



**“UNPAID CARERS ARE
NOT UNSUNG HEROES.
WE ARE FORGOTTEN,
NEGLECTED AND
BURNT OUT”**

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**CARERS
TRUST**

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- The 3,430 unpaid carers who took part in the survey. Carers Trust reads every survey response and thanks unpaid carers for sharing their stories.
- Our Lived Experience Advisory group, who worked alongside Carers Trust to design and analyse this survey and who provided critique to emerging findings and drafts of the report. Particular thanks to Neil, Karen, Victor, Lavinia and Georgine for all their support and expertise throughout this project.
- Carers Trust's network of local carer organisations who reviewed and advised us on the report's recommendations, helped us hear from unpaid carers, and who provide invaluable support for unpaid carers' needs.
- Carers Trust's report team.

ABOUT CARERS TRUST

Carers Trust works to transform the lives of unpaid carers. It partners with its UK-wide network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes, raise awareness, and influence policy. Carers Trust's vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

CONTENTS

FOREWORD.....	4
EXECUTIVE SUMMARY.....	5
KEY FINDINGS FROM THIS SURVEY.....	7
RECOMMENDATIONS.....	10
WHAT OUR SURVEY TOLD US.....	16
IDENTIFICATION AS AN UNPAID CARER.....	16
ARE UNPAID CARERS AWARE OF AND ACCESSING THE SUPPORT AND SERVICES THEY NEED?.....	19
ACCESS TO SUPPORT.....	24
SOURCES OF SUPPORT FOR UNPAID CARERS.....	30
RIGHTS AND ENTITLEMENTS.....	34
BENEFITS RECEIVED BY UNPAID CARERS.....	34
ASSESSMENT, REVIEWS OR REASSESSMENTS.....	37
SUPPORT WITH HEALTH AND WELLBEING.....	39
CONCLUSION.....	41
METHODOLOGY.....	42
APPENDIX.....	43
BIBLIOGRAPHY.....	47

FOREWORD

I never expected to be an unpaid carer. I was aware of people who were carers and felt great admiration for them, giving freely of their time, energy and emotion to care for loved ones. I now realise how naïve I was in my understanding of what the reality really entails.

The great majority of those who care don't do so because they don't want to entrust the care of their loved ones to health or social care services. They do so because support, in practical and financial terms, doesn't exist. They see no alternative, and a lack of action by the UK Government ensures this crisis continues.

This report is a call to action. We depend upon our Members of Parliament and other key decision-makers to represent our views and to take action on our behalf. Carers Trust, in compiling this year's report, has surveyed 3,430 unpaid carers. Unpaid carers save the government a vast amount of money on social care costs by providing critical, life-sustaining care without pay, invariably without training, qualifications or professional support, at enormous cost to themselves.

Unpaid carers do so much more than care. They have to deal with multiple agencies and authorities; represent their loved ones in fighting for support; they often have existing family responsibilities, and they may have to forfeit careers and income to care. Who cares for the carer?

We need more than words, more than empathy, more than gratitude to sustain the unpaid carers across the UK, young and old. We need action through a UK-wide Carers' Strategy and financial support for unpaid carers. I ask every decision-maker, what would you want for your loved ones? How would you provide for their care?

Karen, an unpaid carer and Lived Experience Advisor for Carers Trust.

EXECUTIVE SUMMARY

“ We need validation, recognition and support for what we do. We save the NHS and Government money, and it's time we saw that put back into decent local services we can access quickly and easily.”

This report tells a story of unpaid carers who, despite everything they do to prop up our creaking health and social care systems, feel ignored and undervalued. It also uncovers how these same unpaid carers, through no fault of their own, are struggling to navigate an overly complex system of support that is supposed to be there to help them.

Some of these issues are not new. What the findings in this report show, however, is how certain groups of unpaid carers (like female carers, older carers, LGB+¹ carers and unpaid carers from ethnic minority communities) are finding it harder to access and experience support than those from proportionately less marginalised groups of unpaid carers.

Unpaid carers are fulfilling their caring responsibilities because they have no alternatives. **Just half of the respondents we heard from (49%) felt they had a choice about being an unpaid carer.** Unpaid carers remain unseen and ignored, despite everything they are doing to prop up a health and social care system in crisis. They are taking on increased caring hours because they have to provide care for people with increasingly complex needs.

This disregard for unpaid carers has put them at risk of being left to break down due to burnout, lack of choice, and because the system has become too reliant upon their efforts to fill the gaps². Their caring for others is often to the detriment of their own health needs, wellbeing and economic prosperity.

¹ Unfortunately, we could not include an analysis of statistically significant differences and the experiences of non-binary or transgender unpaid carers due to the small sample size we received as part of this survey. Therefore, we will be using LGB+ to conduct analysis throughout this report.

² The backdrop of diminishing statutory support was reported in the Association of Directors of Social Services (ADASS) 2023 annual survey, finding that nearly half (46%) of directors either strongly agreed or agreed that their council's ability to meet the needs of unpaid carers in their local area had reduced and 91% of directors strongly agree or agree that unpaid carers in their area have been coming forward with an increasing level of need over the past 12 months.

41% of unpaid carers from across the UK told Carers Trust their time spent caring has increased over the last 12 months. Of these:

- More than one-third (36%) of respondents said that their caring role had increased by 20-49 hours a week, and
- One-in-eight respondents (12%) said it had increased by over 50 hours a week.

When asked about the reasons their caring responsibilities had increased:

- 72% of respondents said the person they are caring for needs more care
- 21% said they don't get support from their local authority anymore or that the amount of support they get from their local authority is less than before and
- 21% said they have taken over providing unpaid care from another unpaid carer.

