monday-Friday 9am-4.30pm).

6. Do you feel that caring has had impact on your own mental health?

a) Significantly improved my mental health
b) Slightly improved my mental health
c) Neither negatively nor positively affected on my mental health
d) Slightly worsened my mental health
e) Significantly worsened my mental health

7. Do you feel that caring has had impact on your own physical health?

a) Significantly improved my physical health
b) Slightly improved my physical health
c) Neither negatively nor positively affected my physical health
d) Slightly worsened my physical health
e) Significantly worsened my physical health

8. Do you have a disability?

a) Yes
b) No
c) Prefer not to say

9. Are you happy to continue caring in the future?

a) Yes
b) Yes, with the right support in place
c) No
d) Maybe
e) Sometimes

10. Do you worry about your *ability* to continue caring in the future (please tick all that apply)?

a) Yes, because of my own mental health
b) Yes, because of my own physical health
c) Yes, because of a deterioration in the mental health of the person I support
d) Yes, because of a deterioration in the physical health of the person I support

e) No

11. Do you have a plan in place for what happens to the person you look after if you become unable to support them? (e.g. Emergency plan/ agreement with another relative etc.)

a) Yes
b) No, I do not worry about becoming unable to support them
c) No, but I do worry about what would happen if I became unable to support them
d) No, but I would like to put a plan in place

(If you answered 'no' to the above question, then please do ring Derbyshire Carers Association on 01773 833833 if you would like additional support to make an emergency plan or to talk through options. The phone line is manned Monday-Friday 9am-4.30pm).

12. Have you had any respite in the last 12 months?

a) Yes, daytime only
b) Yes, overnight
c) No, I haven't wanted any
d) No, I haven't been able to access any

13. If yes, how was this respite organised? (If no, please go to question 16.)

a) Through Adult Social Care
b) Through the NHS
c) Privately, through an agency
d) Through a charity (such as Carefree)
e) Another friend or family member took over
f) Other, please specify ____________________

14. If respite was organised through Adult Social Care or the NHS, were you given enough notice of when the respite would be available?

a) Yes, plenty of notice
b) Yes, some notice
c) No, not enough notice
d) No notice

15. Do you feel that the respite offered catered to the needs of your cared for?

a) Yes
b) No
If you answered no, please state why ______________________________________

16. Do you feel well supported in your caring role?

a) Yes
b) No
c) Sometimes

17. Who do you think offers you the most support as a carer (please tick all that apply)?

a) Peer support (i.e. other carers)

b) Friends, family and neighbours
c) Derbyshire Carers Association
d) Another charity (please state __________)
e) GP
f) Hospital team
g) Community teams (including Community Mental Health Team and Salt – please state which_____________)
h) District nurses
i) Admiral nurses/Parkinson's nurses/Marie Curie nurses (or other condition specific NHS help)
j) Palliative care/hospice support
k) Websites
l) Helplines
m) Other (please specify_________)
n) Adult Social Care
o) I do not get any support as a carer

18. Do you feel let down by the support offered by any of the following (please tick all that apply)?

a) Peer support
b) Friends, family and neighbours
c) Derbyshire Carers Association
d) Another charity (please state __________)
e) GP
f) Hospital team
g) Community teams (including Community Mental Health Team and Salt – please state which_____________)
h) District nurses
i) Admiral nurses/Parkinson's nurses/Marie Curie nurses (or other condition specific NHS help)
j) Palliative care/hospice support
k) Websites
l) Helplines
m) Adult Social Care
n) Other (please specify_____________)
o) I do not get any support as a carer

19. Do you feel adequately consulted, and that your opinion is respected, when professionals are making decisions about your friend/family-member's care?

a) Yes
b) No
c) Sometimes
d) Depends on the service

20. Do you feel that there is good communication between all professionals involved in your friend or family member's care?

a) Yes
b) No
c) Sometimes

21. Do you feel well informed about what support is available to you?

a) Yes
b) No

22. Do you feel well informed about what support is available to your friend or family member?

c) Yes
d) No

23. How would you like information about support services to be communicated?

a) Over the phone
b) Via Text message
c) Via WhatsApp
d) Via email
e) On the web
f) In person
g) Via post
h) Other (please specify_____________)

24. What is most likely to stop you accessing a support service?

a) Distance
b) Cost
c) Appropriateness of support
d) Resistance of friend/family member that I am caring for
e) Lack of time
f) Inability to leave friend/family-member unattended
g) Lack of interest
h) Other (please specify ____________)

25. Do you worry about money?

a) Yes
b) No
c) Sometimes
d) Prefer not to answer

26. If you have completed any benefit forms on behalf of yourself, or your cared for, did you find them easy to understand and complete? (e.g. Carers' Allowance, PIP, Attendance Allowance)

a) Yes
b) No

27. If no, please say why (Otherwise, go to question 28.):

____

____

If finances or access to benefits is a concern, then please contact Derbyshire Carers Association on 01773 833833 or the Citizen's Advice Bureau on 0808 278 7954 to find out what help may be available.

28. Has being a carer had a positive impact on your own life?

a) Yes
b) Sometimes
c) In some ways
d) No

29. If you answered a), b) or c) to the above question, what is the greatest positive about being a carer? (Otherwise please go to question 30.)

____
____
____

30. What do you find most challenging about being a carer?

____
____
____

31. What single change would make the biggest difference to your ability to care in the future?

____
____
____

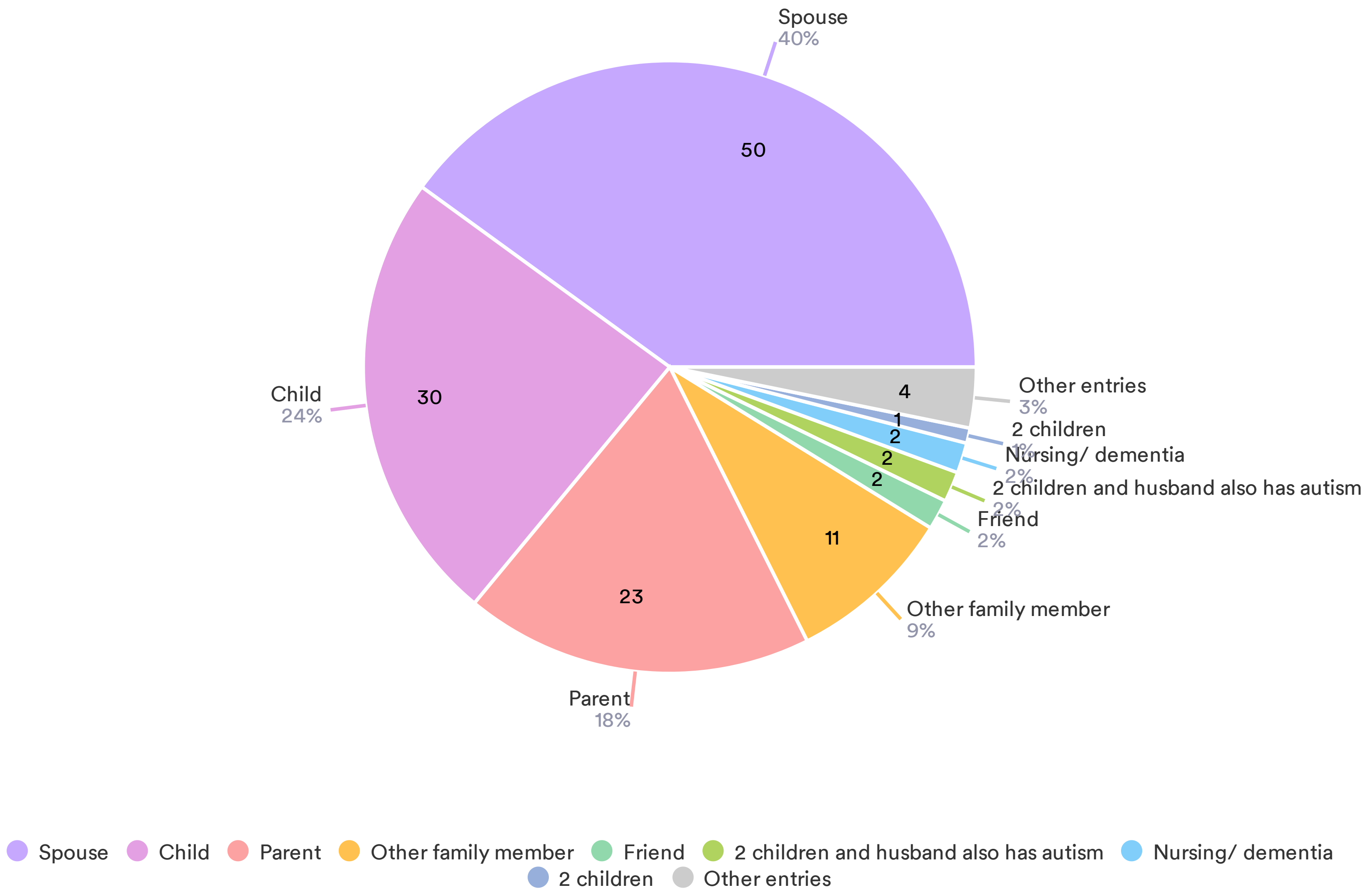
Appendix B – High Peak Consultation Questionnaire Results

High Peak Consultation Questionnaire

High Peak Consultation Questionnaire

Who do you care for (please tick all that apply)?

125 Responses- 3 Empty



If other, please specify

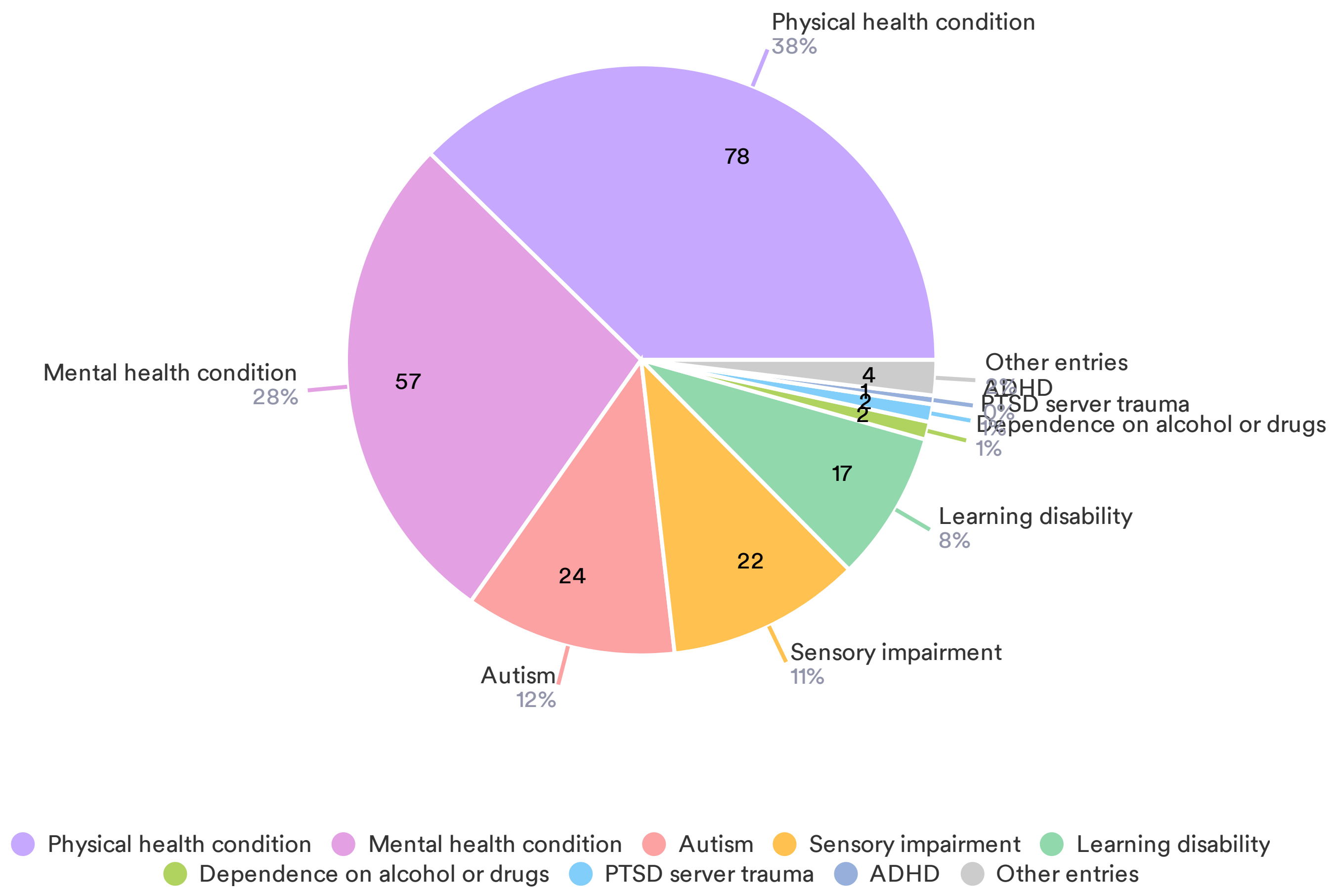
11 Responses- 99 Empty

Data	Respo...
Granson	2
2 children	1
No longer a carer	1
27 year old	1
Work as carer	1
Adult daughter.	1
Adult daughter	1
Grandson	1
Other entries	2

High Peak Consultation Questionnaire

Why does the person (or people) you care for, need your support?

