The unheard voices of
Derbyshire Diverse Carers

Derbyshire Carers Association

NHS

Community Action

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Derbyshire All Age Carers Support Service

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Summary

This report aims to provide insight into the experiences of Carers from ethnic minority communities in Derbyshire; highlighting issues such as cultural challenges and barriers that lead to Carers feeling isolated, alone and excluded from services such as health and social care. Carers from ethnic minority communities play a vital role in supporting loved ones with day to day care but often face unique challenges that limit access to support services. Identifying and understanding these challenges is crucial for breaking down barriers and improving access to support provision for themselves and the person they care for.

The project involved mixed methods to engage with Carers from ethnic minority backgrounds; the most effective being community engagement and working in partnership with existing community groups and services.

Ethnic minority Carers in Derbyshire face multifaceted challenges that require culturally appropriate solutions. It's also important to mention the unique challenges of being a Carer in Derbyshire. Derbyshire encompasses a mixture of urban and rural areas that can often create further barriers for Carers from ethnic minority communities. By addressing these issues, service providers can better support to improve the wellbeing of Carers.

'Stop calling family members a 'hidden army'. We're not invisible, just ignored.' [1]

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[1] theguardian.com/society/2020/jun/10/family-carers-hidden-army-not-invisible-just-ignored

Who is an unpaid Carer?

An unpaid Carer is someone who provides care and support to another person, usually a family member or friend, due to long term illness, disability, physical or mental illness and / or substance misuse. The care provided is often out of love, duty and necessity and involves supporting with daily activities such as washing, dressing, administering medication and providing emotional support.

Carers UK states Carers are *'people who provide unpaid care by looking after someone who is older, disabled or seriously ill. These people are called Carers but they would probably say they were just "looking after someone". Carers help with personal things like getting someone dressed, turning them in their sleep, helping them to the bathroom, helping them move about or administering their medication. Carers also help with things like shopping, laundry, cleaning, cooking, filling in forms or managing money'.*[2]

The NHS states *'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'.*[3]

Unpaid Carers represent a significant portion of the population. The 2021 census tells us that there are 5 million unpaid Carers in England and Wales from ages 5. There are 77,000 unpaid Carers in Derbyshire and 25,000 in Derby City. Unpaid Carers provide a crucial role alongside health and social care but many Carers, particularly those from minority ethnic communities do not identify themselves as Carers.

'New findings from Carers UK and the University of Sheffield show that unpaid Carers in England and Wales contribute a staggering £445 million to the economy in England and Wales every day – that's £162 billion per year. The value of unpaid care is equivalent to a second NHS in England and Wales, which in 2020/21 received an estimated £164 billion in funding'.[4]

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[2] carersuk.org/about-us/why-were-here
[3] england.nhs.uk/commissioning/comm-carers/carers
[4] carersuk.org/press-releases/unpaid-care-in-england-and-wales-valued-at-445-million-per-day

Introduction

The main focus on this project is to support Carers – especially Carers from ethnic minority backgrounds with key aims to:

- Improve access to information and support for Carers from ethnic minority backgrounds

- Improve the health and wellbeing and resilience of Carers from ethnic minority backgrounds

- Improve the identification and raise awareness of caring with both Carers from ethnic minority backgrounds and health, social care and community services

- To engage with Carers from ethnic minority backgrounds to hear the experiences of being a Carer and learn more about the difficulties and barriers when accessing support for themselves and the person they cared for

- To use insight captured from this project and outlined in this report for 'best practice' recommendations when designing future support for Carers

The project also looked at key areas:

- Misconceptions in relation to some communities

- Stigma that is associated with caring especially for mental health conditions

- Barriers and unmet needs which impact on access to support

- Culturally appropriate provision including issues of language, literacy and accessibility

It's important that we acknowledge the use of language in this report. By recognising and understanding the terms used to describe ethnic minority communities, we can increase our understanding and promote inclusivity. There are various terms used to describe people from ethnic minority communities. These include umbrella terms such as; Black, Asian and Minority Ethnic (BAME) and Black and Minority Ethnic (BME). For the purpose of this report we will say *'Carers from ethnic minority*

backgrounds' due to many of the Carers we spoke to not feeling the term BAME and BME recognised or described their ethnicity. *'There is also a problem in that the terms 'BAME' and 'BME' aren't always associated with White ethnic minorities such as Gypsy, Roma and Traveller of Irish Heritage groups, which we know are among some of our most marginalised and disadvantaged communities. To leave these communities out of the very language we use is to marginalise them even further'.*[5]

Reports over the years have shown that ethnic minority Carers are more at risk of poverty, ill health, unemployment and social exclusion. State of Caring 2023 findings state *'ethnic minority Carers were more likely to say the cost-of-living crisis was affecting their health. 74% of ethnic minority Carers said the increase in the cost-of-living was having a negative impact on their physical or mental health, compared with 63% of White Carers and ethnic minority Carers were more likely to feel unsatisfied with social care services. 32% of ethnic minority Carers receiving support from social care services disagreed they were satisfied with the quality of care, compared with 24% of White Carers. 35% of ethnic minority Carers receiving support from social care services disagreed that the support is consistent, compared with 28% of White Carers'.*[6]

Carers from ethnic minority backgrounds therefore experience health inequalities arising both from the caring role and ethnicity, and these can indeed exacerbate health disparities. Factors such as cultural expectations, access to resources and discrimination all influence the outcomes of the Carer and the person they care for; an area that still requires attention to ensure equitable access to support services.

[5] civilservice.blog.gov.uk/2019/07/08/please-dont-call-me-bame-or-bme
[6] carersuk.org/briefings/the-experiences-of-ethnic-minority-carers-updated-briefing/

Methodology

Working in partnership with Community Action Derby who focused on Derby City, our focus was Derbyshire. Derbyshire areas include High Peak, Derbyshire Dales, Chesterfield, Bolsover and North East Derbyshire, Amber Valley, Erewash and South Derbyshire.

Derbyshire's estimated population in 2022 was 803,464. Population demographic in Derbyshire is 90.7% people are white, 5.0% people are Asian, 1.9% people are mixed, 1.4% people are black and 1.0% people are other.[7] Derbyshire is a County of geographical contrasts with heavily built-up towns to large rural areas made up of farmland. *'The small ethnic minority population is mainly concentrated in in districts of Chesterfield, Erewash and South Derbyshire'*.[8]

Keen that this project gives Carers a voice, the methods used to listen to Carers mostly involved community engagement. This included a county wide 'Celebration of Diversity' event for Carers and support services to come together; community engagement is crucial when capturing the voice of Carers, however, this didn't come without challenges and difficulties.

Initially we introduced listening spaces across Derbyshire inviting Carers to come and gain support, and learn more about local Carer support services. We hoped that by creating welcoming spaces we would also be able to listen to the experiences of the Carers who attended. Attendance was very low with 1 or 2 Carers attending each one and the odd professional who wanted to learn more about the project. After the third session we reviewed the small amount of insight we had alongside the barriers we were already aware of, such as language, cultural differences and lack of trust in services. We needed to reconsider how we move forward if we wanted to engage with more Carers.

Past experiences of discrimination or disparities in support can contribute towards distrust and further challenges for ethnic minority Carers. A recent Carers Trust survey states that *'just 16% of those from Black, Asian and minority ethnic communities said they had been signposted to support by*

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[7] observatory.derbyshire.gov.uk/population-and-households
[8] derbyshire.gov.uk/council/news-events/about-derbyshire/about-derbyshire.aspx

their local authority, compared to 31% of white Carers, and only 6% had received support from councils'.[9]

The listening spaces had been introduced as a way of building a rapport with Carers in the hope we could build trust but we needed to reconsider how we was going to move forward if we wanted to do this.

We set about mapping existing groups and support services to raise awareness of the project. These included Derbyshire based support services, community groups and hubs, places of worship, external service meetings and forums and information points. We hoped this would allow us to engage with the community and gain insight into cultural beliefs, values and practices to better understand the barriers and experiences of Carers within these communities. Community engagement is essential for ensuring that the voices of Carers from ethnic minority communities are heard. It fosters a collaborative approach that values lived experiences. This leads to more effective and inclusive support for Carers.

While it is difficult to give an exact amount of Carers and professionals who have been involved in this project based on the breadth of the work we did and the range of initiatives used to engage and raise awareness, we know the following:

- **140 individual Carers from ethnic minority backgrounds were consulted about the project (one to one, in groups, via survey)**

- **93 Carers from ethnic minority backgrounds were provided with ongoing one to one support**

- **58 Carers from ethnic minority backgrounds were new to Carer support services**

- **156 Carers and 121 services/professionals were in attendance at community engagement events, groups and forums**

We also introduced a survey part way through the project to gain further insight. The survey was designed in collaboration with Carers ensuring it addresses relevant issues relating to Carers. For the purpose of this project, we added questions to ensure it was relevant for Carers from ethnic minority backgrounds. The number of Carers who completed the survey was very low. When we approached Carers with the survey there was a hesitancy to participate. Unfortunately this is a common issue

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[9] carers.org/news-and-media/news/post/322-almost-half-of-unpaid-family-carers-not-getting-the-support-they-need-as-caring-hours-soar-carers-trust-survey-finds
[10] bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-021-01489-2

within ethnic minority communities due to barriers such as language barriers and cultural differences; also mistrust in services. BMC – Medical Research Methodology are developing a toolkit to increase the participation of ethnic minority communities in health and social care research. *'Poor recruitment of BAME populations10 in research is due to complex reasons, these include factors such as inadequate attention to recruitment strategies and planning, poor engagement with communities and individuals due to issues such as cultural competency of researchers, historical poor experience of participating in research, and lack of links with community networks. Other factors include language issues, relevant expertise in research team and a lack of adequate resources that might be required in recruitment of BAME populations'*. Although efforts were made to improve inclusivity and cultural sensitivity, we only received 14 completed surveys.