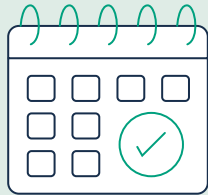
When we asked what support unpaid carers need, they told us:

1. Better support for the person or people they care for
2. A break or respite
3. More money to spend on what they need for their caring role.



KEY FINDINGS FROM THIS SURVEY

Unpaid carers are not getting the support they need. We found:



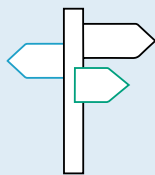
ONLY 32%
OF UNPAID CARERS SAID THEY COULD
ACCESS A BREAK FROM THEIR CARING
ROLE WHENEVER NEEDED.



ONLY 38%
OF RESPONDENTS SAID CARER'S
ALLOWANCE WAS ENOUGH TO MAKE A
MEANINGFUL DIFFERENCE TO THEM. THIS
WAS THE LOWEST RATING OF ALL THE
BENEFITS WE ASKED UNPAID CARERS ABOUT.



1 in 4 UNPAID CARERS (25%)
SAID THEY WERE THE SOLE PROVIDERS OF
CARE AND THAT THEY DIDN'T RECEIVE HELP
TO CARE FROM ANYONE ELSE.



ONLY 55%
OF UNPAID CARERS SAID THEY GOT THE
SUPPORT THEY NEED TO BE A CARER.



UNDER HALF OF UNPAID CARERS (43%)
SAID THAT IN THE LAST YEAR, THEY HAD AN
ASSESSMENT, REVIEW OR REASSESSMENT
OF THEIR NEEDS AS AN UNPAID CARER.



36%

DISAGREED OR STRONGLY DISAGREED THAT THE NHS UNDERSTANDS THEIR CARING RESPONSIBILITIES.

The experiences of unpaid carers across demographic groups are frequently different, and certain groups of unpaid carers may face additional challenges³.

Within our survey, unpaid carers from diverse groups told us they didn't feel they were being listened to as a carer. Statistically significant differences included:



ONLY 3% OF 50-65-YEAR-OLDS AND 8% OF UNPAID CARERS OVER 65 SAID THEY FELT LISTENED TO BY THE UK GOVERNMENT. THIS WAS COMPARED TO:

- 37% of 18-25 year-olds
- 59% of 25 to 30-year-olds
- 74% of 30 to 40-year-olds
- 22% of 40 to 50-year-olds.



ONLY 16% OF UNPAID CARERS FROM LOWER SOCIOECONOMIC GROUPS SAID THEY FELT LISTENED TO BY THE UK GOVERNMENT (COMPARED TO 70% OF UNPAID CARERS FROM HIGHER SOCIOECONOMIC GROUPS).

³ This relates to unpaid carers from Black, Asian and minority ethnic communities, unpaid carers who identify as lesbian, gay or bisexual (or other minoritized sexual orientations), unpaid carers from lower socioeconomic backgrounds and certain age categories of unpaid carers such as those aged 50 and above. Within this report we used personal income as a proxy measure for socioeconomic background.



ONLY 19%
**OF UNPAID CARERS FROM BLACK, ASIAN
AND MINORITY ETHNIC COMMUNITIES
SAID THEY FELT LISTENED TO BY THE UK
GOVERNMENT (COMPARED TO 39% OF
WHITE UNPAID CARERS).**

Other key findings of the different experiences of diverse groups of unpaid carers from this survey include:

- 1.** Certain groups of unpaid carers told us they had to find out about support themselves rather than being signposted to support or that they didn't know about support and services that could help them
 - A higher percentage of 50-65-year-olds, as well as those from lower socioeconomic groups, LGB+ unpaid carers, unpaid carers from Black, Asian and minority ethnic communities, or females providing unpaid care told us they had to find out about support for themselves.
 - A higher percentage of unpaid carers aged 18-25 and 40-50, as well as those from the lowest socioeconomic group or unpaid carers from Black, Asian and minority ethnic communities carers told us they didn't know about/didn't receive support or know about any services that help unpaid carers.
- 2.** A lower percentage of unpaid carers from Black, Asian and minority ethnic communities or unpaid carers identifying as LGB+ told us they received support from statutory services such as their council or local authority, health providers such as mental health services or their local carer organisation.
- 3.** In this survey, a lower percentage of females (compared to males) providing unpaid care said they received Carer's Allowance. The survey also revealed that female carers were less likely than male carers to have reported that they had had an assessment, review or reassessment of their needs over the past year.

RECOMMENDATIONS

Carers Trust makes six key recommendations to improve the provision of support for unpaid carers. These are:

- 1.** The UK Government must urgently and sustainably **fund health and social care.**
- 2.** Professionals must **improve the early identification** of unpaid carers.
- 3.** National and local government must ensure **effective community provision** for unpaid carers, including:
 - Unpaid carers across the UK having a statutory right to short breaks.
 - Health and social care services should learn from and implement the Triangle of Care model which sets out standards for better collaboration and partnership with unpaid carers.
 - The involvement of unpaid carers in the commissioning and designing of services that impact them.
 - Better partnership working between local authorities, statutory services, local carer organisations and unpaid carers.
- 4.** National and local government and wider professionals must ensure the specific **needs of unpaid carers from diverse demographic groups** are understood and met.
- 5.** The UK Government must reform **Carer's Allowance** to ensure a fair deal for unpaid carers.
- 6.** The UK Government must support unpaid carers to **get into or stay in work.**



Our recommendations in detail

1. Urgently and sustainably fund health and social care.

Funding is urgently needed to improve the viability of local carer support. This must include:

- Money that is ringfenced to support unpaid carers, including a ringfenced element within the Better Care Fund in England, and involvement of unpaid carers in how it is spent locally.
- A mechanism to ensure the value of locally awarded contracts can be amended annually in line with inflation. This will ensure contracts are sustainable and in line with the cost of delivery.