207 Responses- 6 Empty



If other, please specify

5 Responses- 105 Empty

Data	Respon...
Dementia & Alzheimers	1
High functioning Autism	1
ME/CFS	1
Dementia	1
Had 2 strokes	1

High Peak Consultation Questionnaire

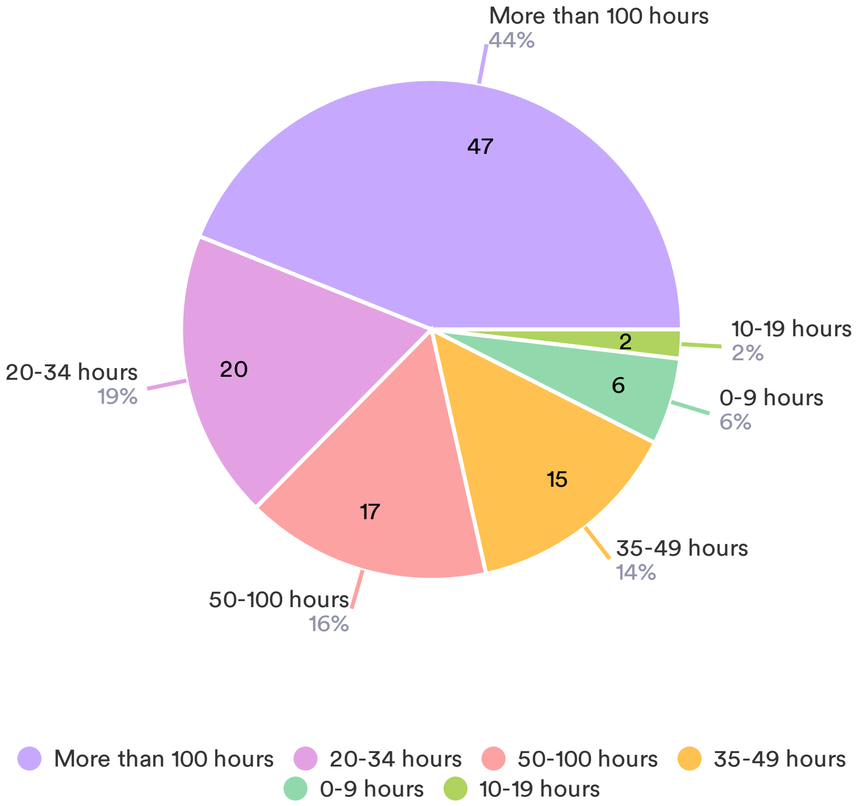
How many years have you been caring for?

98 Responses- 12 Empty

Data	Responses
5	9
2	8
10	7
4	7
7	6
13	5
27	4
16	4
Other entries	48

How many hours a week do you provide care/support?

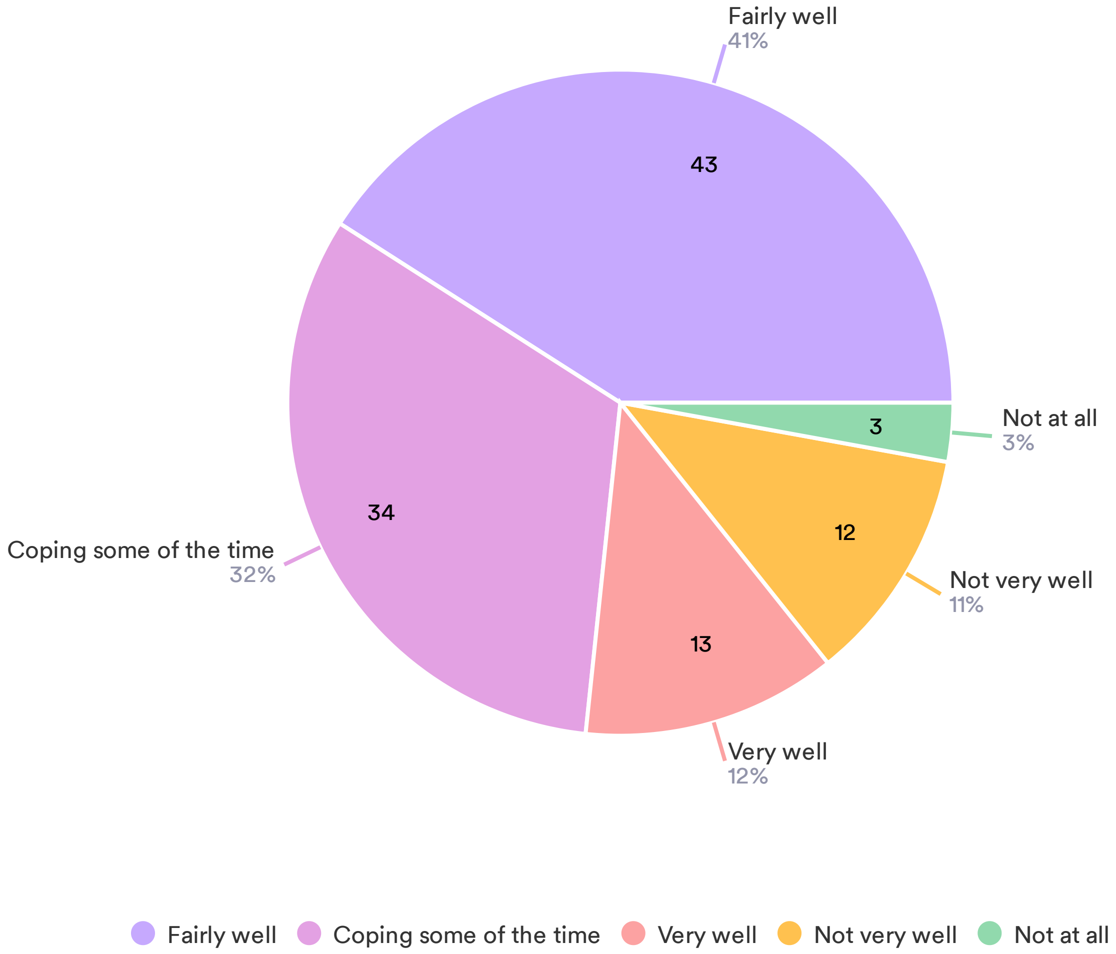
107 Responses- 3 Empty



High Peak Consultation Questionnaire

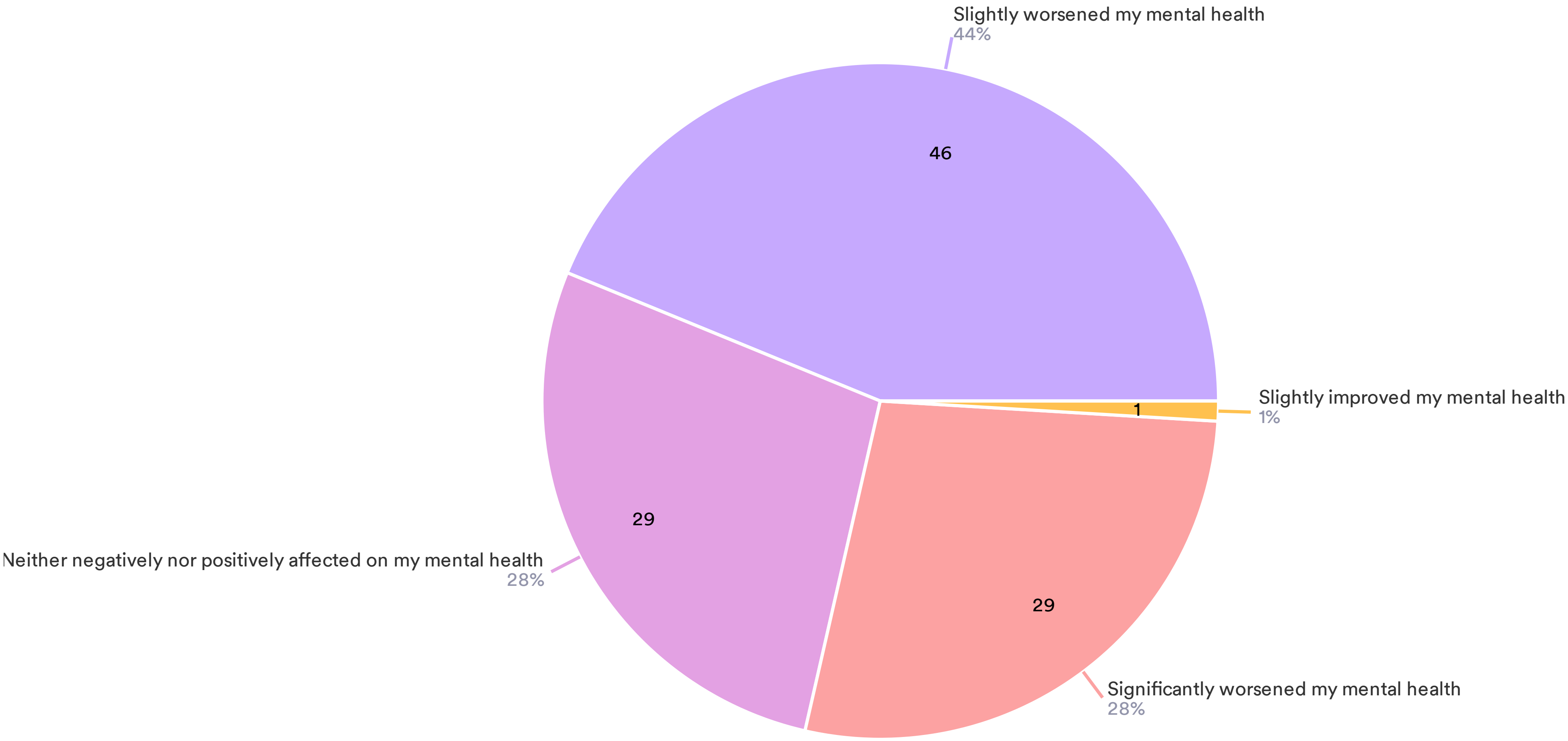
How well do you feel that you are coping well with your caring responsibilities?

105 Responses- 5 Empty



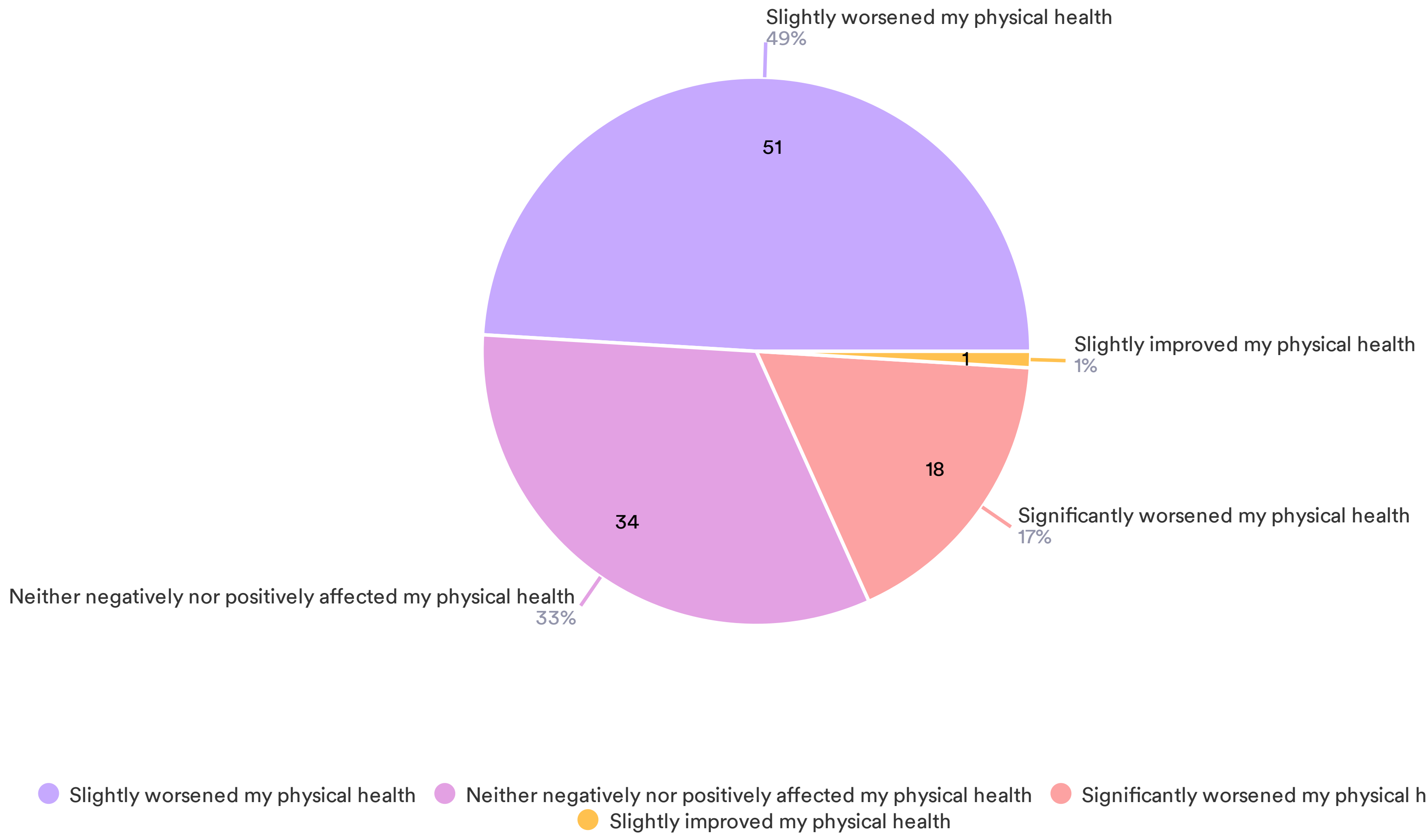
Do you feel that caring has had impact on your own mental health?