What we were told

It's my role and my responsibility

While most Carers feel a strong sense of responsibility and duty to care for their loved one, some Carers from ethnic minority backgrounds often have additional reasons for taking on the role of caregiver.

A, told us that several years ago, he and his wife had to give up work to care for their daughter. They didn't know how to access support or claim benefits and didn't know what was available to them. A, said that even if they did, they probably wouldn't have accessed support. A, stated this was out of pride and a commitment to believing that 'we care for our own'.

A, isn't alone in thinking like this. A large portion of Carers we spoke to said it took a significant amount of time for them to reach out for support due to a strong sense of familial duty and respect. We also heard about the expectations Carers felt when caring for a loved one – this was particular apparent when caring for an elderly relative. This often stems from cultural values such as responsibility and duty, but also limited access to appropriate support and cultural barriers and insensitivity from professionals. Lack of cultural sensitivity and a disregard for beliefs and practices leads to a breakdown in communication and a reluctance to reach out for support. *'Many people believe that good quality care can only be provided at home by the family. People with dementia and their relatives from some ethnic minority groups worry, in addition, about the person with dementia not being understood, about care not being culturally appropriate and about not getting enough food or the kind of food they are used to. Living in a safe environment, surrounded by familiar and caring people who speak the same language is clearly a solid basis for good care. However, it is not a guarantee of good care, especially if Carers struggle without outside support if and when they need it'.*[11]

Another Carer told us about the difficulty of placing her mother into permanent residential care even though she was struggling to juggle caring alongside education, employment and a family of her own. The Carer told us that even though caring had turned her life upside down, caring for her mother was her responsibility and that her Mother also saw it as her duty as a daughter.

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[11] england.nhs.uk/wp-content/uploads/2023/05/intercultural-dementia-care-guide.pdf

It's important to say that while there was a strong sense of familial duty based on cultural beliefs from some of the Carers we spoke to, this wasn't the case for all. Also we shouldn't assume that Carers from ethnic minority backgrounds require no support based cultural values and responsibility. In a 2018 paper on Dementia and Black and ethnic minority Carers, Dr Sahdia Parveen and Professor Jan R Oyebode points out 'Although many minority ethnic Carers feel culturally obliged to provide care, this does not mean that all minority ethnic Carers feel willing to provide care or feel prepared for the various aspects of providing support for the person living with dementia'.[12] Understanding and respecting cultural reasons for taking on the role of caregiver is essential when providing support to Carers from ethnic minority backgrounds.

I don't trust services

Whilst most Carers can talk about a negative experience due to the lack of care and support provision for their loved one, Carers from ethnic minority backgrounds experience inequalities arising both from the caring role and ethnicity.

B, told us that they had lost any trust in services due to difficulty in finding support and then when someone did finally come to the house, they were culturally insensitive to the needs of the person requiring care. They then found that the support available wasn't appropriate.

This, alongside familial duty and a language barrier, is enough to stop Carers reaching out for any support.

54% of Carers told us that they don't feel there is 'good' communication from professionals. Past experiences of poor communication, discrimination and mistrust in services lead to a reluctance to reach out for support. Those Carers we spoke to who were accessing support found this through that one person who took the time to understand, build a rapport and get to know them. Those who were actively involved in their community and attending groups, found great comfort in this and seen it as a lifeline.

"I don't want any more strangers coming to my house. It doesn't help"

– Unknown

"I don't think professionals understand my cultural beliefs"

- Chinese Carer

[12] raceequalityfoundation.org.uk/wp-content/uploads/2022/10/REF-Better-Health-463.pdf

> *"The Carers we have in place are not supportive or appropriate to the needs of the person I care for"*
>
> *– Asian Carer*

> *"For me I find the stigma and the financial challenges the most difficult. No one seems to want to support with this"*
>
> *– Other White Carer*

A report by Early Intervention Foundation found 'one in three survey respondents felt that they were treated unfairly when seeking or receiving support for their family. A further 24% told us they were unsure about whether they had been treated fairly. For some participants this was directly linked to experiences of discrimination; for others it was about a broader sense that they had not been listened to or that their problems had been minimised.[13]

I wasn't aware I was a Carer

Carers UK state that most Carers will say they are *'looking after someone'* rather than use the term *'Carer'*.[14] This can be due to simply seeing their responsibility as looking after the person they love or that the word 'Carer' refers to a paid professional working for a care agency.

In some cultures, caring for a loved one is a natural part of family life and is not seen as a distinct role. Because of this, the Carer may not identify with the word Carer, or even see themselves as a Carer if asked.

"I have to devote all my time to caring for my mother. Due to communication barriers I did not understand what is available for me. I am being supported to register as a Carer with Derbyshire Carers Association, so I'm now hopeful to receive support."

During the project 58 Carers from ethnic minority backgrounds were registered with DAACSS. These were Carers not known to Carer support services before the project started. Most were identified through community engagement, partnership working and awareness raising.

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[13] eif.org.uk/report/improving-the-way-family-support-services-work-for-minority-ethnic-families#:~:text =Initial%20interactions%20with%20support%20services,needs%20of%20minority%20ethnic%20families

[14] employersforcarers.org/resources/definition-of-a-carer

Where possible we asked what the barriers were to reaching out for support from their local Carer support service. We kept hearing *'I wasn't aware I was a Carer'* or *'I didn't know Carer meant me'*.

Whilst it's true that most Carers don't identify with the word *'Carer'* because they see the role as a natural extension to their relationship with the person they care for; the word *'Carer'* creates another barrier for Carers from ethnic minority backgrounds.

As mentioned at the beginning of this report; we started by delivering what we thought were welcoming listening spaces. We designed posters and promoted through various means, including sending to all promotional materials to community groups, hubs and places of worship for that area. Attendance was still low. As the project progressed we learned that the language we used had created a huge barrier – *'Are you a Carer?'* After asking Carers what we should have been using instead, we was given the following ideas: *'Do you help someone in your family?'* *'Does someone in your family help you?'* *'Are you helping someone who requires care?'* *'Do you look after someone?'*

It's essential to recognise that language is more than just words. How we use language can impact how Carers from ethnic minority backgrounds perceive and engage in support services. Being mindful of language used can ultimately improve access to support for Carers and help to identify Carers at the beginning of their caring journey.

> *"No one has ever asked me if I am a Carer"* — *Unknown*

Although we heard 'it's my role and my responsibility', the assumption that Carers from ethnic minority backgrounds don't want help is a misconception often caused by a lack of understanding about cultural differences in caring. In many ethnic minority communities caring is seen as a family responsibility, but this doesn't mean that support isn't wanted or needed. This assumption can lead to support services not offering support and a lack of culturally appropriate support can lead to the Carer feeling obligated to provide the care alone.

It's also true that Carers from ethnic minority backgrounds might face additional barriers such as finding employment, accessing housing or being in receipt of benefits. In a report by Carers UK, *'58% of Black, Asian and minority ethnic respondents agreed with the statement "I am worried about my financial situation" compared to 37% of White Carers'*.[15]

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[15] carersuk.org/media/c5ifvji0/carersukbamecovidreport2022.pdf

54% of Carers told us that they worry about money and 90% told us that they found completing benefit forms difficult. This alongside the demands of caring can further exacerbate financial instability, especially if they have to reduce hours of work or leave employment all together to provide care.

I feel overwhelmed and exhausted and isolated. There has also been a huge financial hit on me as I have had to give up work to care and Carers allowance is not enough.

I found the stigma, alongside the cost of living crisis the most challenging.

There's a lot of information and support but none of it feels relevant to me

While the overall ethnic makeup of Derbyshire may be less diverse than its counterpart Derby City, it's important for services to be responsive to the needs of all individuals.

Research shows that many existing services may not be adequately addressing the needs of ethnic minority communities. This is due to a lack of cultural competence training, diverse representation within services, lived experience input, language support services and culturally appropriate services. Early Intervention Foundation talk about the importance of having 'No wrong doors'. 'Local areas must make the idea of 'no wrong door' a reality for minority ethnic children, young people or families who reach out for help. Early help and wider family support services must be designed to better respond to the needs of minority ethnic families'.[16]

"There isn't any support out there for people like me"

– Gypsy Carer

"Services aren't culturally appropriate"

– Pakistani Carer

"I don't know how to find support"

– Pakistani Carer

[16] eif.org.uk/report/improving-the-way-family-support-services-work-for-minority-ethnic-families#:~:
text=Initial%20interactions%20with%20support%20services,needs%20of%20minority%20ethnic%20families

Implementing channels for feedback and listening to the voices of Carers from ethnic minority backgrounds can help to understand and address the barriers to Carers reaching out for support. This will not only help improve the effectiveness of the support provided but co-produced resources and support can help Carers from diverse ethnic backgrounds self-identify as Carers and reach out for help. Having inclusive resources in multiple languages using culturally appropriate terminology helps Carers identify a service that is for them.

Carers also told us that diverse representation within support services can significantly increase the chances of Carers reaching out for support. When speaking with someone from Derbyshire BME Forum they told us that they would be more likely to reach out for support, if they could see themselves in our service.

It's important to remember that Carers often have their own health concerns and disabilities and as a result can face various challenges. Ethnic minority Carers with disabilities face a unique set of challenges that have multiple layers of disadvantages and discrimination. These can limit access to information and advice for themselves and the person they care for and create further barriers to support such as attending groups and activities. 62% of Carers told us that they prefer to access support face-to-face.