2. Improve the early identification of unpaid carers

Identifying as an unpaid carer is the first step towards seeking and accessing help. To improve the consistency of identifying unpaid carers across the system, the UK Government should:

- Introduce a legal duty for professionals within the NHS to identify unpaid carers.
- Invest in a national communications campaign to help unpaid carers identify themselves and others in their local communities. This will allow more unpaid carers to see themselves as unpaid carers and help them realise they are entitled to help. This should be distinct from paid care workers.



3. Ensure effective community provision for unpaid carers



In England, the Health and Care Act 2014 gave new powers to the Care Quality Commission (CQC) to assess how well local authorities are delivering their legal duties, including those related to assessing unpaid carers' needs and meeting those needs. This has the potential to ensure local areas are adhering to their legal duties and to spread good practices. Councils should use toolkits such as those developed by the [Local Government Association](#)⁴ and supported by Carers Trust and others to help them with CQC assurance.

- Unpaid carers across the whole of the UK should have a statutory right to short breaks. Ringfenced funding must be available to local authorities for unpaid carer support, including personalised, flexible breaks. This must be accompanied by replacement care and accessible information to unpaid carers on the different types of breaks they can take.
- Health and social care services should learn from and implement the [Triangle of Care model](#), which sets out six key standards for better collaboration and partnership with unpaid carers throughout the service user's and carer's journey through services.
- In England, Integrated Care Boards must adhere to their new duties in the Health and Care Act 2022 to involve unpaid carers and their local representatives in the commissioning and designing of services that impact them.
 - Local carer services and unpaid carers must be supported and receive funding to take part in relevant decision-making at all levels and have the capacity to do so.
- Better partnership between local authorities, statutory services, local carer organisations, and unpaid carers.

⁴ Local Government Association (2023) *Unpaid carers and Care Quality Commission assurance*



4. Pay attention to the different needs of unpaid carers

Unpaid carers from different demographic groups have different experiences, and some groups of unpaid carers experience particular barriers to knowing about or accessing support. Carers Trust recommends that:

- An intersectional approach to support and services must be prioritised to ensure support is inclusive and accessible for all unpaid carers. This approach must include better training for staff and improved collection of good-quality demographic data.
- Lessons from successful services reaching unpaid carers from seldom-heard groups must be captured and shared to improve practice. For instance, learning from local carer organisations delivering Carers Trust's [Making Carers Count programme](#). Intersectional approaches must be part of the funding process.
- Connections between carer organisations, organisations representing people from seldom-heard groups and local statutory partners must be encouraged and facilitated to promote the development of services which have an intersectional approach to inclusion. Commissioners should ensure specialist organisations are available and that there are established signposting and referral routes for unpaid carers from seldom-heard groups.
- Further research should examine inequalities and gendered experiences of providing unpaid care and in the journeys of accessing the support required.



5. Reform Carer's Allowance

Carer's Allowance must be completely reformed. Carers Trust recommends that:

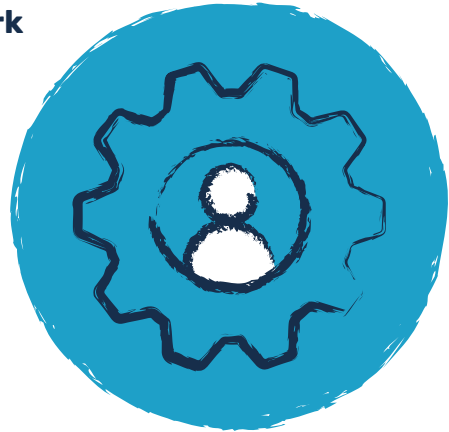
- The earnings threshold for Carer's Allowance must be increased to ensure unpaid carers who are also in employment are not deterred from increasing their working hours due to concerns over losing their entitlement. In reforming the earnings threshold for Carer's Allowance, the earnings cliff-edge that carers currently face, should be removed. Carer's Allowance should also rise in line with inflation and with increases in minimum and living wage rates, whichever is higher.
- The amount of Carer's Allowance must be increased to ensure unpaid carers are not at risk of living in poverty due to their caring role.
- Reduce the qualifying 35-hour eligibility criteria for Carer's Allowance.
- Revoke the pension eligibility criteria to claim Carer's Allowance. Currently, if you receive a full State Pension you will not get a Carer's Allowance payment.
- The 21-hour study rule should be scrapped so unpaid carers can be enrolled in full-time education courses and receive Carer's Allowance.
- If caring for more than one person, unpaid carers should be able to combine their total caring hours.



6. Support for unpaid carers staying in work

To improve labour market outcomes for unpaid carers, Carers Trust calls for following recommendations:

- Carer's Leave should be paid. Carers Trust welcomes the Carer's Leave Act but believes this should be a first step in supporting unpaid carers in the workforce.
- Unpaid carers having access to good quality alternative care if they are to seek work or training opportunities.
- All workplaces having a dedicated unpaid carer policy to support unpaid carers. At a minimum, this should include the following:
 - Workplaces should become accredited as carer-friendly organisations with the necessary policies and processes to support unpaid carers and reduce the stigma of caring in the workplace.
- More specialist unpaid carer employability programmes should be commissioned, offering holistic, individually tailored support. These programmes should include the input of local carer organisations, employability providers and employers to ensure the carers' needs are met. Programmes should be evaluated to build the evidence base on 'what works' to support unpaid carers to enter and remain in the workplace.
- Carer Passports should be more widely used. Carers Trust and Carers UK worked on a Department of Health and Social Care-funded project to develop Carer Passports for the workplace. [A Carer Passport](#)⁵ provides structure to support a conversation about the flexibility needed to combine work and care. This conversation involves balancing the needs of the employee with the needs of the business within existing company policies.