105 Responses- 5 Empty



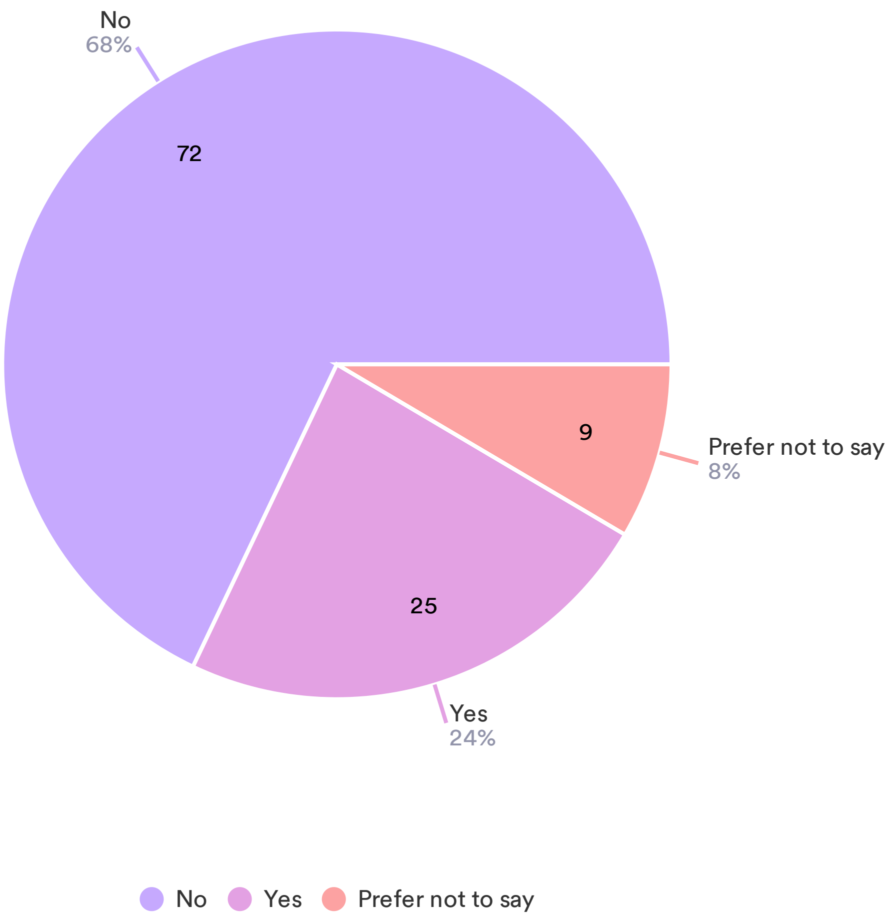
Do you feel that caring has had impact on your own physical health?

104 Responses- 6 Empty



Do you have a disability?

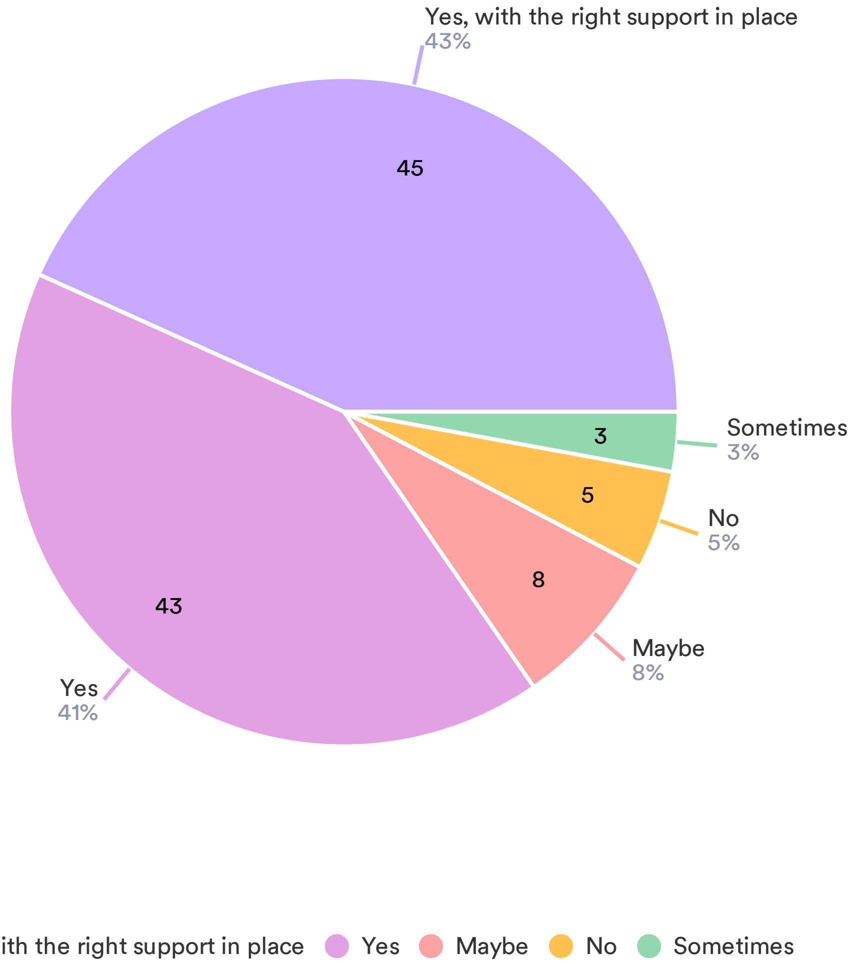
106 Responses- 4 Empty



High Peak Consultation Questionnaire

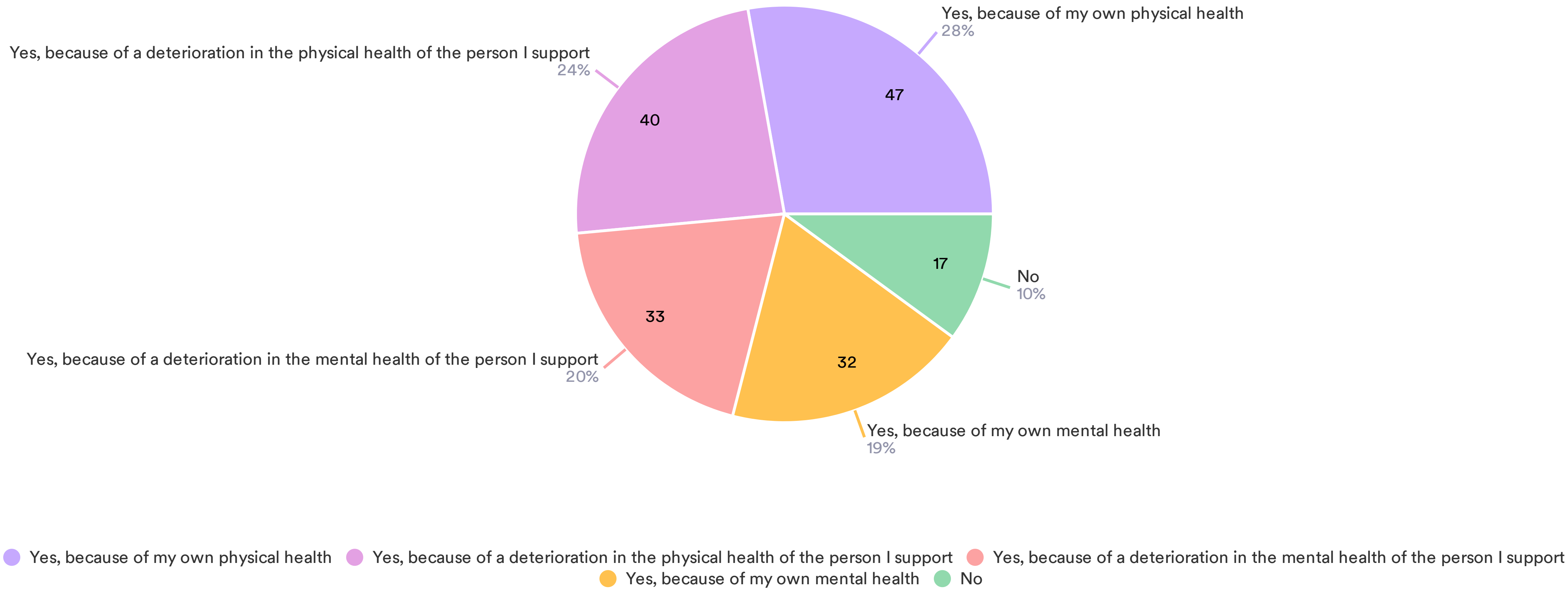
Are you happy to continue caring in the future?

104 Responses- 6 Empty



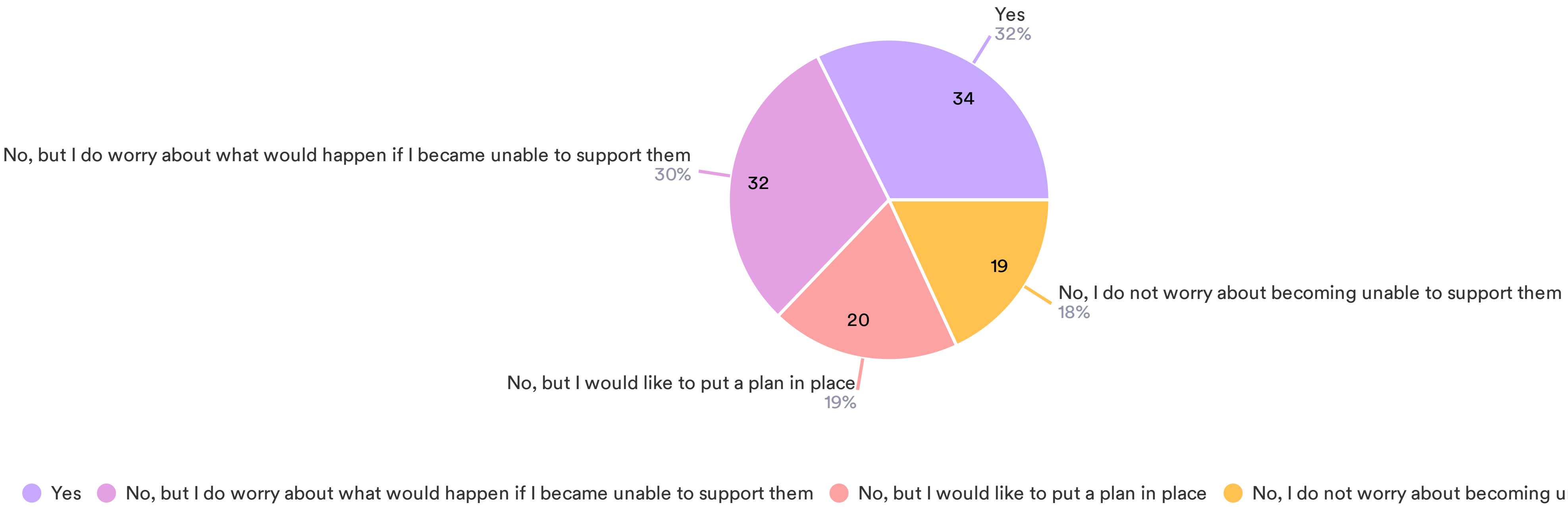
Do you worry about your ability to continue caring in the future (please tick all that apply)?

169 Responses- 4 Empty



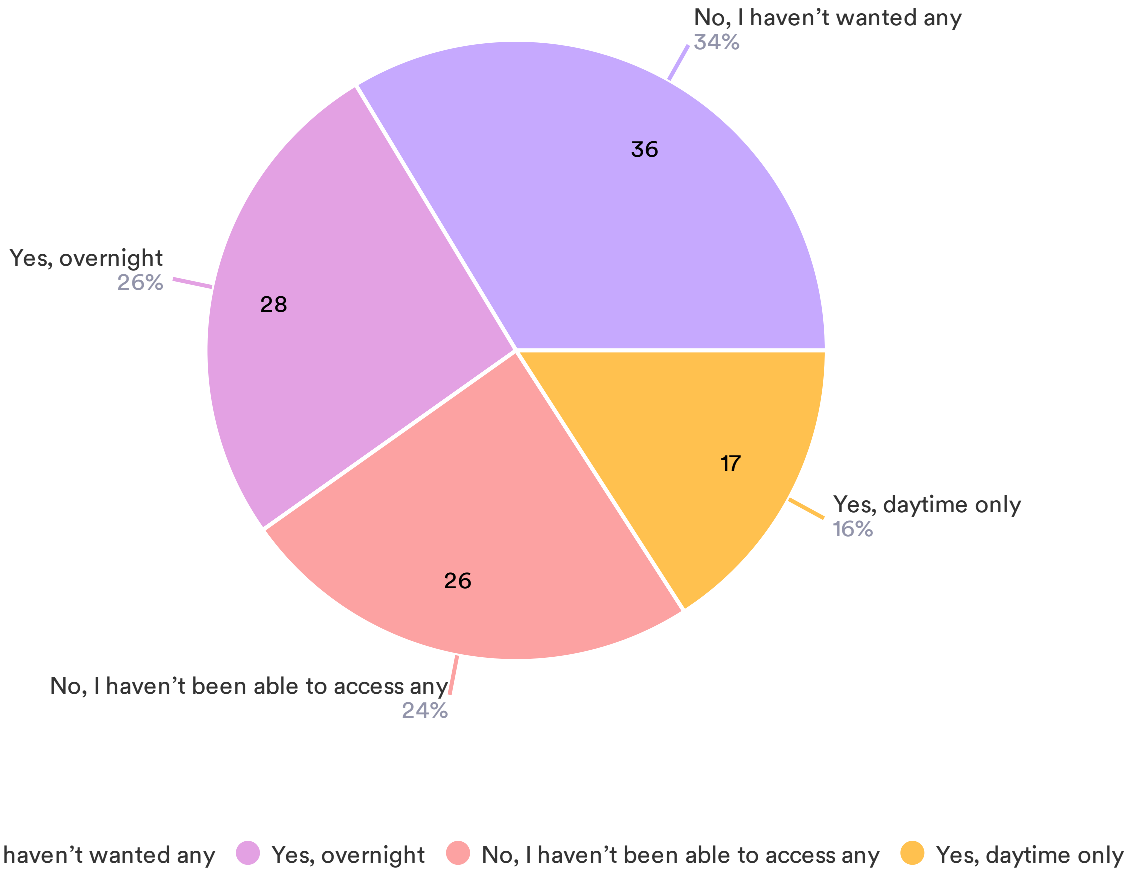
Do you have a plan in place for what happens to the person you look after if you become unable to support them? (e.g. Emergency plan/ agreement with another relative etc.)