A recent report published by Derbyshire All Age Carers Support Service showed that General Practices can have a significant impact on the experiences of Carers.[17] As part of Derbyshire Diverse Carers consultations, a number of Carers told us that the cultural sensitivity within General Practices is often non-existent. One Carer told us about their experiences when they took their mother for an examination. When they got there the appointment was with a male GP and no option to see a female GP was given. The mothers' belief necessitates that females must see a female health professional for examinations. Because of this they cancelled the appointment and haven't been able to access another since. This has created further worry for the Carer.

Another Carer told us of his experiences after his wife had a stroke.

Mr A was self-employed and had to give up work immediately to provide care. No one spoke to them about their options and support available and sadly their circumstances worsened. They were unable to continue living in their home and ended up homeless with no money coming in. Mr and Mrs A spoke no English and had significant difficulty navigating services

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[17] derbyshireCarers.co.uk/blog/high-peak-consultation-project-2023

and accessing the correct support. They were moved into a bed and breakfast that had no cooking facilities and wasn't appropriate for Mrs A's care needs. The couple were referred to two different benefit advice services, both said they were unable to support due to language barrier and having no interpreters. They were signposted to Universal Credit helpline but wasn't able to call due to not speaking English. There was little understanding of the couple's circumstances and due to services not having the time or resources, they were increasingly becoming forgotten about.

Conclusion

Our conclusion is that Carers from ethnic minority communities feel isolated, lonely and excluded. They are more likely to suffer higher levels of disadvantage due to difficulty accessing support and insufficient culturally appropriate support services. Exclusion from support services significantly impacts on their health and wellbeing and creates further mistrust in professionals and services.

Ethnic minority Carers in Derbyshire also face additional challenges due to the regions mixture of urban and rural areas. These challenges create further barriers such as accessibility and lack of support services. Rural isolation and lack of transport links make accessing healthcare services and appropriate support services difficult. This reinforces the importance of 'making Carers everyone's business' particularly services such as General Practices (GPs). The sparseness of culturally appropriate support for Carers from ethnic minority communities alongside language and cultural barriers, lack of transport links, economic factors such as financial difficulty and reduced employment create further layers of barriers to Carers receiving support. Some areas such as High Peak and South Derbyshire also experience poor internet connectivity which makes accessing information and advice difficult. This coupled with the many challenges faced by Carer's means that they are at increased risk of health and wellbeing deterioration.

We identified a number of areas of recommendation as a result of listening to Carers from ethnic minority communities, but it's important to mention that Black, Asian and Minority Ethnic communities are not homogenous. There is significant differences in experiences, needs and difficulties between different ethnic groups and one of the limitations of this project is the small sample sizes of some of the ethnic groups who spoke to us about their experiences. Additional research is necessary to accurately understand the perspectives of Carers from various backgrounds. This will help ensure support services are appropriately meeting the need of Carers from various communities.

Here are some key points to consider from what Carers have told us: Diverse representation within support services encourage Carers to reach out for support. Carers are more likely to build trust with someone who shares a similar cultural background and support workers from diverse backgrounds are more likely to better understand cultural nuances, beliefs

and practices; which helps the Carer to feel supported and understood. Diverse representation can also help break down some of the barriers around language and communication, meaning the support provided is more appropriate and accurate.

Providing culturally appropriate support is essential when delivering support to Carers from diverse backgrounds. Recognising and valuing cultural differences not only builds trust but also helps Carers reach out for support and see a service that is for them. Involving Carers in the design and delivery of services is crucial when designing and implementing inclusive support systems.

Community Engagement is vital when supporting Carers from diverse backgrounds. Carers are more likely to reach out for support from someone they trust; such as a community leader / group.

Giving time to support Carers, especially those from ethnic minority communities, is crucial for the wellbeing of Carers the quality of support provided and also the relationship between the Carers and person proving support.

An example of a good Carer's experience

❝ At the start of the Ukraine war, I was extremely worried for my parent's safety; I could not sleep and was having panic attacks. My mum saw how this was affecting me so agreed she would try to come to the UK.

My husband and I went to Poland to collect them, which took a long time, as it was an awful time for all Ukrainian people. The process was hard and we had to wait 12 days for their visas. Whilst waiting my dad had a stroke and I worried that the stress would kill him. I felt full of guilt that I had caused him to have a stroke with wanting to take him from the Ukraine.

We finally got back to the UK and for the first year, it was very stressful as everything was on my shoulders. It was worse for my parents as they had to leave their own country, everything they had, they spoke no English and living with us had no privacy.

Mum was mentally struggling to adapt and all the stress she was feeling was put onto me.

I had many things to sort, my parents registering with a GP, what income they would have and dementia support for my father. He was in the first stages of his dementia journey and the GP was so helpful. The G.P put me in touch with adult social care and Derbyshire Carers Association. This is when I

felt less lonely & stressed on my journey and the chain of support started. The barriers I personally had was a lack of experience of form filling and I had so much to complete which was overwhelming. Initially it was hard trying to get support but I saw how hard it was for English people to access the right support. Once social care was involved, our process was very easy and I felt we were very lucky, as we did not have to wait. I was now my father's Carer and I wanted to feel like his 'daughter' again so managing my own stress was my main issue.

I was so thankful to Derbyshire Carers Association for their support and assisting us to register with the GP surgery as Carers. Since this, my mum never had to wait for a GP appointment and gets one the same day she calls.

As a support worker, I see how the tenants I support have to wait so long for an appointment and we didn't have to.

My father is now in a care home and the staff have been so helpful and even learned some of the Russian language so they can communicate with him. Dad is happy there which makes it easier for us, although he no longer recognises us, which is hard.

Mum is happier and attending English classes at the Ukraine Association which she enjoys and has the opportunity to meet with other people. I sometimes go with her and it has made me realise it is never too late to learn.

Overall I am very happy with the support I have received. 99

Recommendations

- Use inclusive recruitment practices in the recruitment of staff, volunteers and board of trustees.

- Ensure this includes management roles to influence organisational cultures and decision making.

- Provide training and regular learning opportunities on cultural competence and diversity for all staff, volunteers and board of trustees.

- Access to interpretation and translation services with no waiting lists and expensive fees. This will help Carers access support in a timely manner and reduce how many people they have to speak to before receiving appropriate support.

- Design and develop culturally appropriate resources with Carers. This will help ensure that resources are effectively tailored to meet the diverse needs of Carers.

- Consider where to use the word 'Carer' and gain knowledge on culturally specific practices. Use language that is inclusive, sensitive and respectful.

- Diverse Carers' panels / focus groups and workshops specifically for Carers from minority ethnic communities to input on current services and give suggestions for improvement.

- Have language services available to ensure inclusive representation at panels / focus groups.

- Co-design and produce resources with Carers from diverse backgrounds to reduce barriers such as language.

- Introduce culturally appropriate surveys that have been designed with Carers from ethnic minority communities.

- Facilitate sessions where Carers work alongside services such as health and social care to improve support services.

- Educate policy makers and gather insight and data to develop clear, evidence based policy proposals.

- Work with community groups who have established trust and can identify Carers.

- Be visible within communities and provide opportunities for Carers to talk about their experiences.

- Hold culturally appropriate events, activities and workshops and participate in community events.

- Work in partnership with services such as health, social care and education and raise awareness of the needs of Carers from ethnic minority communities.

- Ask the Carer how they would like to be supported. *Consider barriers such as communicating over the telephone, using technology or transport restrictions.*

- Provide time to understand specific cultural needs and preferences and be respectful.

- Be that one person who shows recognition. This can change how Carers from ethnic minority communities access support.

DAACSS Pledge

You said	We did / we will
Services aren't culturally appropriate	Arranged mandatory annual Equality Diversity and Inclusion (EDI) training and Unconscious Bias training for all teams within Derbyshire Carers Association. Design (with Carers and employees) culturally appropriate service policies. Create learning opportunities for support teams to continue self-development to provide culturally appropriate support. As part of Carer awareness sessions, include information on Carers from ethnic minority communities and the multiple layers of barriers to accessing support. Use findings from this report to raise awareness for Carers in Derbyshire. Introducing a workplace EDI Champion will be a big part of ensuring we as a service continue to offer an inclusive workplace and support service. To be part of The Big Promise to tackle racial inequality. Work towards being a Racial Equality Matters Trail Blazer.
I don't identify with the word 'Carer'. The word 'Carer' means nothing to me	Change all of our resources from 'Are you a Carer' to 'Do you look after someone', 'Do you care for a loved one'?
I don't feel that support services are for me	Creating inclusive resources using Carer insight. Updated our website to ensure there is a translation option. Work towards having and inclusive diverse Carers panel to build on the project and co design support services with Carers. Facilitate sessions where Carers work alongside services such as health and social care to improve support offer. Design and deliver with Carers - inclusive Carer groups, activities and events.

I don't trust services and professionals / I prefer someone from my own community to support me / I didn't know I was a Carer or that there was support for me	Continue to work with services and groups such as Links CVS, BME forums and Community Action Derbyshire to offer support to communities who may not otherwise reach out for support. Create the opportunity for a consistent approach where the Carer is allocated one support worker to build a rapport. Give time to be able to provide appropriate support. Look at funding opportunities to introduce Community Carer Champions to identify, support and signpost to services. Create a 'No Wrong Doors' and 'Carers are Everyone's Business' policy. To have regular involvement and attendance at meetings such as BME Forum and South Derbyshire EDI meetings. Continue partnership working.
I am more likely to access support if I see myself in a service	Design (with Carers) a recruitment campaign to recruit more trustees / board members from diverse backgrounds. Volunteer campaign to recruit volunteers from diverse backgrounds to offer telephone befriending to Carers whose first language isn't English. Ensure our recruitment process is inclusive and aim to create a diverse workforce.
I feel excluded / invisible	Champion lived experience and involve ethnic minority Carers in the design and delivery of services. Create Carer-friendly Communities throughout engagement, Carer awareness, partnership working and Community Carer Champions.