⁵ You can find more information out about Carer Passports at: <https://carerspassports.uk/employment>

WHAT OUR SURVEY TOLD US

Identification as an unpaid carer

Existing [research](#)⁶ suggests that nearly three-quarters (73%) of those who provide or have provided unpaid care said they do not identify as or call themselves an unpaid carer.

176 respondents (5% of respondents to our survey) said they didn't consider themselves an unpaid carer before starting our survey.

It is vital to ensure that unpaid carers are supported to identify and recognise their additional responsibilities and that they can access the information, advice and support they need to help them with their caring role. Unpaid carers told us some of the reasons for not describing themselves as a carer. These included:

Sense of responsibility/identity as a partner, parent, family, or friend first:

“I think of myself as his mum first and as a carer second.”

“I am just helping my friend.”

“It's my family; it's the least I can do.”

“A carer is someone you pay to come in and help.”

“I don't really think of emotional support as caring for someone.”

Their employment status:

“I have a job – I'm just doing bits and pieces to help Mum alongside that.”

⁶ Carers Week (2023) *I care: Carers Week report on unpaid carer identification*

Sharing the responsibility of caring with someone else:

“I’m a carer, but I’m not – my mum looks after my dad more.”

Having paid or formal help:

“We get help from paid carers. I’m just supporting my parents.”

“My main role is supervising the care workers who look after Mum.”

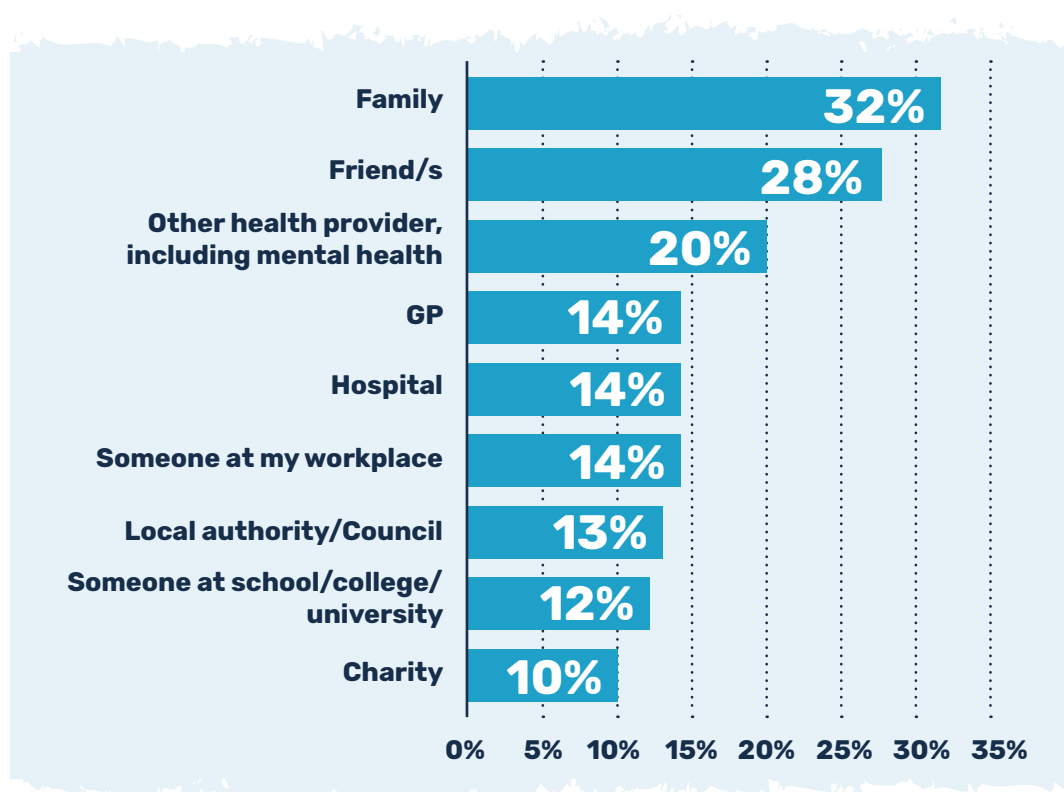
Not living with the person or people they care for:

“I don’t think of myself as a carer because I don’t live with him.”

27% of unpaid carers reported that someone else suggested they were an unpaid carer rather than recognising themselves as one.