105 Responses- 5 Empty



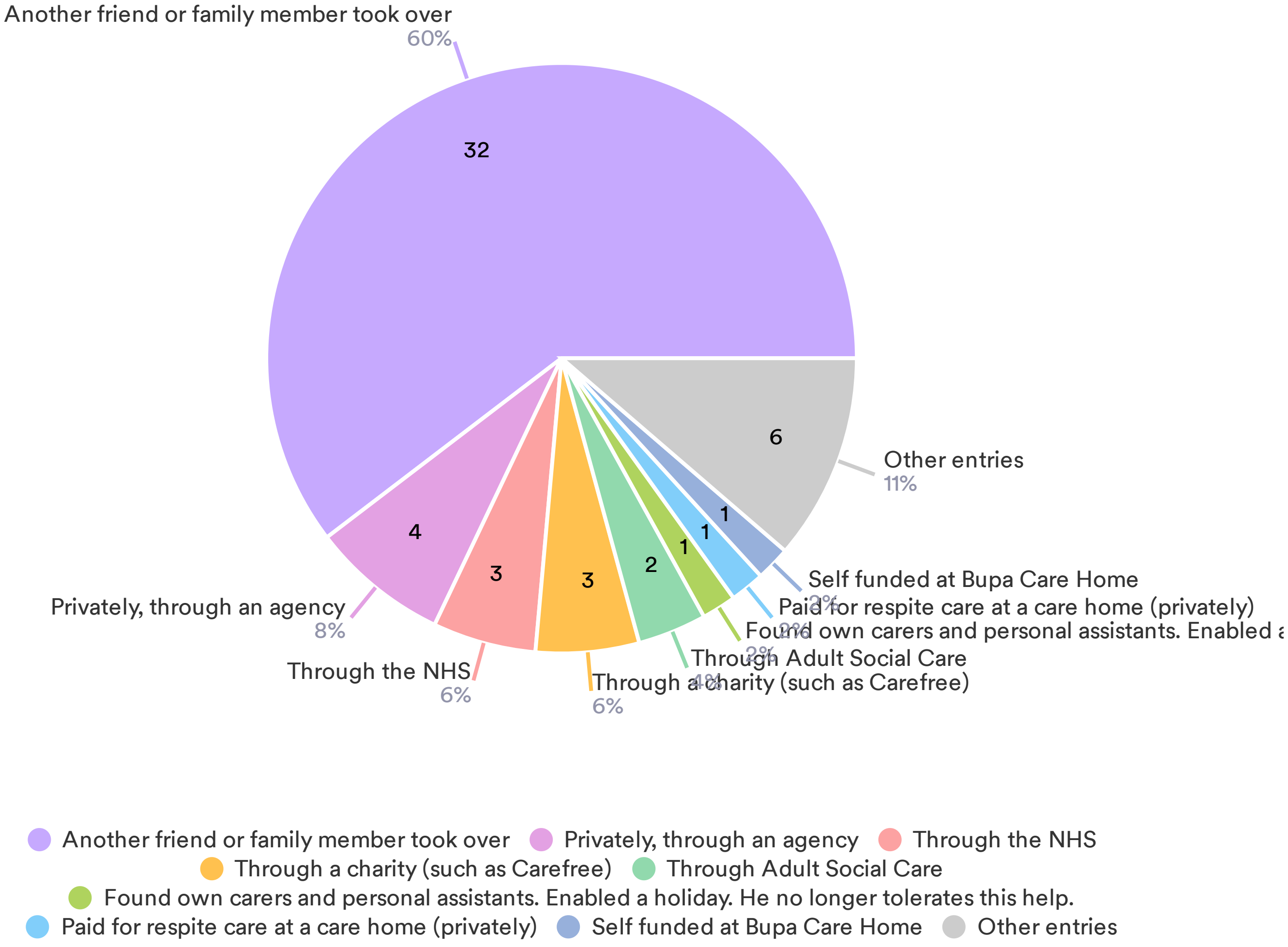
Have you had any respite in the last 12 months?

107 Responses- 3 Empty



If yes, how was this respite organised?

53 Responses- 57 Empty



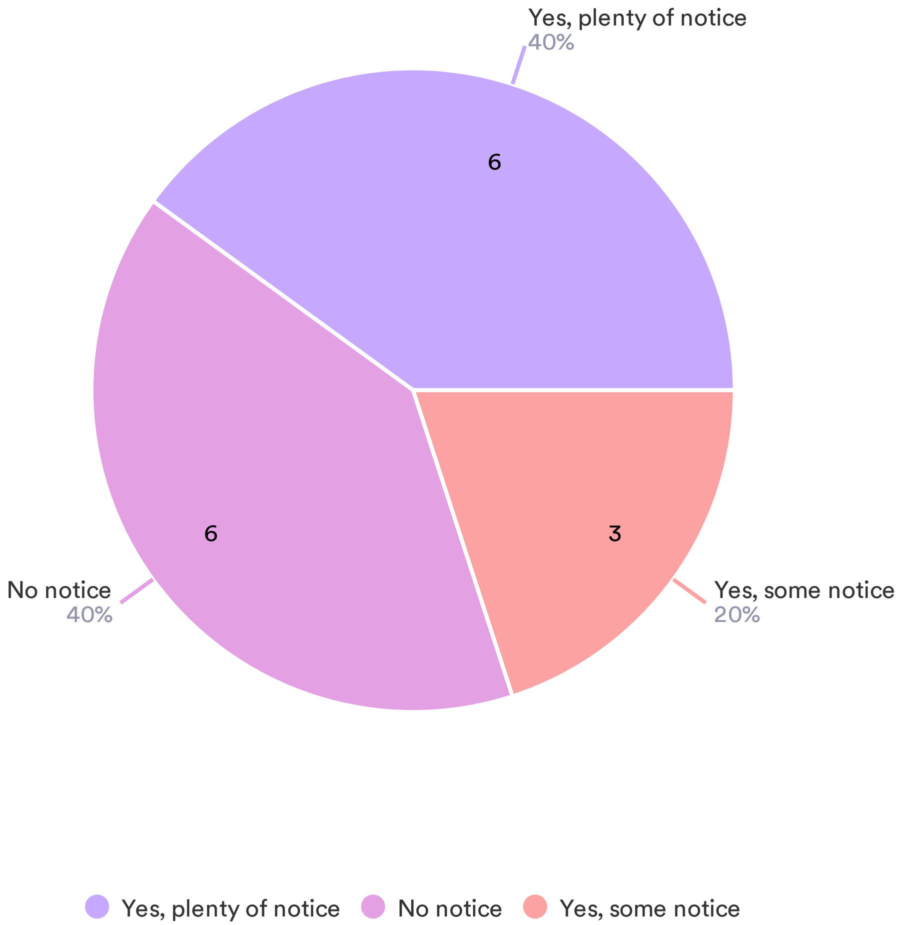
If other, please specify

11 Responses- 99 Empty

Data	Responses
DCA	1
carefree	1
Day trips organised by me	1
Tried Agency, social services carer trial but these were horrendous. Befriender from Bureau and one I organised do work.	1
It’s difficult as my son and daughter- in- law are coping with terminal brain cancer.	1
Brook View, Alderley Edge	1
Both through friends and family and privately through an agency	1
My friend or PA will step in	1
Other entries	3

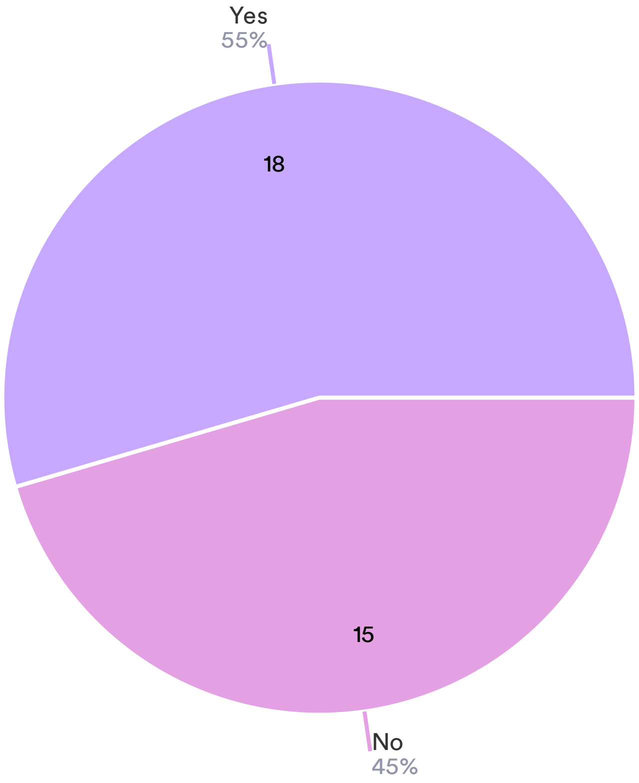
If respite was organised through Adult Social Care or the NHS, were you given enough notice of when the respite would be available?

15 Responses- 95 Empty



Do you feel that the respite offered catered to the needs of your cared for?

33 Responses- 77 Empty



● Yes ● No

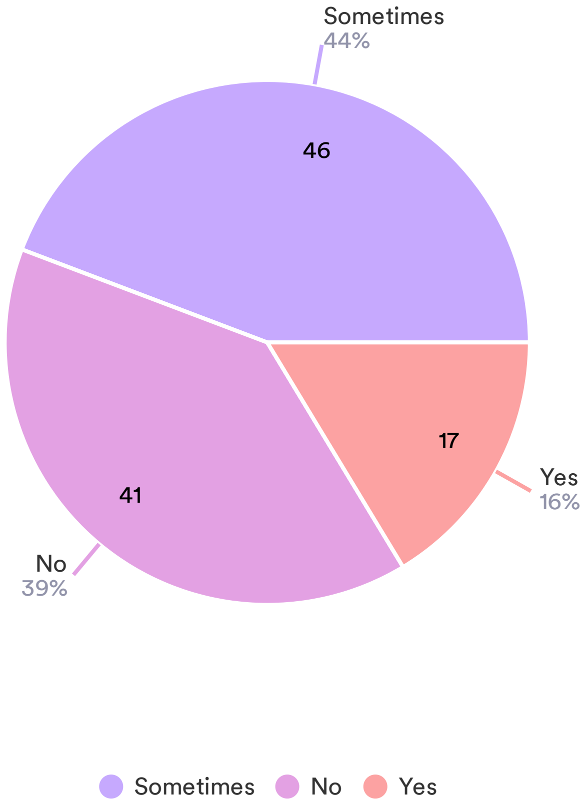
If no, please specify why

16 Responses- 94 Empty

Data	Responses
Husband not as well able to look after mental health needs of kids	2
I had to return early he was too difficult towards them .	2
Offering was ok but delivery was horrendous, loads of issues	1
I still felt worried and responsible	1
Not applicable	1
But still constantly worried	1
I don't want respite for him	1
N/A	1
Other entries	6

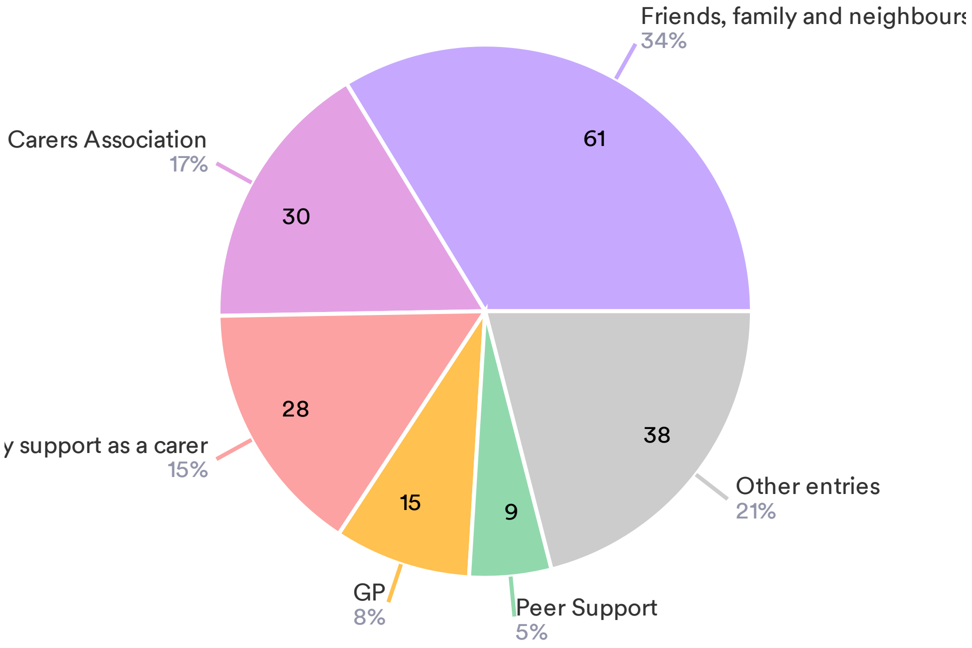
Do you feel well supported in your caring role?

104 Responses- 6 Empty



Who do you think offers you the most support as a carer (please tick all that apply)?