Appendix
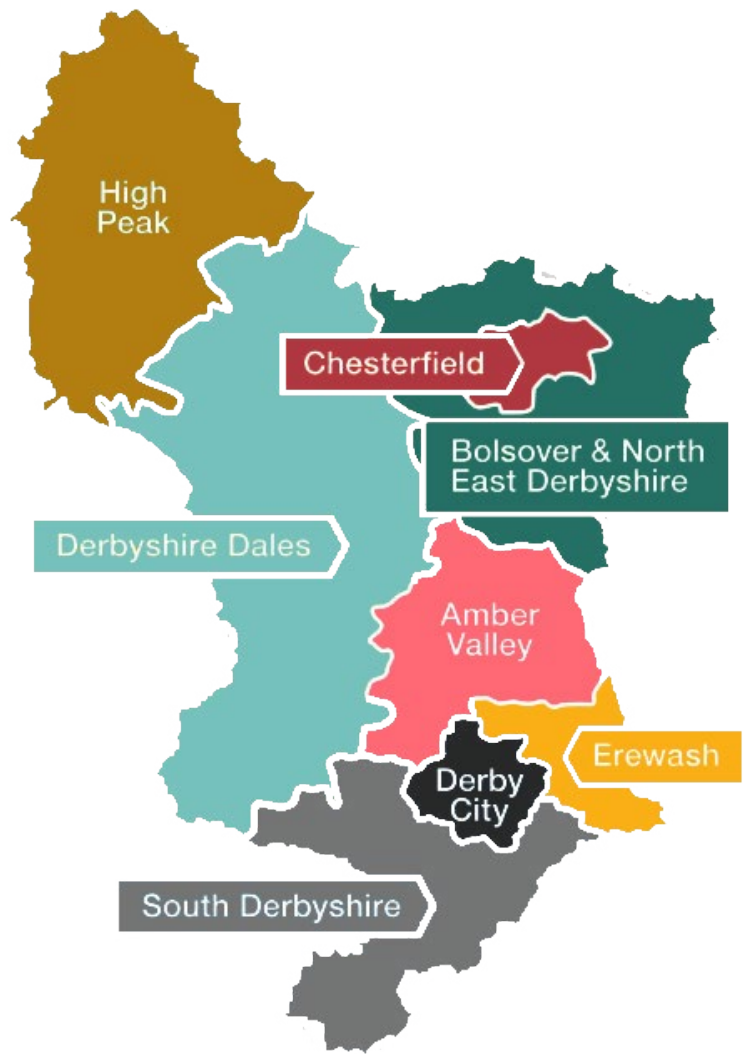
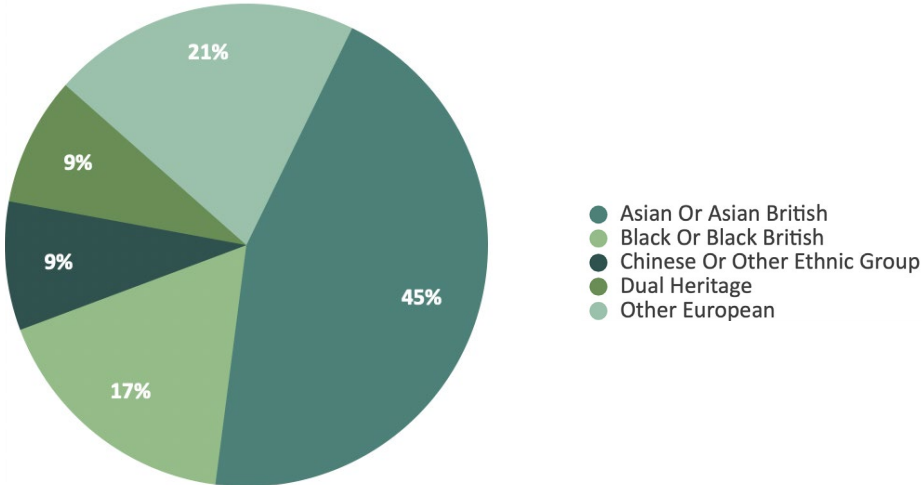**Celebration of Diversity**
Tina Curran and Raphael Tate

"I just wanted to say thank you again for today it was a much needed break and I can't tell you just how grateful I am – everything was perfect thank so much I am truly so grateful to you all"
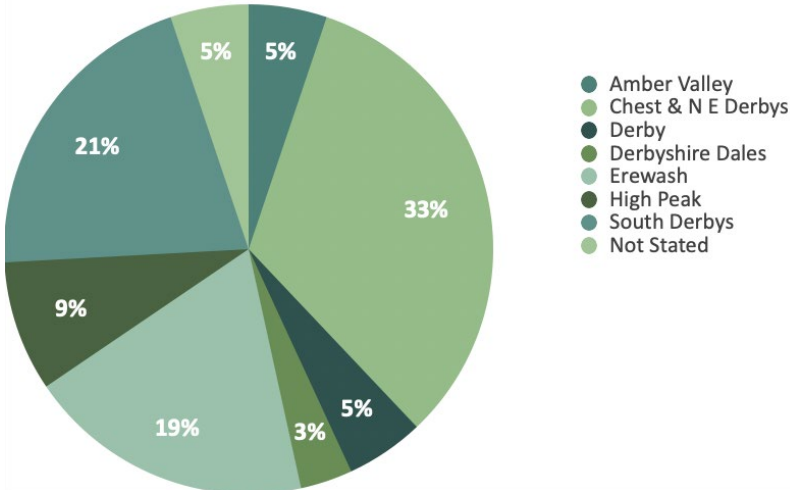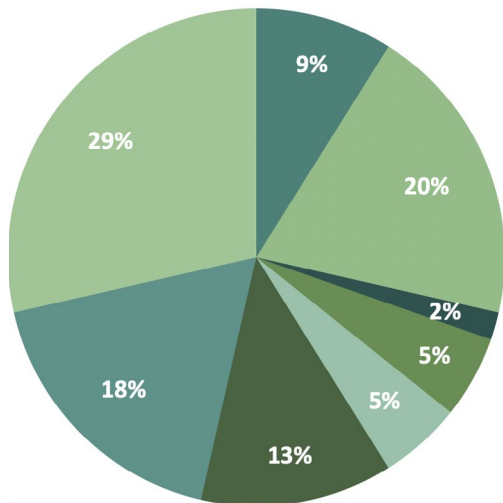
# Newly identified Carers during the project

Breakdown of ethnicity

- Asian Or Asian British
- Black Or Black British
- Chinese Or Other Ethnic Group
- Dual Heritage
- Other European

45%
17%
9%
9%
21%

Breakdown of area

- Amber Valley
- Chest & N E Derbys
- Derby
- Derbyshire Dales
- Erewash
- High Peak
- South Derbys
- Not Stated

5%
5%
33%
21%
9%
19%
3%
5%

Breakdown of health condition for cared for

- Autistic spectrum
- Dementia
- End of Life/Palliative Care
- Frail/elderly
- Learning disability
- Long-term health condition
- Mental health condition
- Physical disability

9%
20%
2%
5%
5%
13%
18%
29%

Breakdown of Carers age
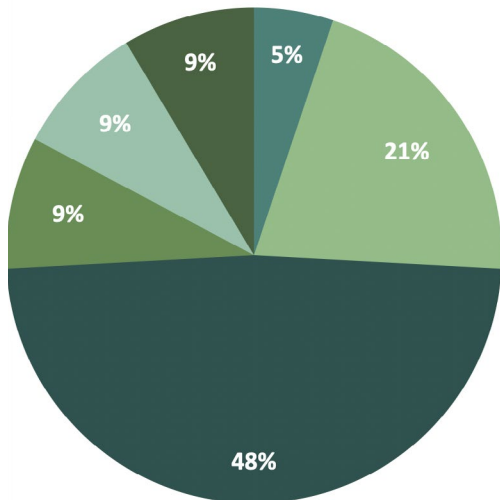
- 18-25
- 26-49
- 50-64
- 64-74
- 75+
- Not stated

5%
21%
48%
9%
9%
9%
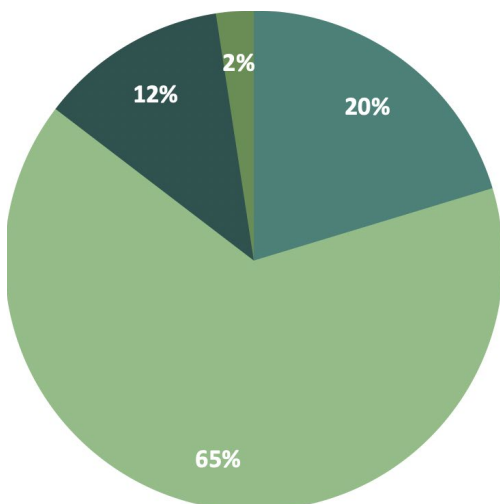
Referral source

- Health Sector Referrer
- Self/Family/Friend Referral
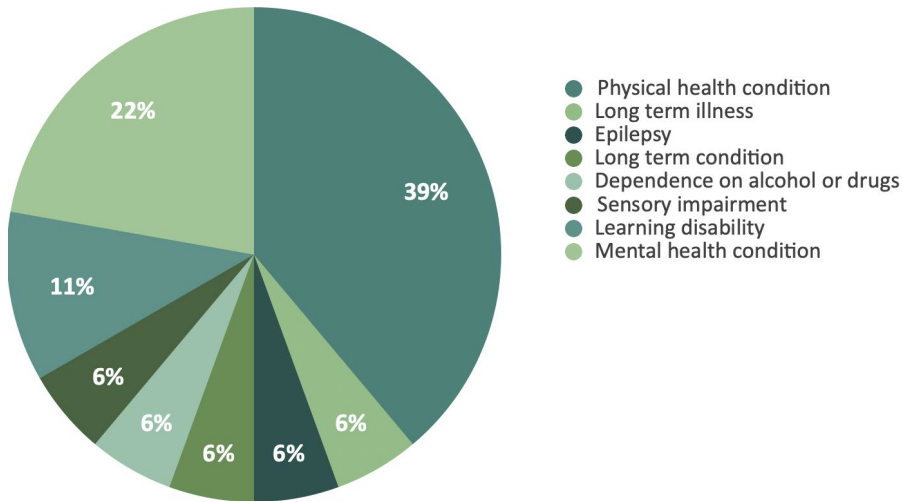- Social Service Referrer
- Voluntary Sector Referrer