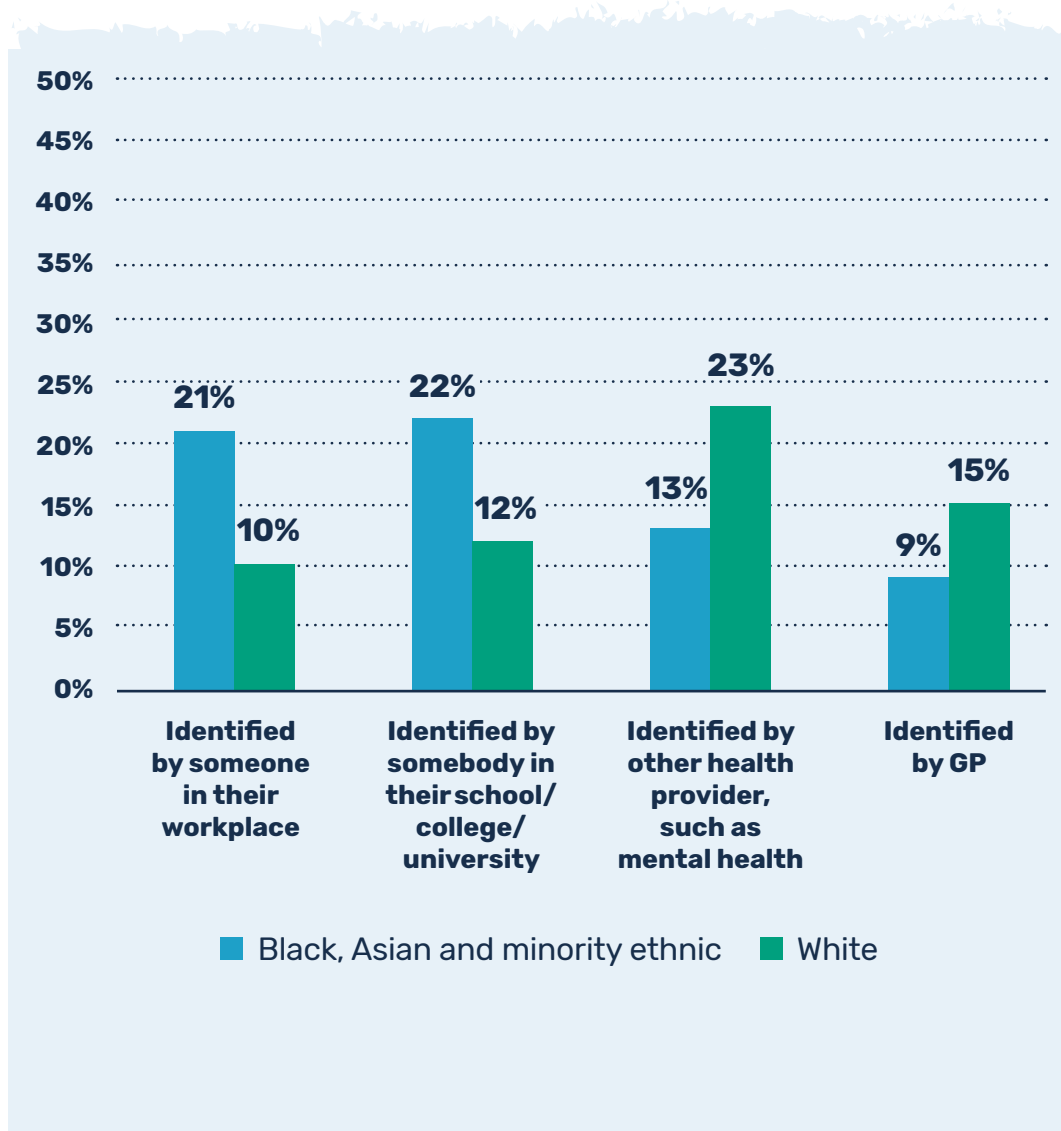
The most common way people told us they were identified was by someone in their personal network, such as family or friends.

Figure 1: 'Who suggested or pointed out that you were/are a carer?' (n=850)



Unpaid carers were identified as carers differently amongst diverse populations. Statistically significant differences in our survey included:

Figure 2: 'Who suggested or pointed out that you were/are a carer?' by demographic group



This data indicates that a higher percentage of certain groups of unpaid carers are being identified within statutory authorities, compared to more informal routes to identification such as through family or friends.

This data shows significant scope for GPs, staff within health settings, charities, local authorities, workplaces, and schools/colleges/universities to identify and help unpaid carers know about the support they are entitled to.



Are unpaid carers aware of and accessing the support and services they need?

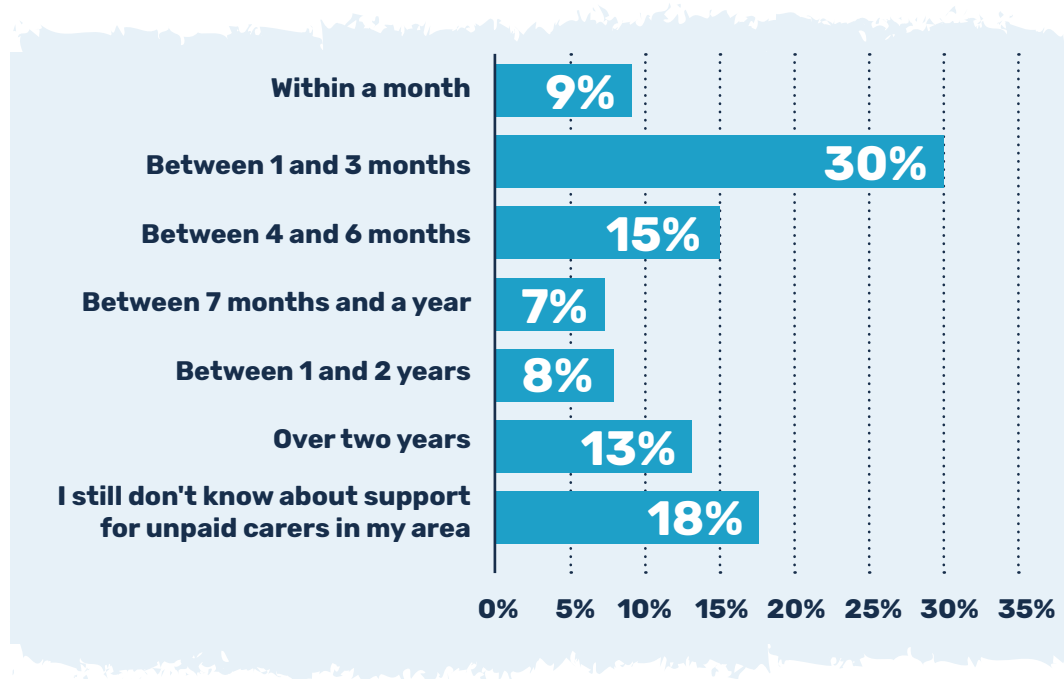
When our survey asked whether anyone helps them in their caring role, 25% of unpaid carers told us they are the sole care providers. This was especially the case for unpaid carers from older age groups (47% of unpaid carers aged 65+ said they were the sole provider of care) and those from lower socioeconomic backgrounds (38% said they were the sole provider of care).