181 Responses- 5 Empty



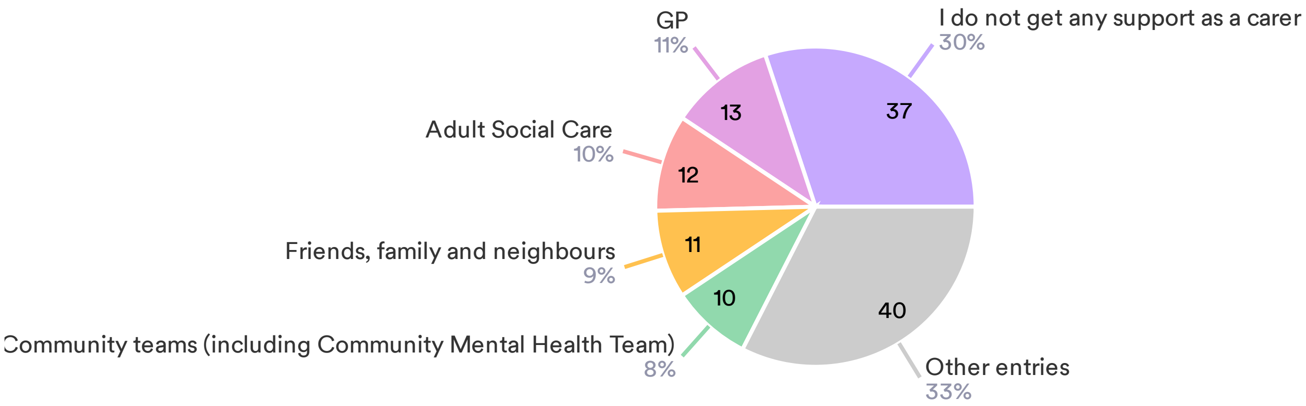
If other, please specify who

13 Responses- 97 Empty

Data	Responses
Valley Care	1
Blythe House	1
Dementia choir	1
Other charities	1
Alzheimer's Society	1
Counsellor. Befriender from the Bureau. Befriender I found independently.(both for husband))	1
I am supported by my husband. Pay privately for carers 2 hours per day. I still work as a nurse 25 hrs/week	1
My Therapist. She has relentlessly tried to access support for my son. Her and the Carers Association are my only sources of support.	1
Other entries	5

Do you feel let down by the support offered by any of the following (please tick all that apply)?

123 Responses- 35 Empty



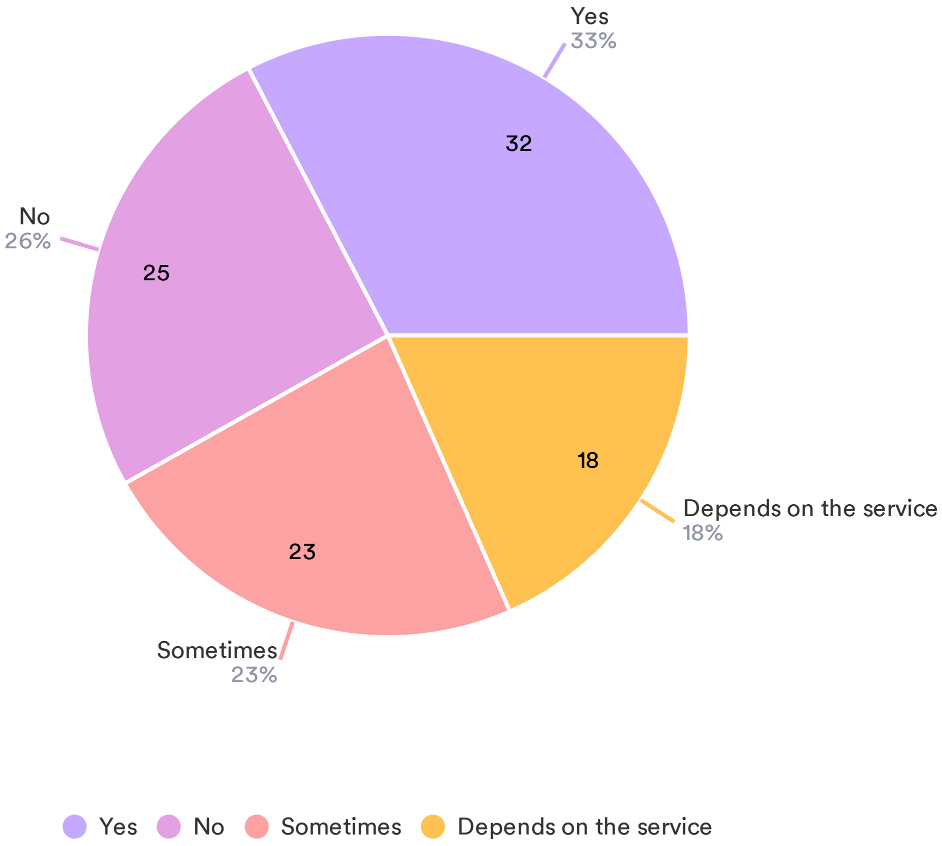
If other, please specify who

14 Responses- 96 Empty

Data	Responses
Apart from friends and family	2
Volunteer Bureau	1
CAMHS, Corbor View	1
CAHMS	1
I worry about myself providing transport for shopping hospital doctors chemist etcmake a big hole in my persona finances	1
What is offered is not what I need.	1
So far I haven't had a night or more away for 3 years	1
Have not really been offered support. Mum has breast cancer, vascular dementia and is severely sight impaired. I feel I have no other life than 'caring', in work and at home. Feel we have been excluded from some services due to mum's income.	1
Other entries	5

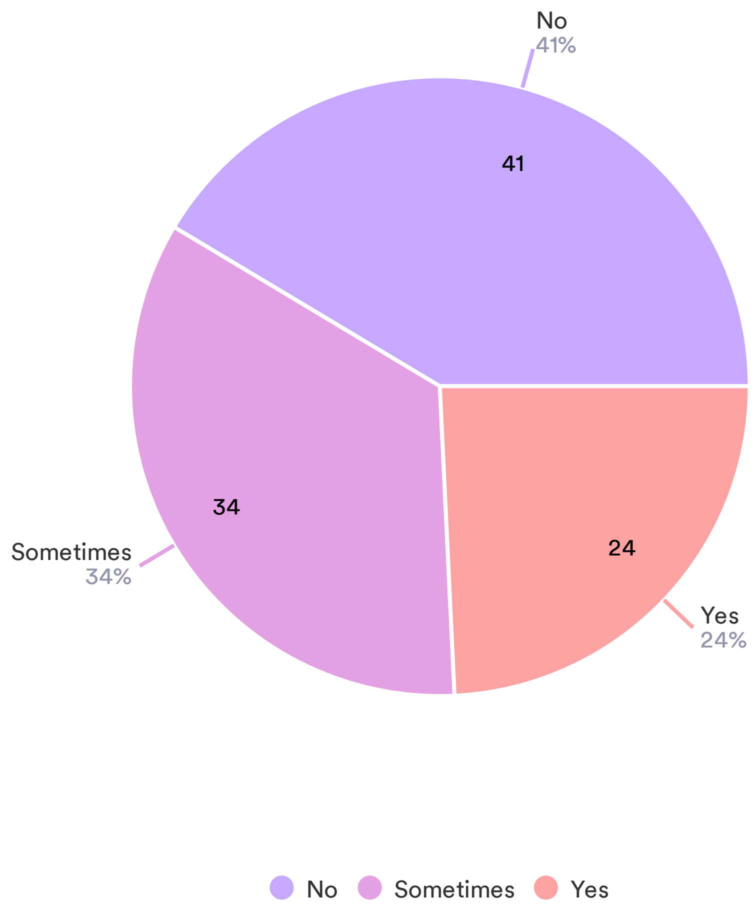
Do you feel adequately consulted, and that your opinion is respected, when professionals are making decisions about your friend/family-member's care?

98 Responses- 12 Empty



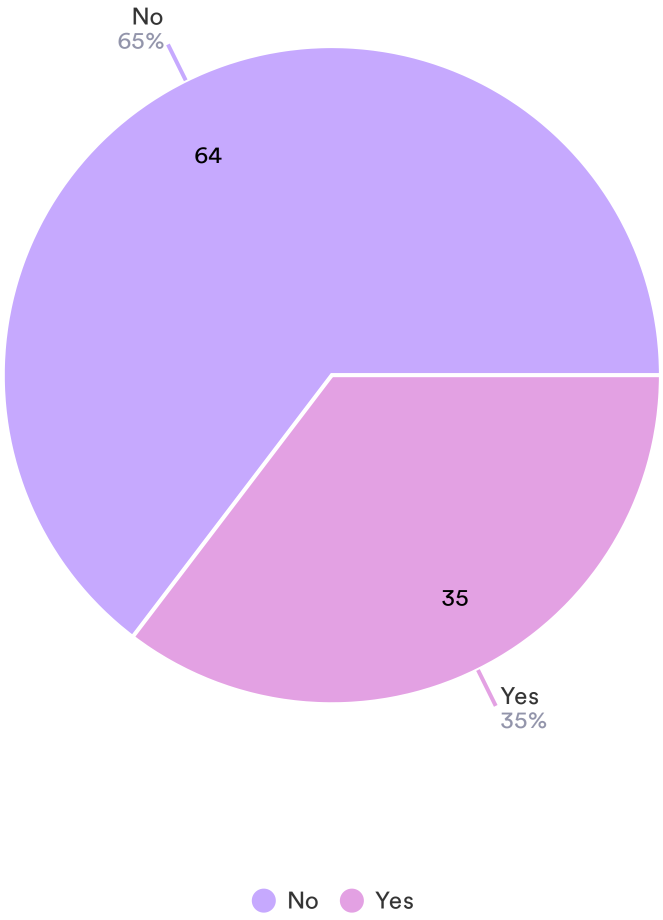
Do you feel that there is good communication between all professionals involved in your friend or family member’s care?

99 Responses- 11 Empty



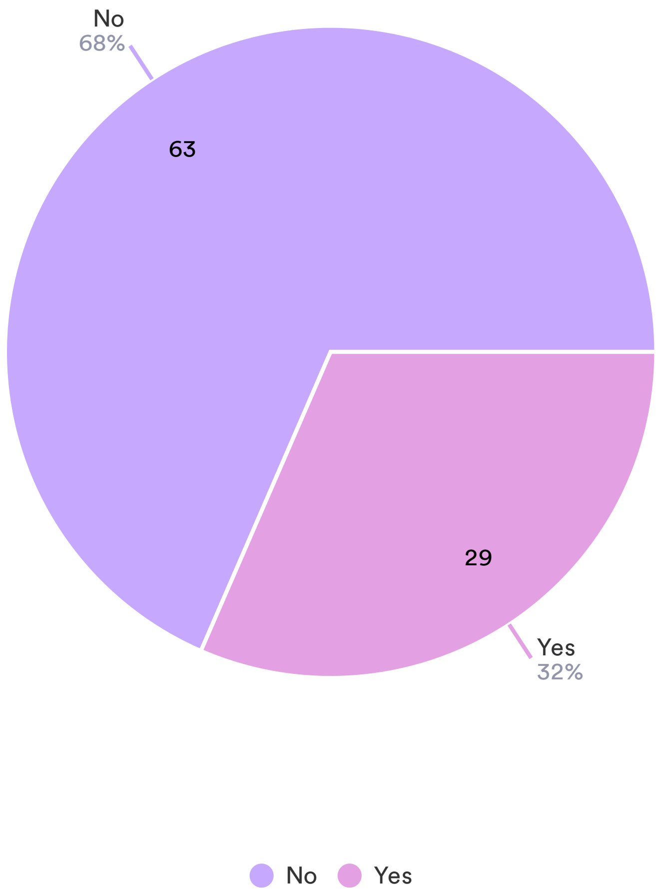
Do you feel well informed about what support is available to you?

99 Responses- 11 Empty



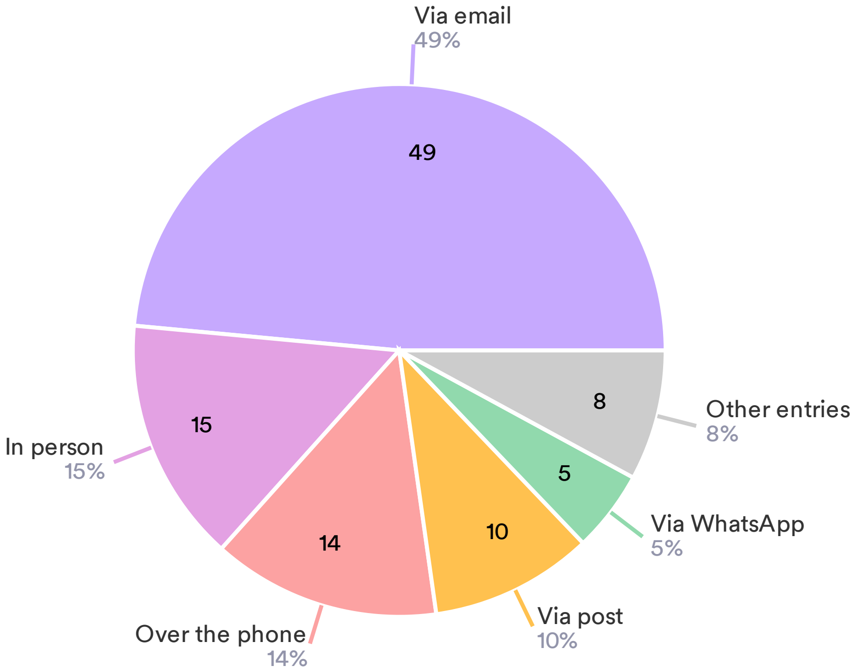
Do you feel well informed about what support is available to your friend or family member?

92 Responses- 18 Empty



How would you like information about support services to be communicated?