2%
12%
20%
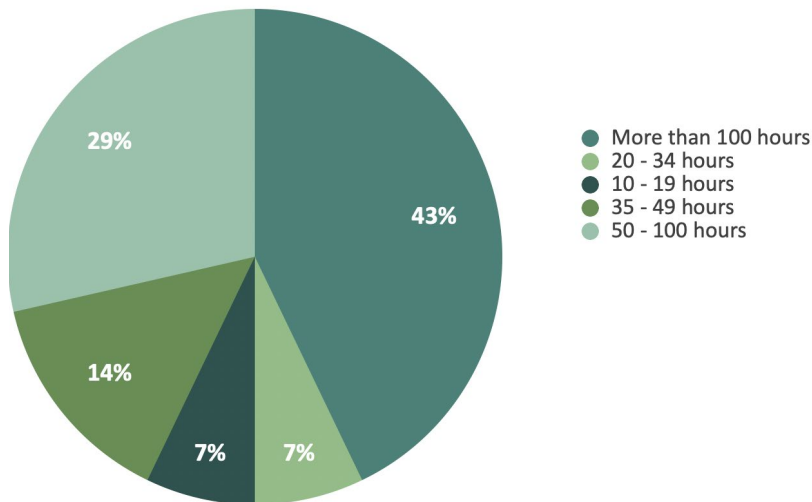65%

Survery results

Who do you care for?

- Parent — 43%
- Spouse or partner — 14%
- Child — 14%
- Other family members — 14%
- Other — 14%

Ethnicity

- Asian / Asian Britsh - Pakistani — 43%
- Asian / Asian Britsh - Chinese — 7%
- White, Irish — 7%
- Any other ethnic group — 21%
- Any other White background — 21%

Health of cared for

- Physical health condition
- Long term illness
- Epilepsy
- Long term condition
- Dependence on alcohol or drugs
- Sensory impairment
- Learning disability
- Mental health condition
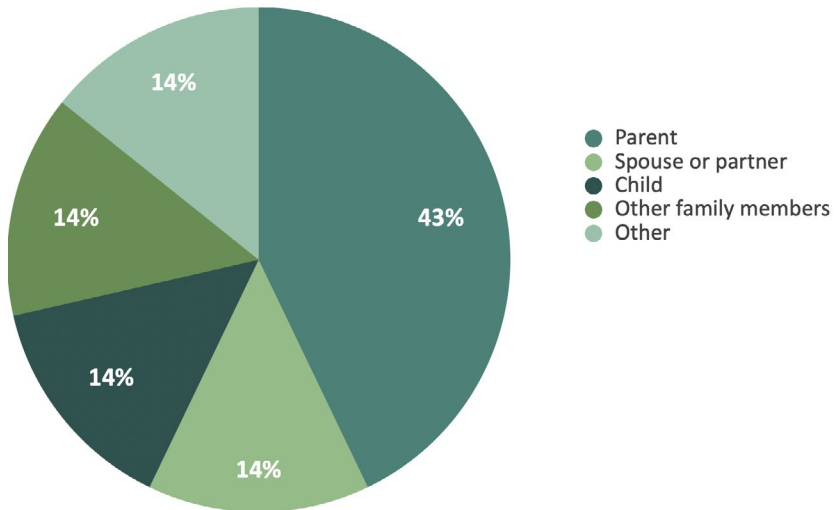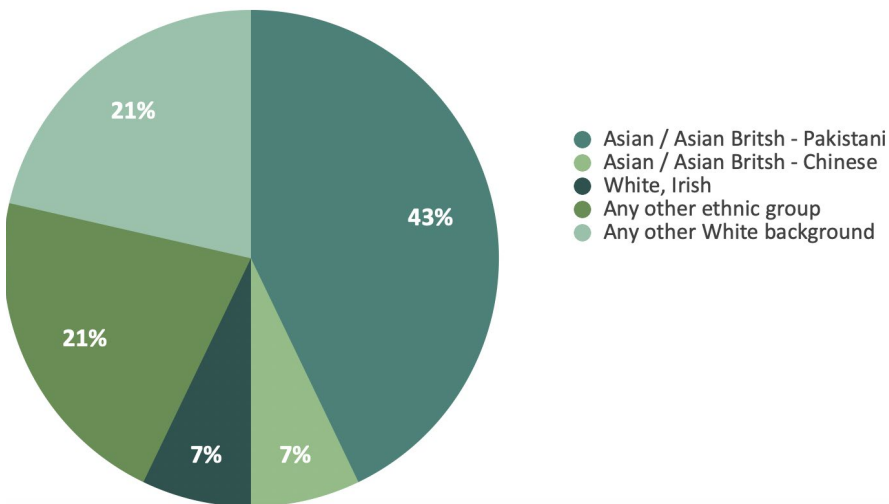
How many years have you been caring?

Data	Response
2 years	1
10+ years	1
4 years	1
2 years	1
15 years	1
12 years	1

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

- 43% More than 100 hours
- 7% 20 - 34 hours
- 7% 10 - 19 hours
- 14% 35 - 49 hours
- 29% 50 - 100 hours

Legend:
- More than 100 hours
- 20 - 34 hours
- 10 - 19 hours
- 35 - 49 hours
- 50 - 100 hours

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

- 43% Coping some of the time
- 7% Not at all
- 14% Not very well
- 14% Very well
- 21% Fairly well

Legend:
- Coping some of the time
- Not at all
- Not very well
- Very well
- Fairly well
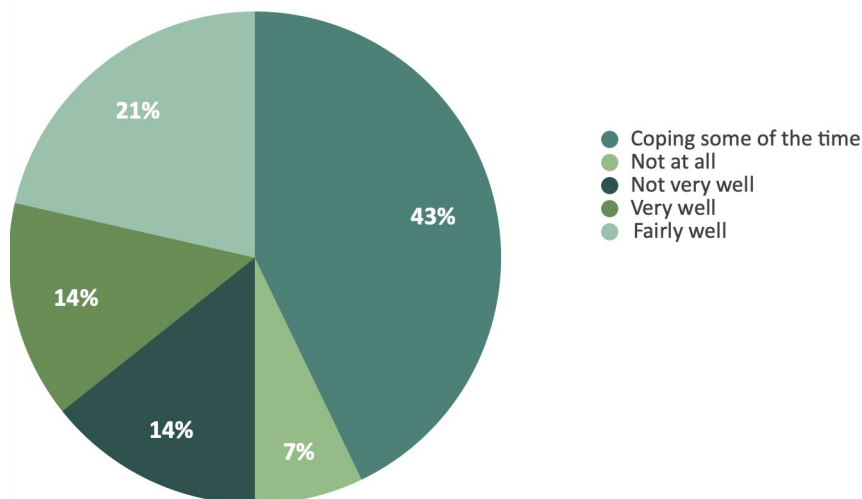
Do you feel that caring has had impact on your own mental health?

- 54% Slightly worsened my mental health
- 9% Significantly improved my mental health
- 27% Significantly worsened my mental health
- 11% Neither

Legend:
- Slightly worsened my mental health
- Significantly improved my mental health
- Significantly worsened my mental health
- Neither
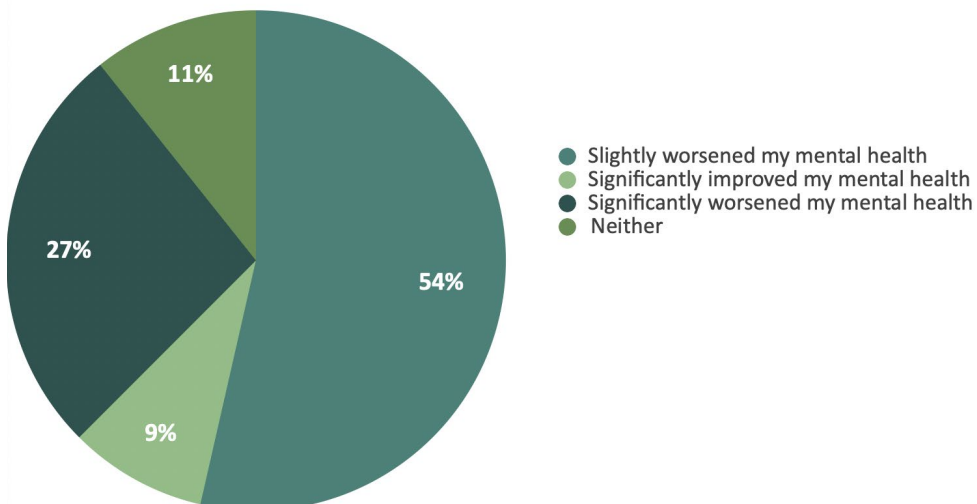
Do you feel that caring has had impact on your own physical health?