Signposting to support

When asked whether they were signposted to support or services that would help them, **26% of respondents said they had to find out about support themselves.** However, **the second highest response was that 18% of respondents who identified as an unpaid carer were still unaware of support for unpaid carers in their area.** 13% of respondents stated it took them over two years to become aware of the support available for unpaid carers.



Figure 3: 'How long did it take you to know about support for unpaid carers?' (n=3368)



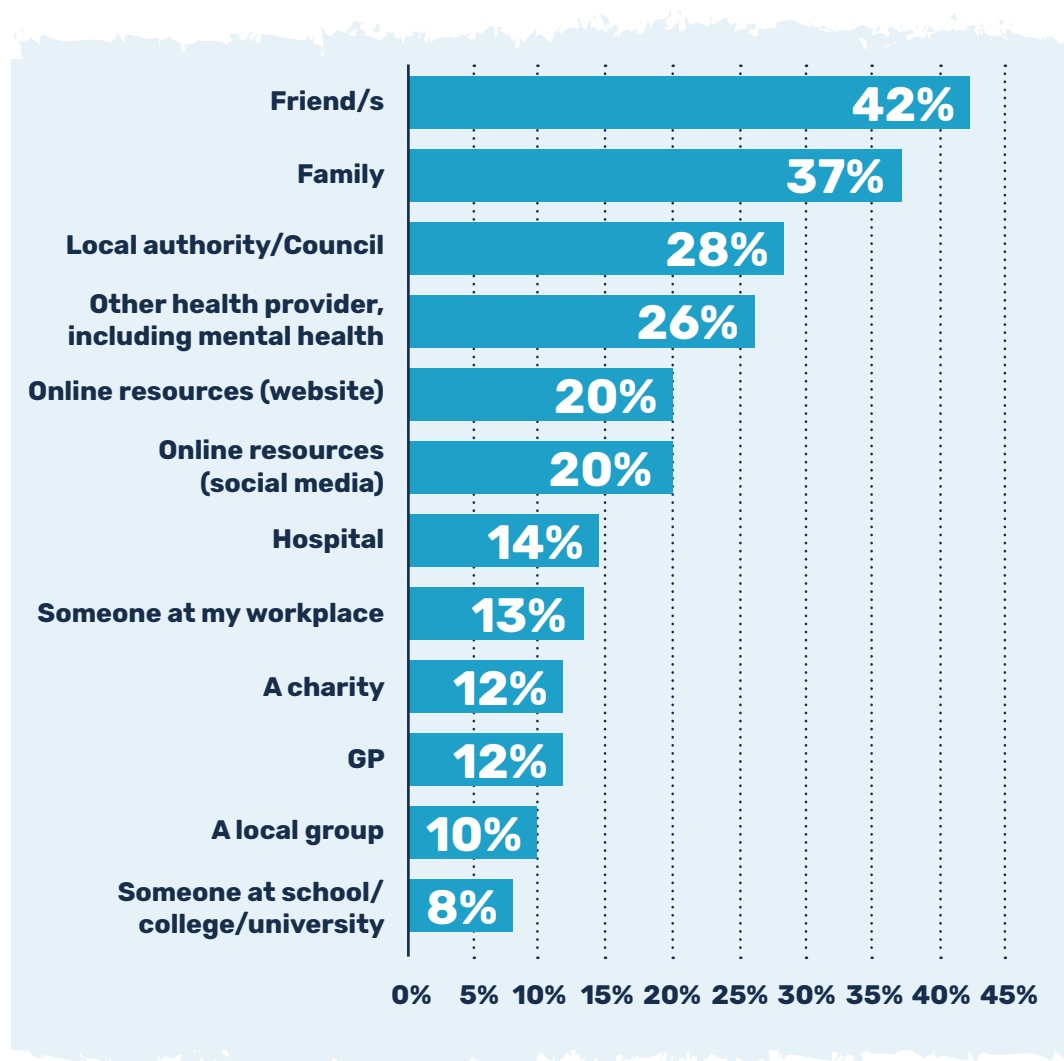
There is a clear need to improve the provision of information to unpaid carers in a way that is accessible and easy for them to understand and navigate.⁷

The majority of unpaid carers who were signposted to support heard about it from their personal networks, such as friend/s (42%) and family (37%), followed by their local authority/ council (28%).



⁷ Research such as findings from the Survey of Adult Carers in England (2021/22) found that the percentage of unpaid carers who found it easy to find information or advice about support, services or benefits decreased from 16% in 2018-19 to 14% in 2021-22. 15% of unpaid carers reported finding it very difficult to source information.

Figure 4: 'Please tell us where you found out about support or services to help unpaid carers' (n=2984)



Different populations told us that they were not signposted to support for unpaid carers. For instance, a higher percentage of the following groups of unpaid carers reported having to find out themselves about support for unpaid carers rather than being signposted:

- **Older unpaid carers** 42% of 50-65-year-olds and 37% of 40- to 50-year-olds, compared to:
 - 11% of 18-25 year-olds
 - 19% of 25-30 year-olds
 - 11% of 30-40 year-olds.
- **Unpaid carers from lower socioeconomic backgrounds** (37% compared to 18% of those with the highest socioeconomic backgrounds)

- **Females** who provide care (28% compared to 22% of males who provide unpaid care)
- **LGB+ unpaid carers** (31% compared to 25% of heterosexual unpaid carers)
- **Unpaid carers from Black, Asian and minority ethnic communities** (29% compared to 26% of White unpaid carers)