101 Responses- 9 Empty



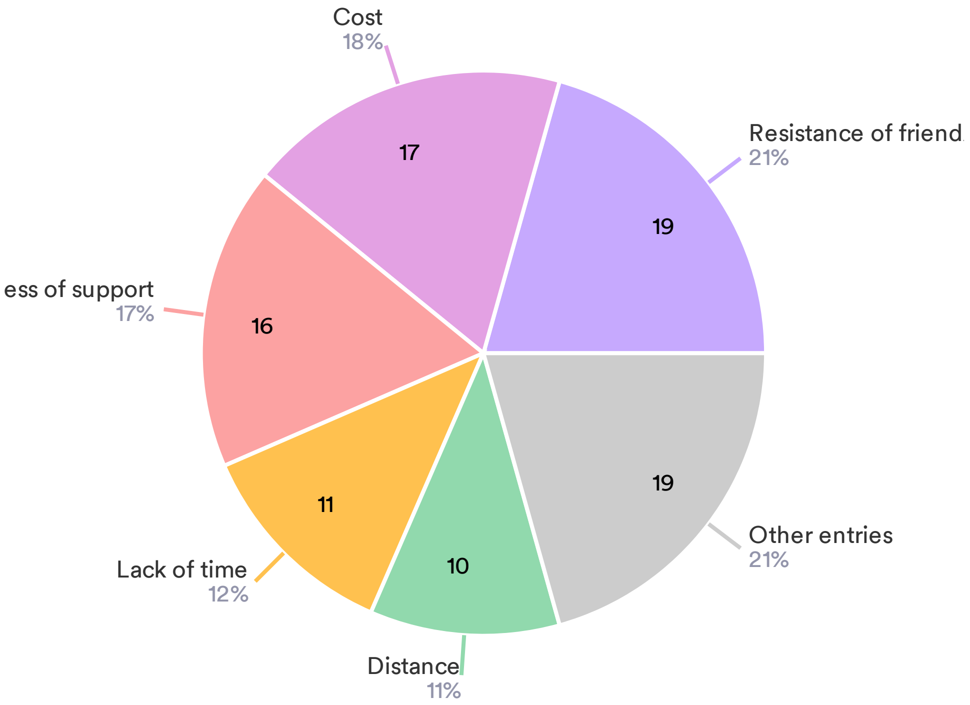
If other, please specify

12 Responses- 98 Empty

Data	Responses
in person	2
person, post	1
web, in person, post	1
email	1
web	1
All	1
email, in person, via post	1
web, in person	1
Other entries	3

What is most likely to stop you accessing a support service?

92 Responses- 18 Empty



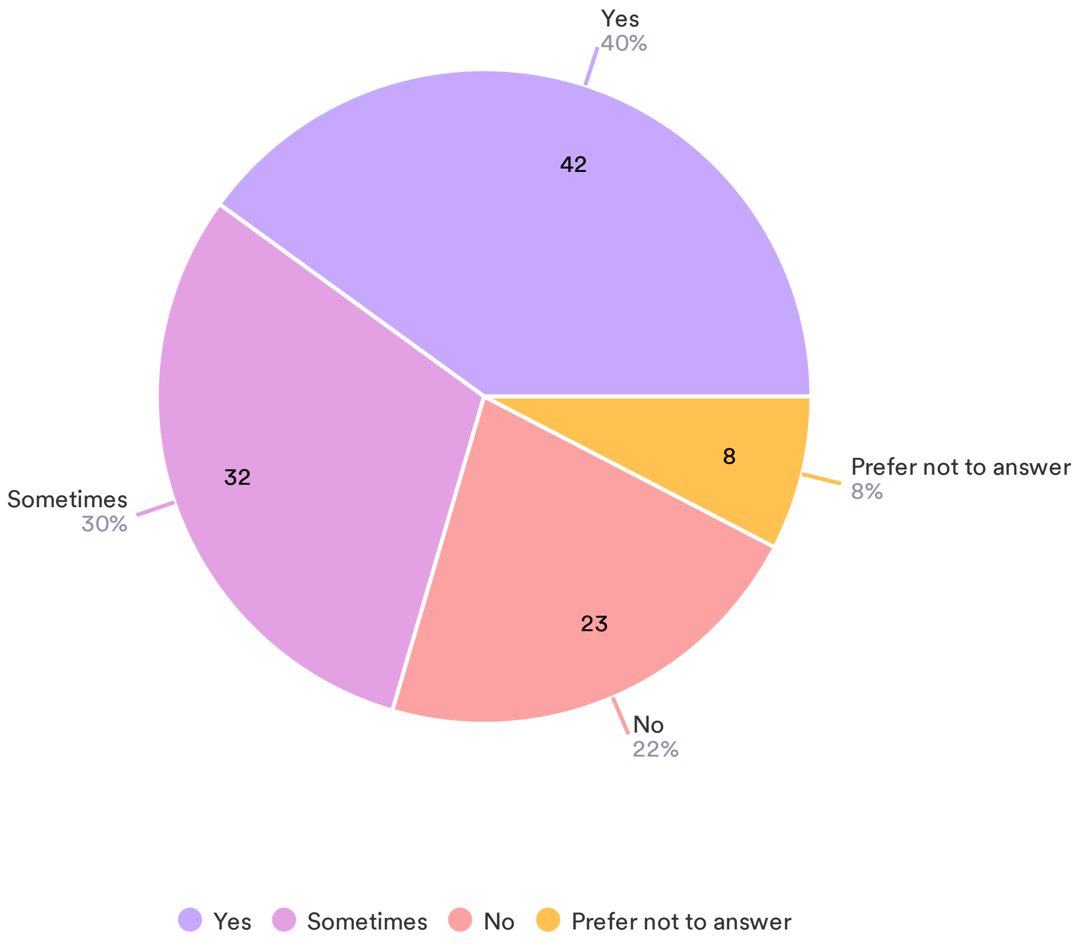
If other, please specify

26 Responses- 84 Empty

Data	Responses
appropriate support	2
I am also immunosuppressed so still avoid closed in spaces and groups due to Covid .	2
cost, lack of time, cant leave CF	1
cost	1
resistance	1
can't leave CF	1
cost and cant leave person	1
inability to leave person	1
Other entries	16

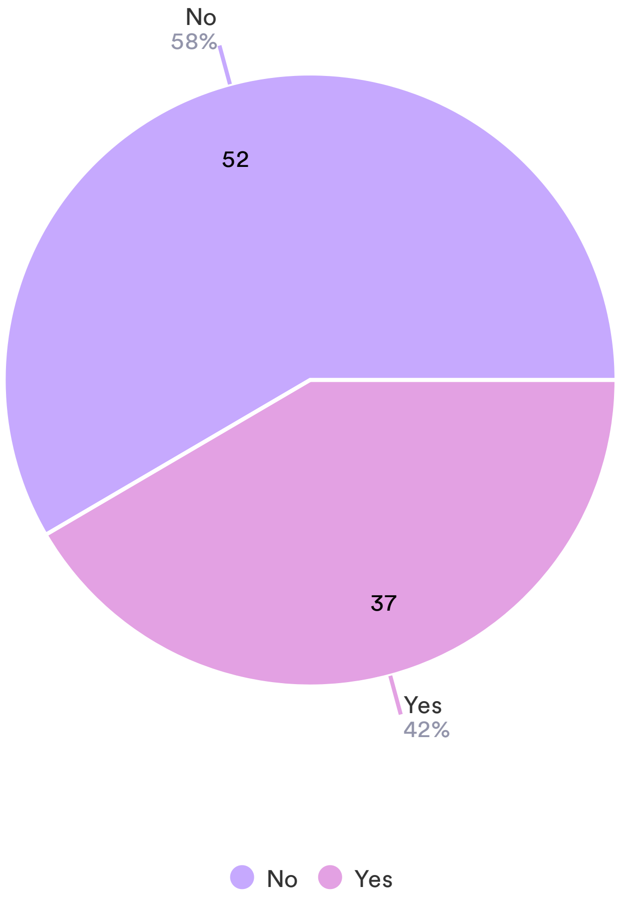
Do you worry about money?

105 Responses- 5 Empty



If you have completed any benefit forms on behalf of yourself, or the person you care for, did you find them easy to understand and complete? (e.g. Carers' Allowance, PIP, Attendance Allowance)

89 Responses- 21 Empty



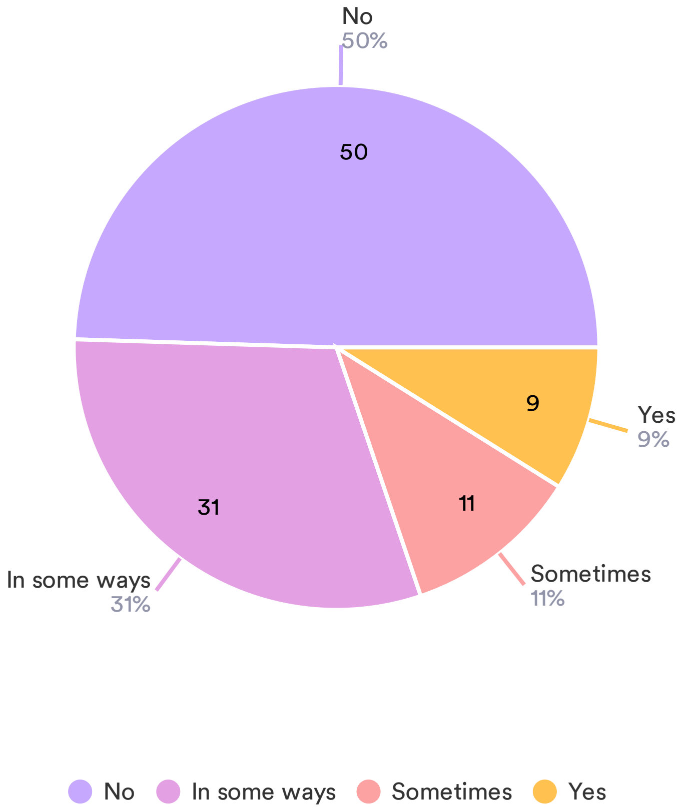
If no, please say why

49 Responses- 61 Empty

Data	Responses
None completed	2
Dla - hard to apply criteria to autism (son Pip - hard to apply criteria to me/CFS (daughter	2
We got help from Disability Stockport . My husband responds better to an outsider . The forms were completed with help.	2
They are extremely time consuming, lengthy. My daughter requires 24/7 care. I simply do not get time, we have no respite.	2
Required help	1
They make them as hard as possible and every attempt ends up going to tribunal - it stresses you out.	1
Only because I used to work for DWP	1
Husband did them before he got dementia	1
Other entries	37

Has being a carer had a positive impact on your own life?

101 Responses- 9 Empty



If you answered a), b) or c) to the above question, what is the greatest positive about being a carer?

37 Responses- 73 Empty

Data	Responses
Just helping my lovely mother makes me positive about being her carer	2
Seeing the tiny milestones my daughter has achieved, we were told at diagnosis that she wouldn't do this	2
The closeness it has brought to my relationship with my daughter	1
Having to give up work and not having to juggle carers role with a professional role	1
learning to cope with unpredictable dementia	1
Being able to provide help so that cared for person can enjoy life as much as possible. I have been impressed by support available to carers here.	1
Meeting lovely people with similar problems. Being able to share some of the awful experiences with them. Meeting people who really understand what we're going through.	1
time with cared for	1
Other entries	27

What do you find most challenging about being a carer?

89 Responses- 21 Empty

Data	Responses
Trying to anticipate what types of food to prepare and purchase.	2
No breaks for myself	2
Ironing bedding keeping clean	2
Isolation , frustration, verbal abuse , loss of personal freedom.	2
Being tired	2
Doing it alone and being relied on for everything. Having to reduce my work hours to enable me to work and care.	2
Lack of support and understanding, especially when trying to make appointments (mostly Doctors) I also work, trying to juggle my daughters needs and work is a mission, but bills need to be paid. No respite. No access to support or groups for my daughter as we live in New Mills and get forgotten. I don't have access to a car most of the time, accessing public transport is a challenge. Barriers to most things that would make life so much easier. I hear the words No/We can do that/not available in Derbyshire too many times, yet other authorities allow.	2
Travel times / distances to appointments	1

What single change would make the biggest difference to your ability to care in the future?

81 Responses- 29 Empty

Data	Responses
Arthritic knees getting worse(mine)	2
More breaks for myself	2
Ironing faster	2
if my husband was to recommence having epileptic seizures. He becomes too unpredictable and aggressive.	2
Help with housework/shopping chores at times	2
To be listened to of what would make our lives easier and not hear the word No etc.	2
Being able to drive	1
Occasional days respite	1
Other entries	67

Appendix C – Young Carer Questionnaire

Young Carers' High Peak Consultation Questionnaire

Derbyshire Carers Association is running a Consultation Project across the High Peak until the end of 2023. The High Peak Consultation Project wants to do two things: firstly to listen to the experiences of young carers in High Peak, and secondly to make suggestions for what services could do in the future to help people like you.

The questions below have been inspired by interviews with carers.

Answers may be quoted in the Consultation Project's final report, but any identifying features will be removed, and all answers are anonymous.

Please make sure that you have a parent or guardian's consent to answer these questions.

If there are any questions that you would prefer not to answer, then please just skip to the next one.

If you would like to get more involved with the Consultation Project, then please ring Emma Beestone on 07816 283550 or email emma.beestone@derbyshirecarers.co.uk

Thank you.

1. Do you have your parent or guardian's consent to answer these questions?

a) Yes

b) No

2. Who do you care for (please tick all that apply)?

a) Parent
b) Other family member (Please specify ______________)
c) Friend
d) Neighbour
e) Other (Please specify ________________)

3. How many hours a week do you provide care/support?

a) 0-9 hours
b) 10-19 hours
c) 20-34 hours
d) 35-49 hours
e) 50-100 hours
f) More than 100 hours

4. How well do you feel that you are coping with being a carer?

a) Very well
b) Fairly well
c) Coping some of the time
d) Not very well
e) Not at all

(If you would like to talk to someone about what support is available for young carers, then please ring Derbyshire Carers Association on 01773 833833 between 9am and 4.30, Monday-Friday).

5. Do you feel that caring has had impact on your own mental health?

a) Made my mental health much better
b) Made my mental health a bit better
c) Had no impact on my mental health
d) Made my mental health a bit worse
e) Made my mental health significantly worse

6. Do you feel that caring has had impact on your own physical health?

a) Made my physical health much better
b) Made my physical health a bit better
c) Had no impact on my physical health
d) Made my physical health a bit worse
e) Made my physical health significantly worse

(If you would like to talk to someone about what support is available for young carers, then please ring Derbyshire Carers Association on 01773 833833 between 9am and 4.30, Monday-Friday).