- ● Neither
- ● Significantly worsened my physical health
- ● Slightly worsened my mental health

50%
33%
17%
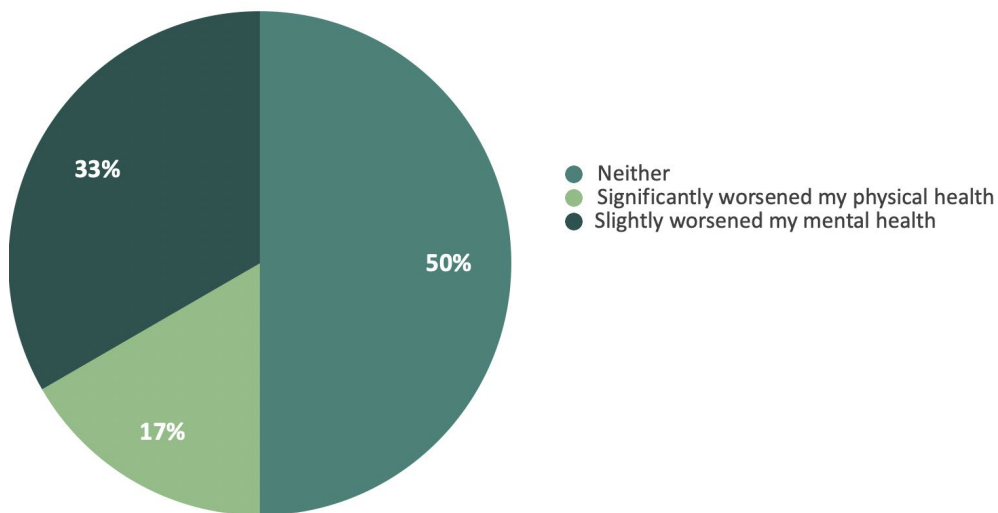
Do you have a disability?

- ● No
- ● Yes

23%
77%
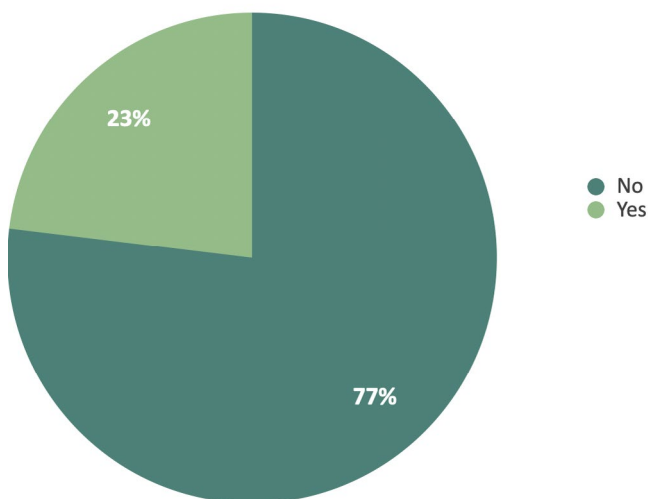
Are you happy to continue caring in the future?

- ● Yes
- ● No
- ● Yes, with appropriate support

43%
43%
14%
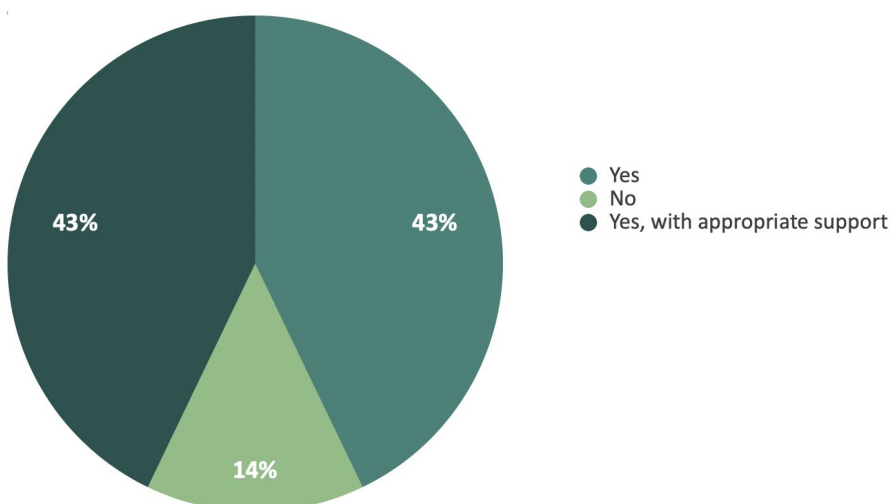
Do you worry about your ability to continue caring?

- 24% — No
- 29% — Yes, because of my own health
- 14% — Yes, because of a deterioration of the mental health of the person I care for
- 14% — Yes, because of my own physical health
- 19% — Yes, because of the deterioration in physical health of the person I care for
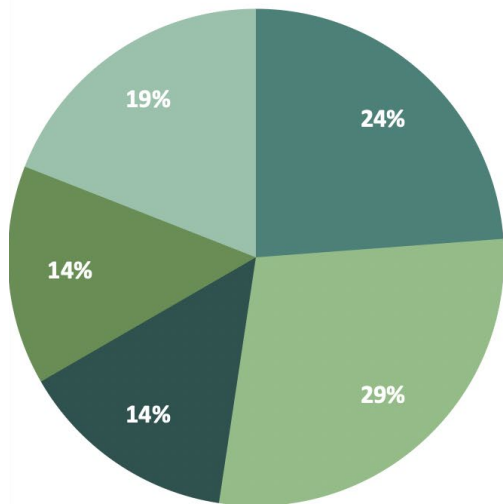
Legend:
- No
- Yes, because of my own health
- Yes, because of a deterioration of the mental health of the person I care for
- Yes, because of my own physical health
- Yes, because of the deterioration in physical health of the person I care for

Do you have a plan in place for what happens to the person you care for if you become unable to support them?

- 54%
- 9%
- 27%
- 11%
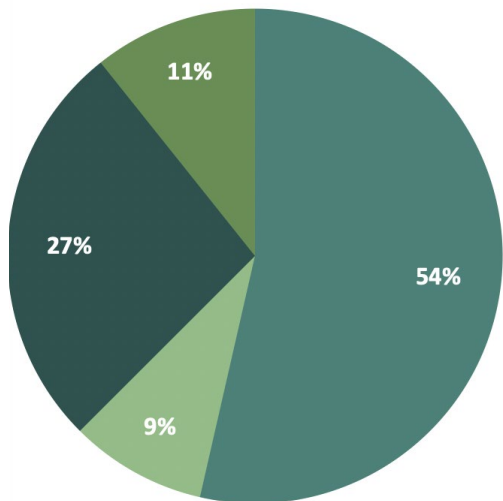
Legend:
- No, I do not worry about becoming unable to support them
- Yes
- No, I would like to put a plan in place
- No, but I do worry about what would happen if I became unable to support them
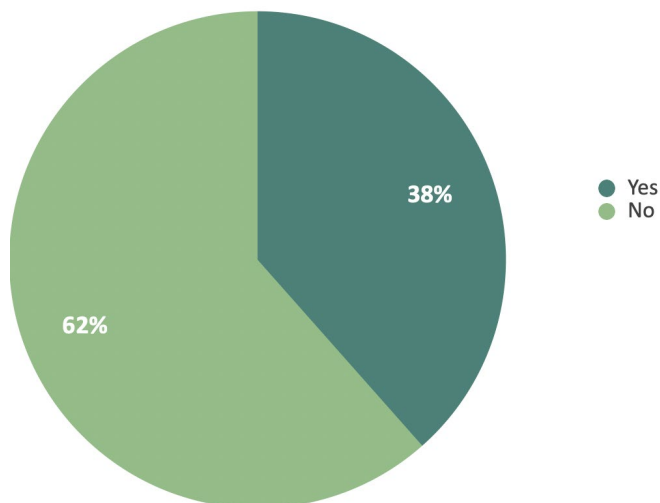
Have you had any respite in the last 12 months?

- 36%
- 9%
- 55%
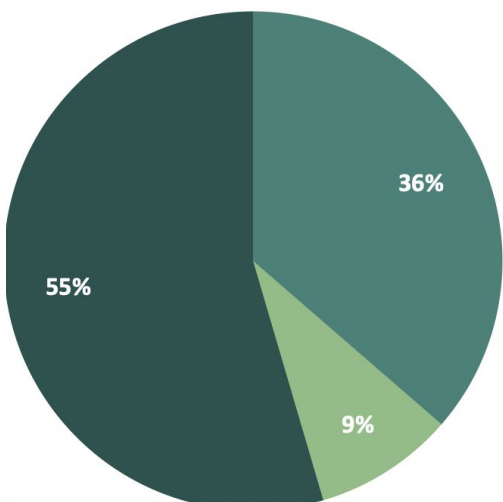
Legend:
- No, I haven't been able to access any
- Yes, overnight
- No, I haven't wanted any

If yes, how was this respite organised?