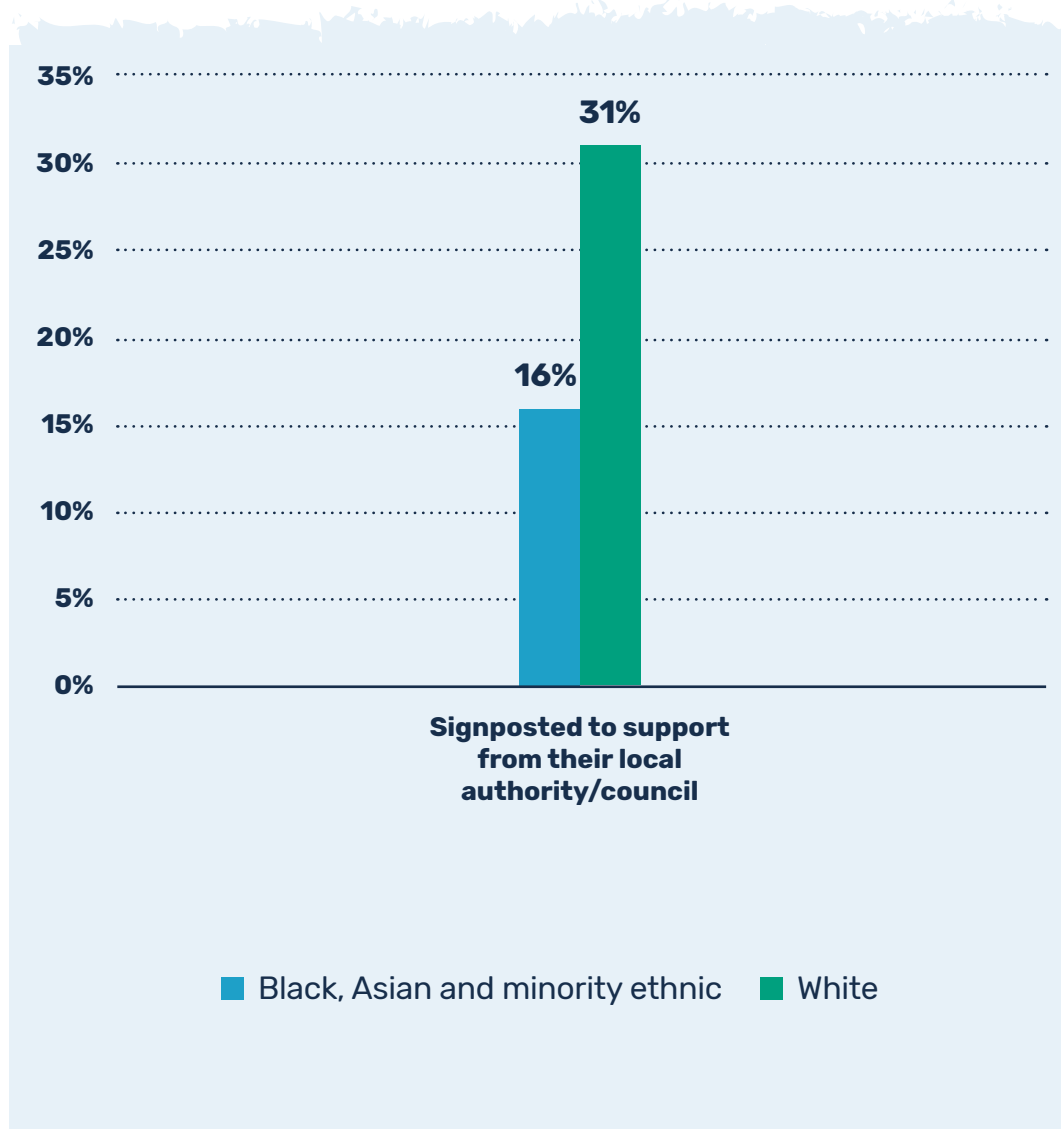
Furthermore, a higher percentage of the following groups of unpaid carers reported that they didn't know about or receive any support to find out about services:

- **Unpaid carers aged 18-25 and 40-50 years old** (19% for both) reported that they didn't know about or receive any support to find out about services. This was compared to:
 - 15% of unpaid carers aged over 65
 - 14% of 50-65 year-olds
 - 5% of 30-40 year-olds
 - 6% of 25-30 year-olds.
- **Unpaid carers with lower socioeconomic backgrounds** (15% compared to 6% from the highest socioeconomic backgrounds)
- **Unpaid carers from Black, Asian and minority ethnic communities** (13% compared to 11% of White unpaid carers)



Our survey also uncovered significant variation in the degree to which carers told us that stakeholders across the system signposted them to support. Statistically significant differences include:

Figure 5: Where unpaid carers found out about support or services to help them



This data provides information about where unpaid carers across diverse groups are accessing information and gives us a snapshot of where improved provision of information and more proactive identification of unpaid carers across diverse groups is needed.

Access to support

Just over half (55%) of unpaid carers told us they get the support they need to be an unpaid carer. The feeling of not getting enough support to be an unpaid carer was particularly prevalent amount certain demographic groups, including:

- **Unpaid carers aged 50-65** felt most strongly that they don't get enough support to be an unpaid carer (73%). This was followed by unpaid carers aged 65+ (58%) and 40-50 years old (56%).
- **Unpaid carers from lower socioeconomic backgrounds:** 64% said they don't get enough support to be an unpaid carer compared to 11% of those from the highest socioeconomic backgrounds,
- **Females providing unpaid care:** 58% said they don't get enough support to be an unpaid carer compared to 27% of males providing unpaid care.

Furthermore, a lower percentage of unpaid carers providing the highest number of hours of care per week reported feeling that they had enough support.