7. Are you happy to continue caring in the future?

a) Yes
b) Yes, with the right support in place
c) No
d) Maybe
e) Sometimes

8. Has being a carer had a positive impact on your own life?

a) Yes
b) Sometimes
c) In some ways
d) No

9. If you answered a), b) or c) to the above question, what is the greatest positive about being a carer? (Otherwise please go to question 10.)

____
____
____

10. What do you find most challenging about being a carer?

____
____
____

11. What single change would make the biggest difference to your ability to care in the future?

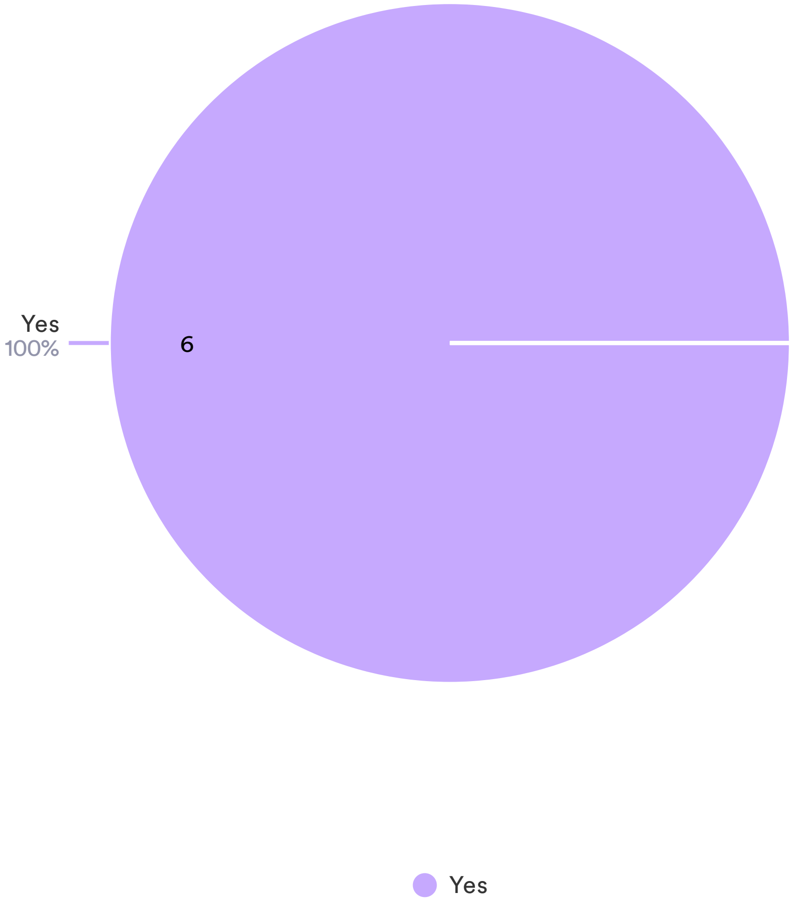
____
____

Appendix D – Young Carer Questionnaire Results

Young Carers High Peak Consultation Questionnaire

Do you have your parent or guardian’s consent to answer these questions?

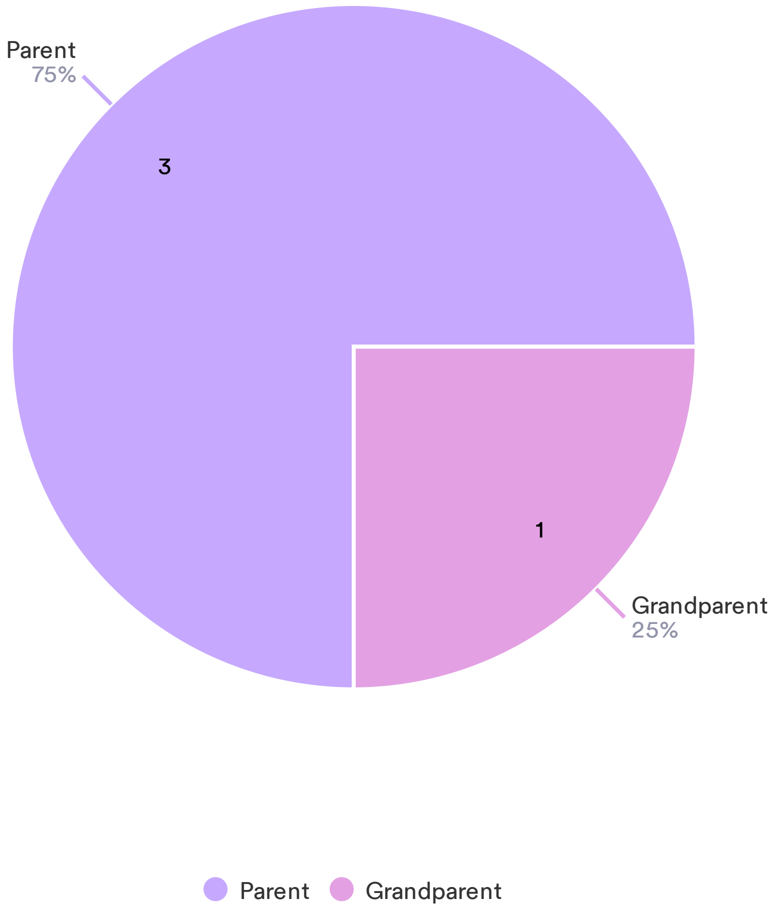
6 Responses- 1 Empty



Young Carers High Peak Consultation Questionnaire

Who do you care for (please tick all that apply)?

4 Responses- 3 Empty



If other family member, please specify

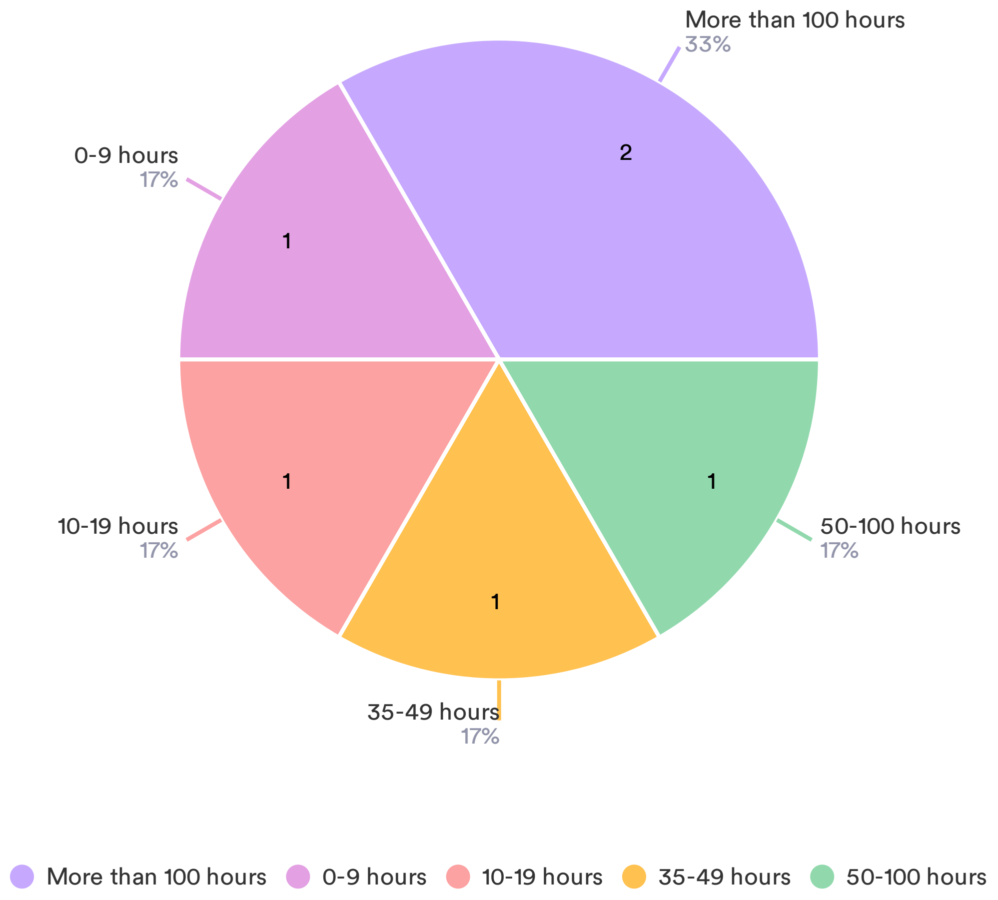
1 Response- 6 Empty

Data	Responses
Grandparent	1

Young Carers High Peak Consultation Questionnaire

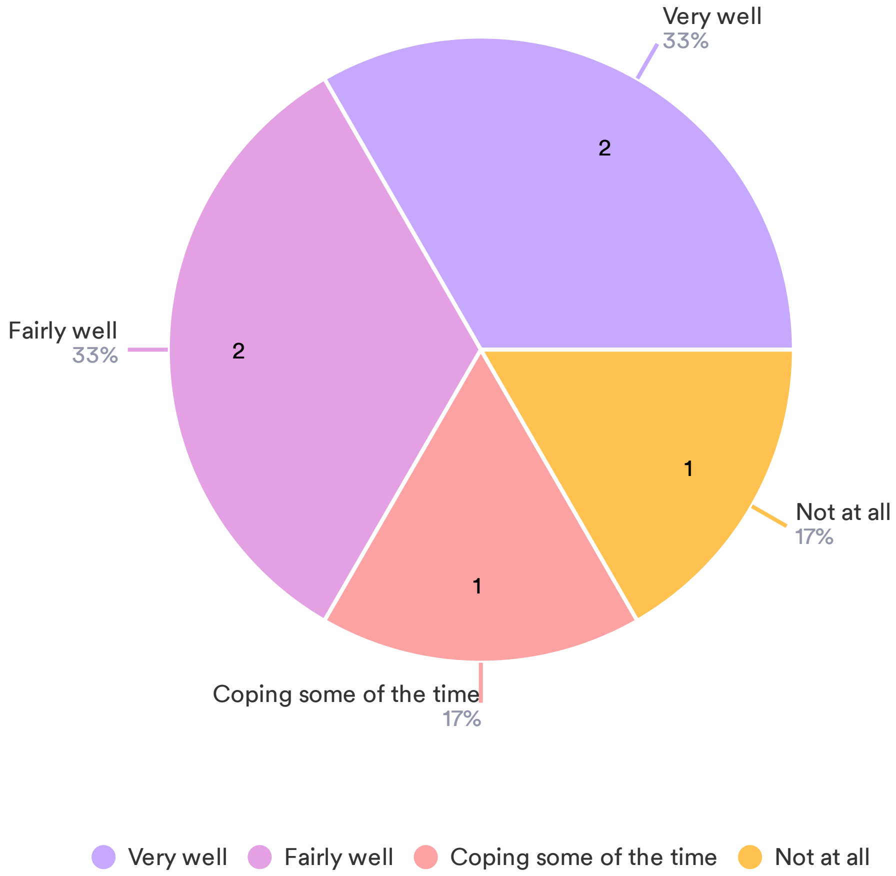
How many hours a week do you provide care/support?

6 Responses- 1 Empty



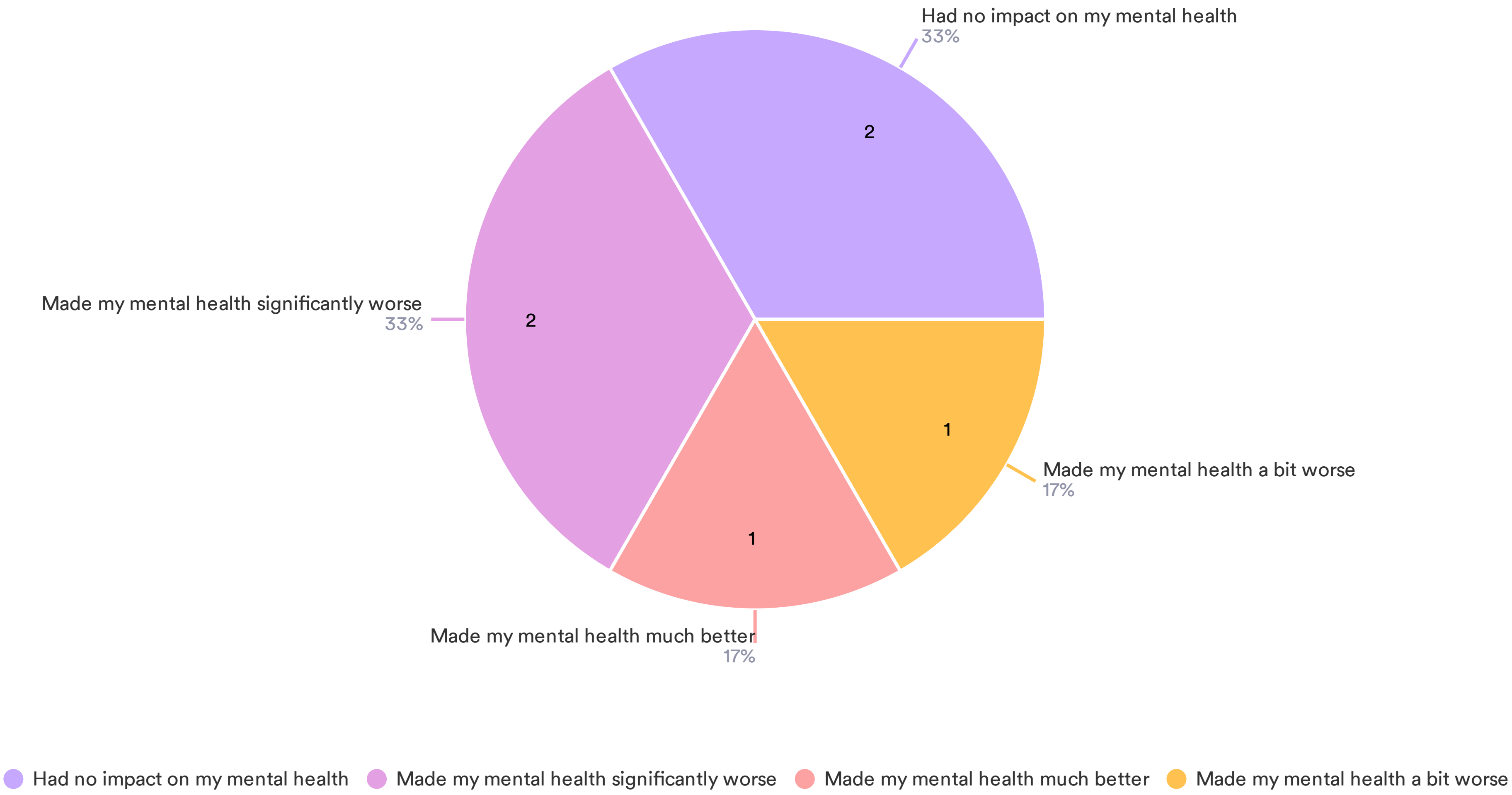
How well do you feel that you are coping with being a carer?