100%

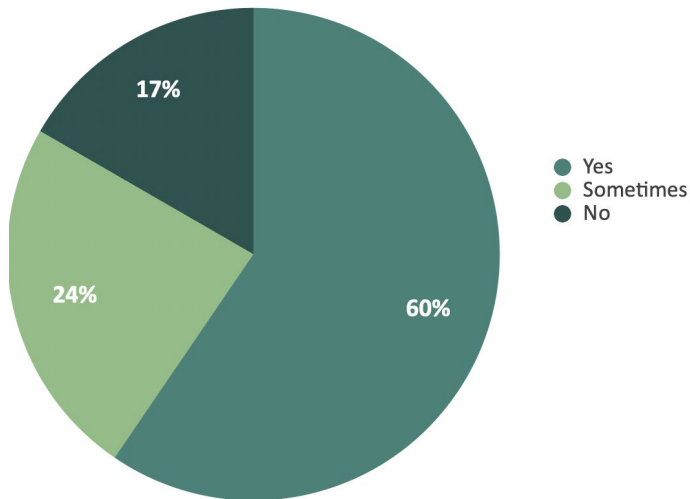● Through Adult Social Care
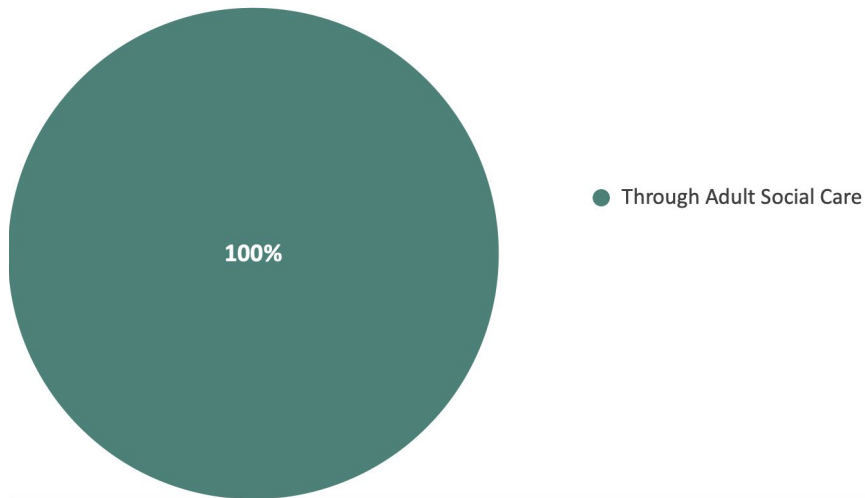
Do you feel that the respite offered catered to the needs of the person you care for?
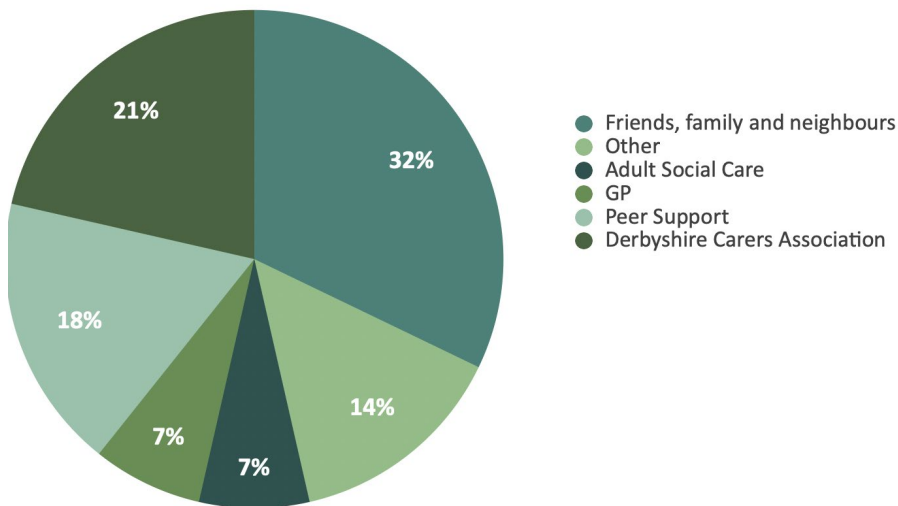

38%

62%

● Yes
● No

If you answered no, please state why.

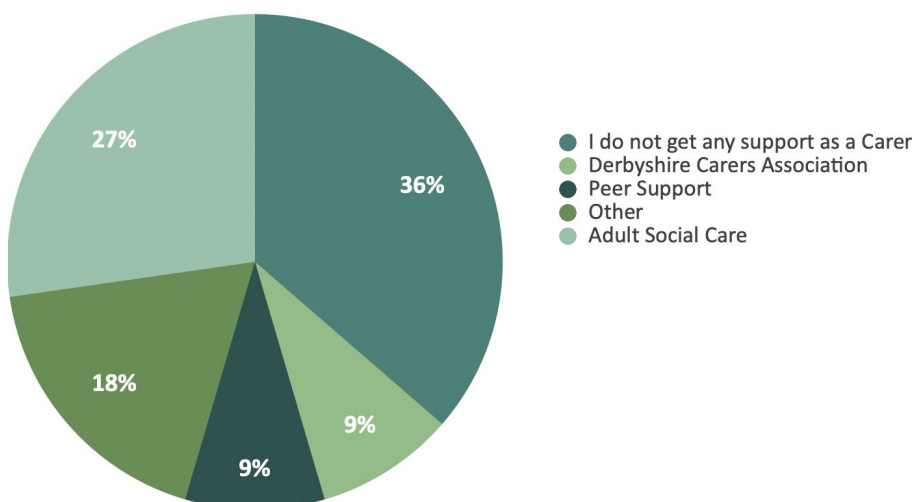| Comments |
|---|
| In the past we have selected respite provider which have multicultural staff |
| Not been able to access any |

Do you feel well supported?

- Yes
- Sometimes
- No

60%
24%
17%

Who do you think offers you the most support in your caring role?

- Friends, family and neighbours
- Other
- Adult Social Care
- GP
- Peer Support
- Derbyshire Carers Association

32%
14%
7%
7%
18%
21%

Do you feel let down by support offered by any of the following services?

- I do not get any support as a Carer
- Derbyshire Carers Association
- Peer Support
- Other
- Adult Social Care

36%
9%
9%
18%
27%

Do you feel adequately consulted and that your opinion is respected when professionals are making decisions about your friend / family members care?
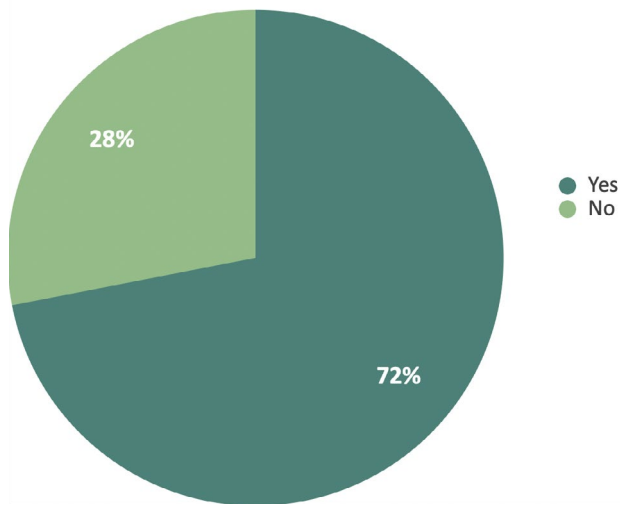

- Depends on the service
- Sometimes
- No
- Yes

54%
18%
18%
11%
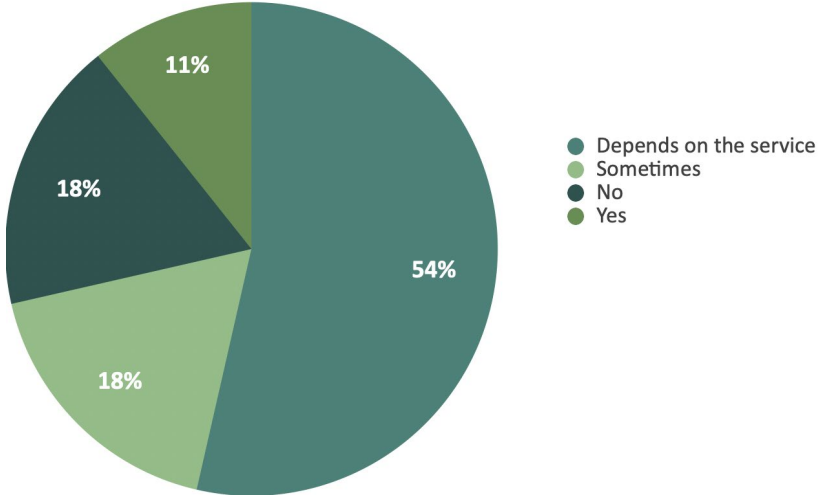
Do you feel that there is good communication between all professionals involved in your friend or family members care?
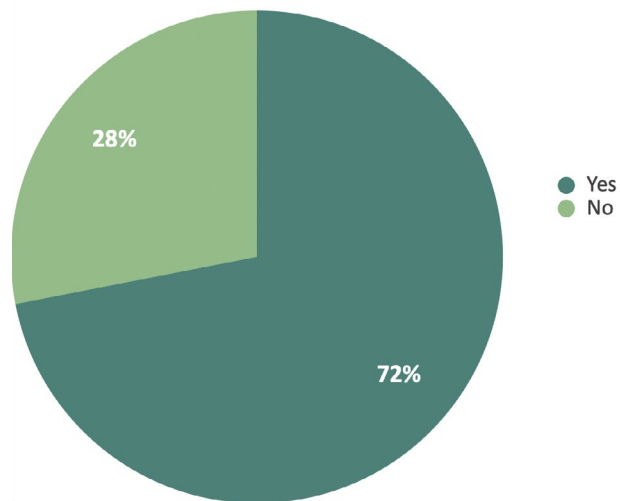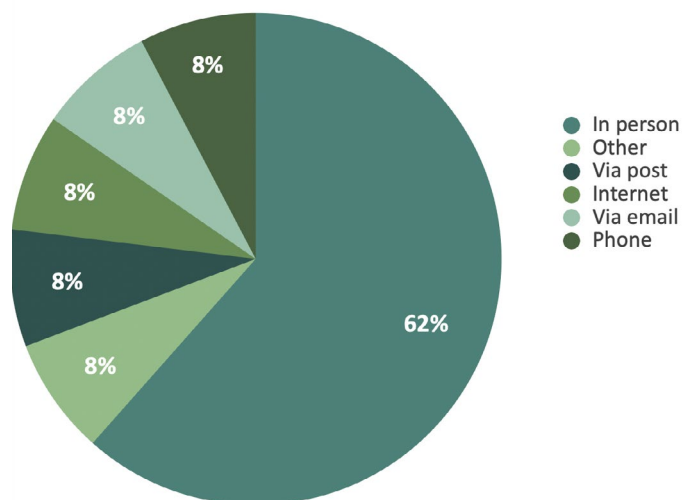

- No
- Sometimes
- Yes

67%
19%
13%
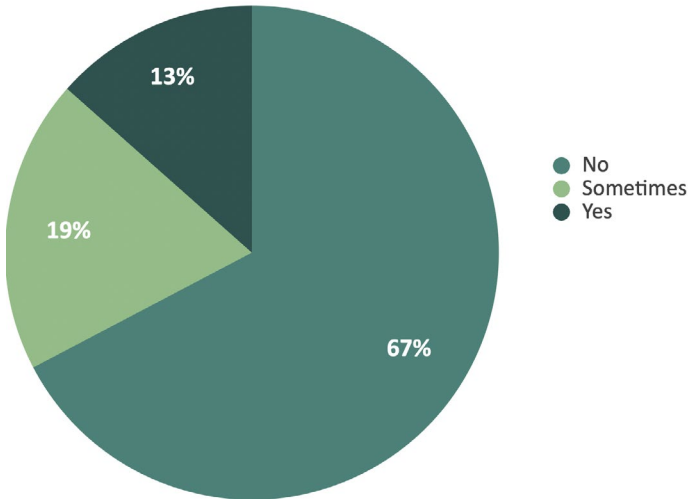
Do you feel well informed about what support is available to you?
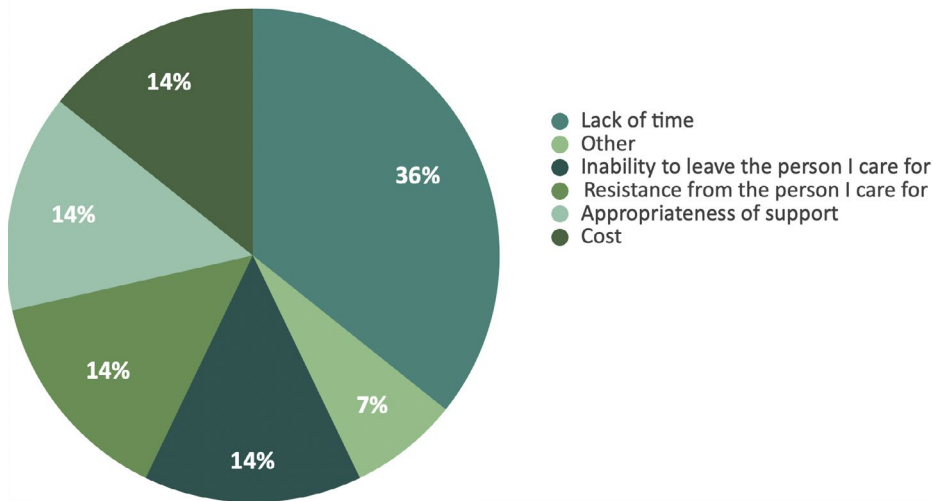

- Yes
- No

28%

72%

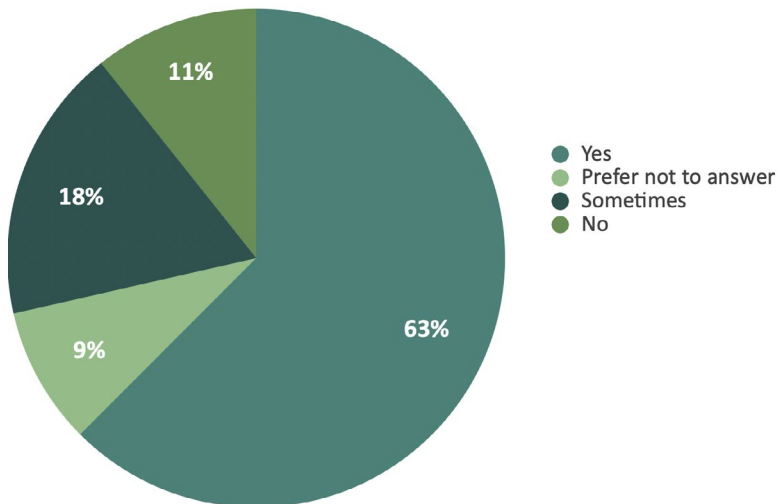## Do you feel well informed about what support is available for the person you care for?

- Yes
- No

28%

72%

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

- In person
- Other
- Via post
- Internet
- Via email
- Phone

8%

8%

8%

8%

8%

62%

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

- Lack of time
- Other
- Inability to leave the person I care for
- Resistance from the person I care for
- Appropriateness of support
- Cost

36%
7%
14%
14%
14%
14%

Do you worry about money?

- Yes
- Prefer not to answer
- Sometimes
- No

63%
9%
18%
11%

If you have completed any benefit forms, do you find them easy to understand and complete?

- No
- Yes

76%
24%
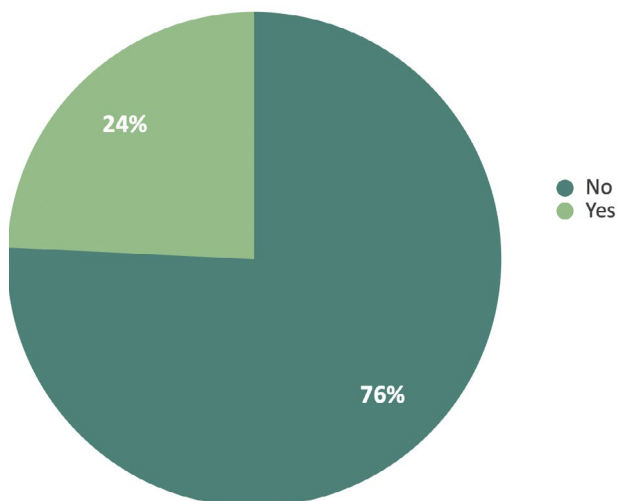
Comments
English is not my first language
They are overwhelming
I find them difficult to understand
There is no option to expand on the problems faced by the claimant
No literacy skills
My wife completes all forms

Has being a Carer had a positive impact on your life?

- No
- Yes
- Sometimes
- Insome ways

45%
27%
18%
11%
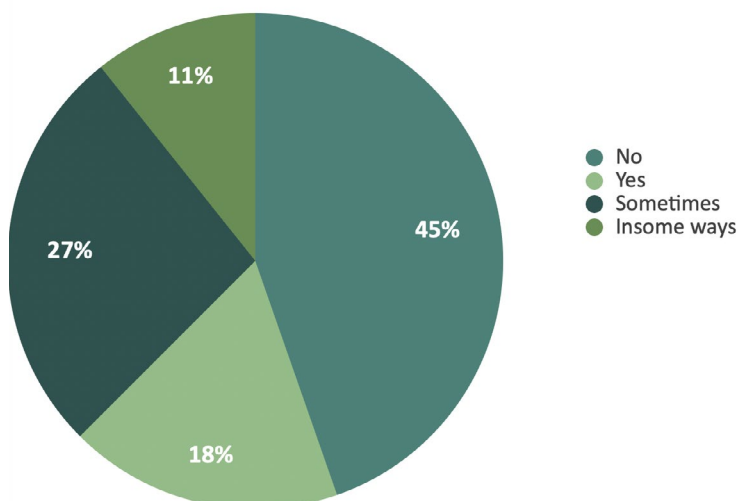
What is the greatest positive about being a Carer?
I feel happy caring for my mum
Feeling good about caring and helping them to do the things that they can't
I did not know that I was a Carer as I had no idea what a Carer was as I felt that taking care of my mother was my duty
I get tired
Caring is the most amazing thing I have ever done. Sometimes caring does impact on my mental health as I do not get much time to relax. I find attending Derbyshire Carer Association events helps as I can debrief and have some pampering.
Make life continue in best way possible for person I care.
Spending time with my wife and her appreciation of everything I do.

What do you find most challenging about caring?

I feel overwhelmed and exhausted and isolated. There has also been a huge financial hit on me as I have had to give up work to care. Carers Allowance is not enough.

Spending more time on mum than myself.

Not having time for you but they need more support than the things you need.

The stigma and challenges especially the cost of living crisis.

I share responsibilities of caring for my mother and my son so I often feel exhausted. As English is not my first language I feel translating my feelings is difficult and also transport to my mums appointments.

Tiredness.

Time.

I have to devote all of my time to caring for my mother. Due to communication barriers I did not understand what is available for me. I am being supported to register with Derbyshire Carers Association so hopefully I will receive support.

What single change would make the biggest difference to your caring role?

Nothing.

Improved rate of Carers Allowance and recognition of the work I do.

More information about what is available to me.

To have one to one conversations to discuss schooling, homework and social connections with friends.

Support with communicating and respite to give me more time as I am trying to learn English at college.

More things that I can attend to unwind.

Having respite and the opportunity to have more time for myself and my husband.

If the person I am trying to care for showed some appreciation.