6 Responses- 1 Empty



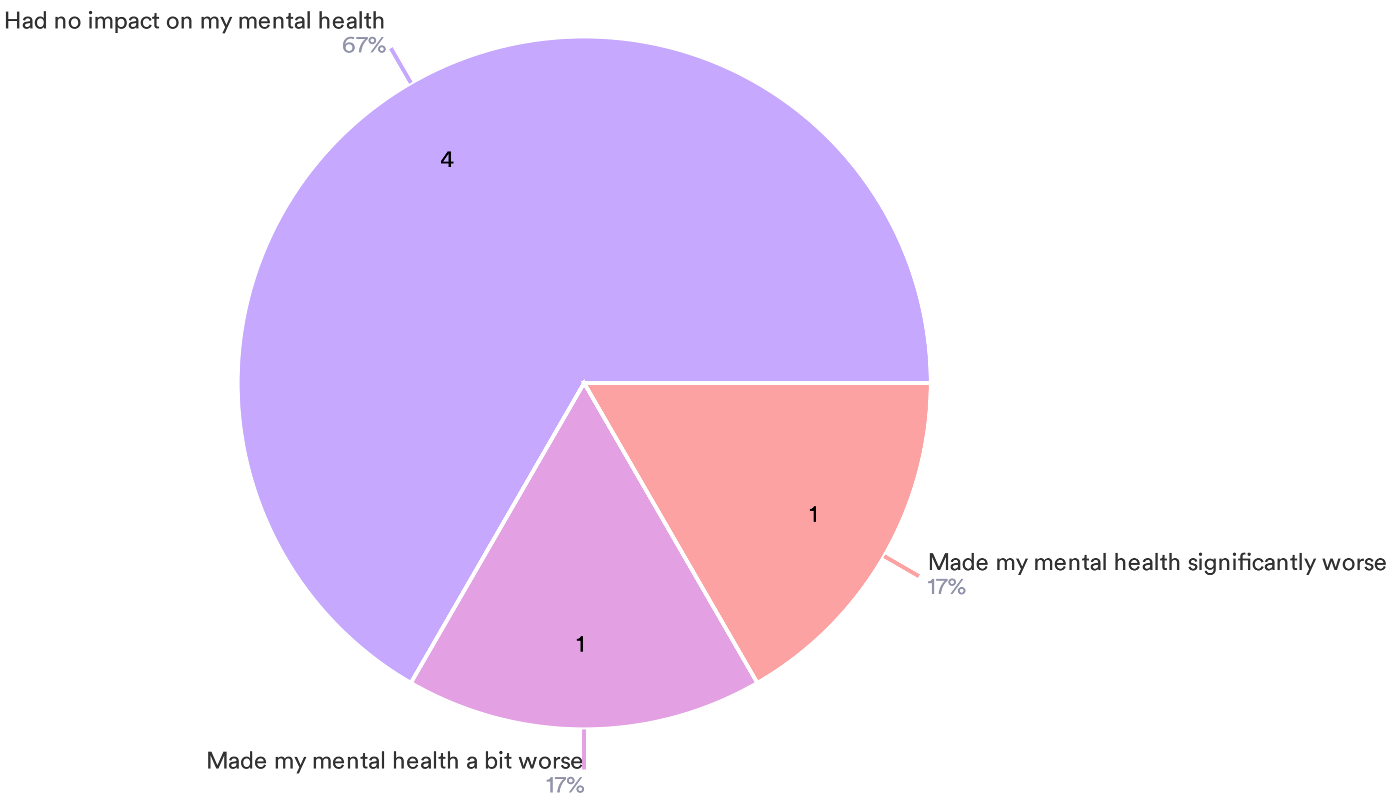
Do you feel that caring has had impact on your own mental health?

6 Responses- 1 Empty



Do you feel that caring has had impact on your own physical health?

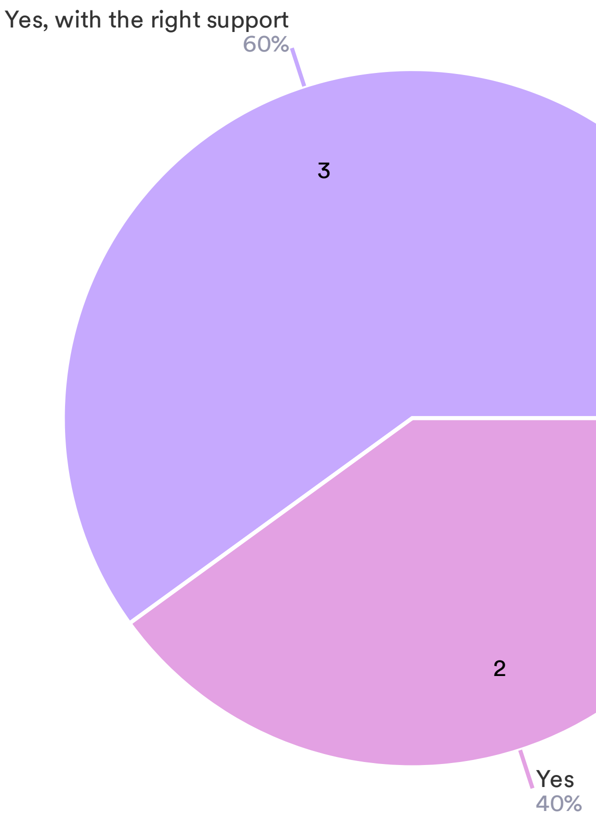
6 Responses- 1 Empty



● Had no impact on my mental health ● Made my mental health a bit worse ● Made my mental health significantly worse

Are you happy to continue caring in the future?

5 Responses- 2 Empty

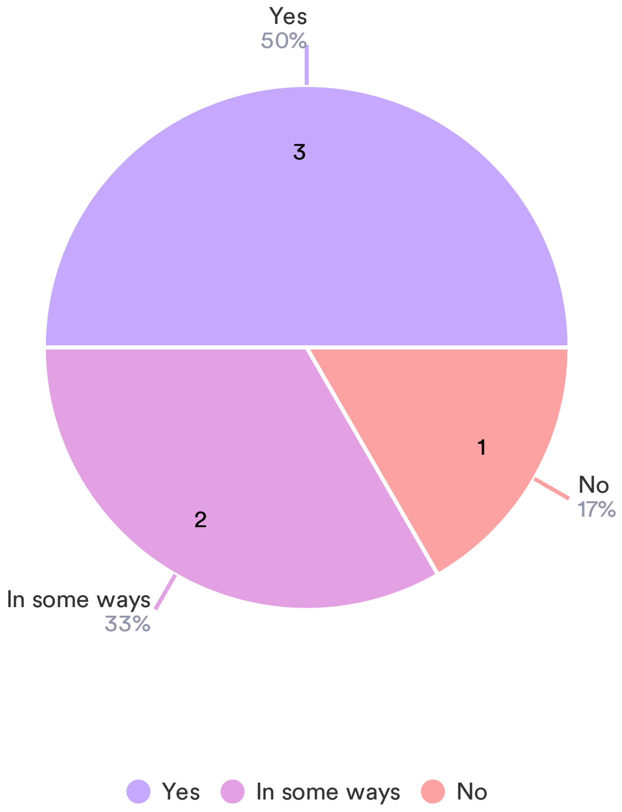


● Yes, with the right support ● Yes

Young Carers High Peak Consultation Questionnaire

Has being a carer had a positive impact on your own life?

6 Responses- 1 Empty



If you answered 1), 2) or 3) to the above question, what is the greatest positive about being a carer? (Otherwise please go to the next question.)

5 Responses- 2 Empty

Data	Responses
Don't know.	1
Helping my mum, ensuring she is happy.	1
I've got closer to my [grandparent]. The support from teachers.	1
Young Carer Activity Days.	1
It has made me more mature. It meant I knew how to cope with a friend's disability. DCA Young Carers' events, which are good.	1

Young Carers High Peak Consultation Questionnaire

What do you find most challenging about being a carer?

6 Responses- 1 Empty

Data	Responses
[Cared-for] keeps asking questions again and again, and that frustrates me.	1
No.	1
Having energy. Only able to attend school two days a week.	1
Don't know.	1
No character building, just misery. I don't like sympathy. Coping with [younger sibling's] emotions.	1
Socialising.	1

What single change would make the biggest difference to your ability to care in the future?

6 Responses- 1 Empty

Data	Responses
Don't know.	2
Getting out of the house, both for me and [my grandparent] (despite [their] disability). Socialising.	1
More Young Carer Activity Days.	1
More support from school, who have been useless with no understanding for lateness. School counselling.	1
More time to myself, more time to socialise out of school (because school is stressful). I hate not being social. I need someone to talk to.	1

Appendix E – “You Said, We Did”

You said, we did

You said	We did
Carers in High Peak were struggling to find out what appropriate support was available to them.	We introduced the Information Roadshow and delivered three in-person information events across High Peak. We plan to introduce these in each locality in Derbyshire Carers Association’s new engagement model.
Carers need more information about available support earlier on their caring journey, and crucially before a crisis point.	We have designed a Welcome Booklet. The booklet has been developed using insight from carers. A draft copy of the booklet has been given to carers who are involved in our Carers’ Voice panel for feedback and once finalised will be introduced in April to all new carers who register with us.
Carers disliked being directed to online services/support and/or were overwhelmed by the number of leaflets given.	We provided opportunities to speak to support services in person. (With services invited to Roadshow events based on what carers would like to see and what is available in their community).
Carers who are not confident online felt that the increasing digitalisation of care increases their caring burden and is a source of stress.	We: • Partnered with Rural Action Derbyshire to survey existing internet usage and access amongst carers • Are introducing digital awareness training for all frontline staff • Are incorporating digital training into our new carer learning model • Will ensure that, wherever possible, our service remains accessible to carers who are not online or are not confident online.
Carers felt forgotten about and that carer events were too far away.	Derbyshire Carers Association delivered several activities based on carer feedback. Insight has been used to plan future carer wellbeing and learning sessions as well as activities.
Carers felt let down by services and that no one was listening.	Derbyshire Carers Association established direct reporting links into Healthwatch.
Carers emphasised how important the relationship with GP Surgeries and how fraught that relationship could be at times.	Derbyshire Carers Association appointed a GP Liaison Worker in High Peak to provide Carer Awareness Training, Carers' Pledge and ongoing Carers' Champion support.
Carers said that keeping on top of household chores and gardening could be a barrier to taking a break and created anxiety.	Derbyshire Carers Association partnered with Time Swap and for every hour a carer gave to the Carers’ Voice project, they could bank an hour and claim back to use towards a service

	they required. Carers also had access (where eligible) to a carers’ personal budget.
Carers want to share their knowledge and have a voice.	Derbyshire Carers Association have introduced a county-wide Carers’ Voice Co-production panel and we already have a group of passionate eager carers involved.
Carers want their know that their feedback is being listened to and acted upon.	We have: • Incorporated co-production into our future service design • Changed the day and time of our Glossop Support Group to better accommodate carers • Strengthened links between our offices in High Peak and Ripley

You said, we will

Carers want to be better informed about possible disease progression, especially for Dementia.	Derbyshire Carers Association are currently working alongside Derbyshire Dementia Support Services and other specialist services to discuss the potential of a collaborative learning model.
Carers said they would like an online support group for neuro divergent carers.	Derbyshire Carers Association partnered with specialist services to provide an online learning session and will look to include an online group in future provision.
Male carers feel under-acknowledged / overlooked and are underrepresented at existing support groups.	Derbyshire Carers Association have gathered insight to learn more about the challenges facing male carers, particularly when establishing groups/activities. This insight is being used in the planning and design of new carer learning and wellbeing model, and will be a focus topic for the Carers’ Voice Panel.
What would happen in the event of a crisis is causing considerable stress and worry.	Derbyshire Carers Association will work to improve communication of Carer Emergency Planning and discuss options such as ‘planning for the future' programme with commissioners.
Carers said there is not enough support when caring comes to an end.	Derbyshire Carers Association will strengthen the existing support package that is offered for 12 months after caring comes to an end, and will work in partnership with Blythe House and the Bereavement Service to provide a pathway to support.

Young carers reported the importance of opportunities to socialise for themselves and the person they care for.	Through coproduction, Derbyshire Carers Association will support young carers and their families to design, plan and implement an activity and learning model.
Carers said that they valued existing services such as the support groups and young carer events.	We will continue to provide these under the new contract that launches in April 2024.
Carers worry that the High Peak will cease to be a priority after the end of the consultation, that it will get ‘forgotten’.	We will not stop here. Derbyshire Carers Association will continue to refine and develop our service on the basis of carers’ feedback. The end of the consultation project does not mark the end of interest in the High Peak. Indeed, a pilot for in-person, interest based digital support sessions in the High Peak is currently being proposed and will be developed in consultation with carers.