- **Unpaid carers providing 50+ hours of care per week:** 54% said that they don't get enough support to be an unpaid carer compared to 29% of those providing 20-49 hours of care per week and 45% of those providing 0-19 hours of care per week.

When asked about their experiences accessing support, unpaid carers provided great detail about some of the challenges, such as:

1. **The system of support is complicated for unpaid carers to navigate.** Unpaid carers told us there is no central information point that outlines available support. While there is much information on support, none of it is joined up. This makes accessing information about support for unpaid carers very time-consuming and complicated. It acts as a barrier for many to access or know about support.
2. Unpaid carers told us that **the system of support and services is fragmented**, with little information-sharing between services. Unpaid carers told us they often have to repeat their story across several services. Many unpaid carers told us they feel like they are being passed around the system. The result is that their previous time has been wasted and they still haven't accessed support.

Many unpaid carers told us that having a single point of contact to help them navigate and access support across the system would be incredibly beneficial:

“I wish we had someone who could support me through this journey and help me understand what’s out there – I just want to feel guided on how to be the best carer I can be, but you are left from day one to get on with it. No wonder unpaid carers feel so alone at times”.

“Carers need one contact to help navigate their different needs – someone who takes responsibility for coordinating. The current system is inefficient.”

3. Unpaid carers told us that support is often short-term and not timely when they need it:

“I need support there and then, not four weeks down the line because of capacity issues or long waiting times. Many unpaid carers will only ask for help at times of real crisis – you can’t typically plan that far ahead with our role”.

4. Unpaid carers told us that support is not personalised or appropriate for their needs or for those of the person needing care. Unpaid carers provided several examples of this, including:
 - a. Support often occurs during traditional work hours, so working unpaid carers experience difficulties accessing it.
 - b. Support often does not come with replacement care, which is a barrier to attending. This was particularly the case with respite opportunities which many unpaid carers told us they had to pass up.
 - c. Support for unpaid carers feels information-centric rather than being a delivery of practical help⁸.

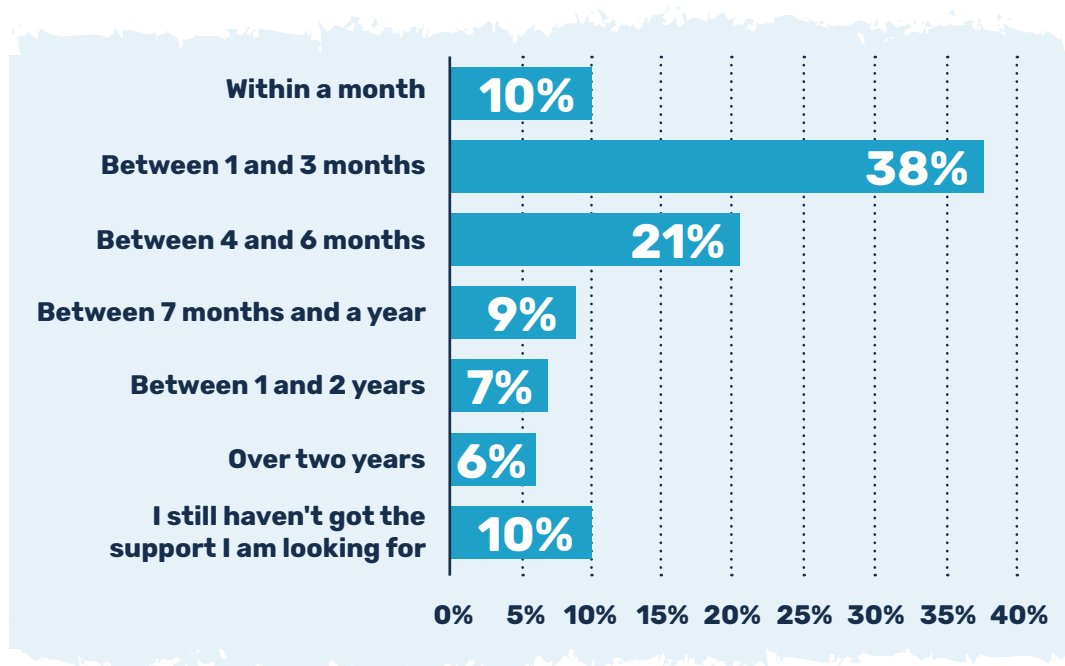
⁸ Unpaid carers telling us that support feels like mainly information rather than practical support is found in research such as the [SALT data collection](#), which found that of unpaid carers supported or assessed/reviewed in 2021-22 in England, the most common support consisted of information, advice and other universal services or signposting (55.6%). Only 18.1% received Direct Payment, 1.7% received Part Direct Payments, Only 3.1% received a Local Authority Managed Personal Budget, only 3.1% received a Local Authority Commissioned Support only. The Kings Fund report *‘caring in a complex world’* (2023) similarly found that there has been a shift in the type of support carers receive, away from paid support such as direct payments, personal budgets, and commissioned support towards advice, information and signposting and that the number of people provided with respite care to support carers has fallen from 2015-16 (57,000) to 33,000 in 2021-22.

5. Unpaid carers also told us that they often experience a lack of recognition by professionals in shaping or being consulted on care for the person in receipt of care. Many unpaid carers provided stories of when this resulted in inappropriate support for the person in receipt of care. This resulted in more work for the unpaid carers who now needed to remedy the situation⁹:

“When I speak up for what my son needs, I’m dismissed and looked at as if I have no idea what I’m talking about. No one listens to me, no matter how loud I shout.”

Regarding the time it took unpaid carers to try and access support, **13% of respondents said it took them over a year to access support, and 10% of respondents said they still haven’t got the support they are looking for:**

Figure 6: ‘How long did it take you to try and get some of the support you had found out about’ (n=2775)

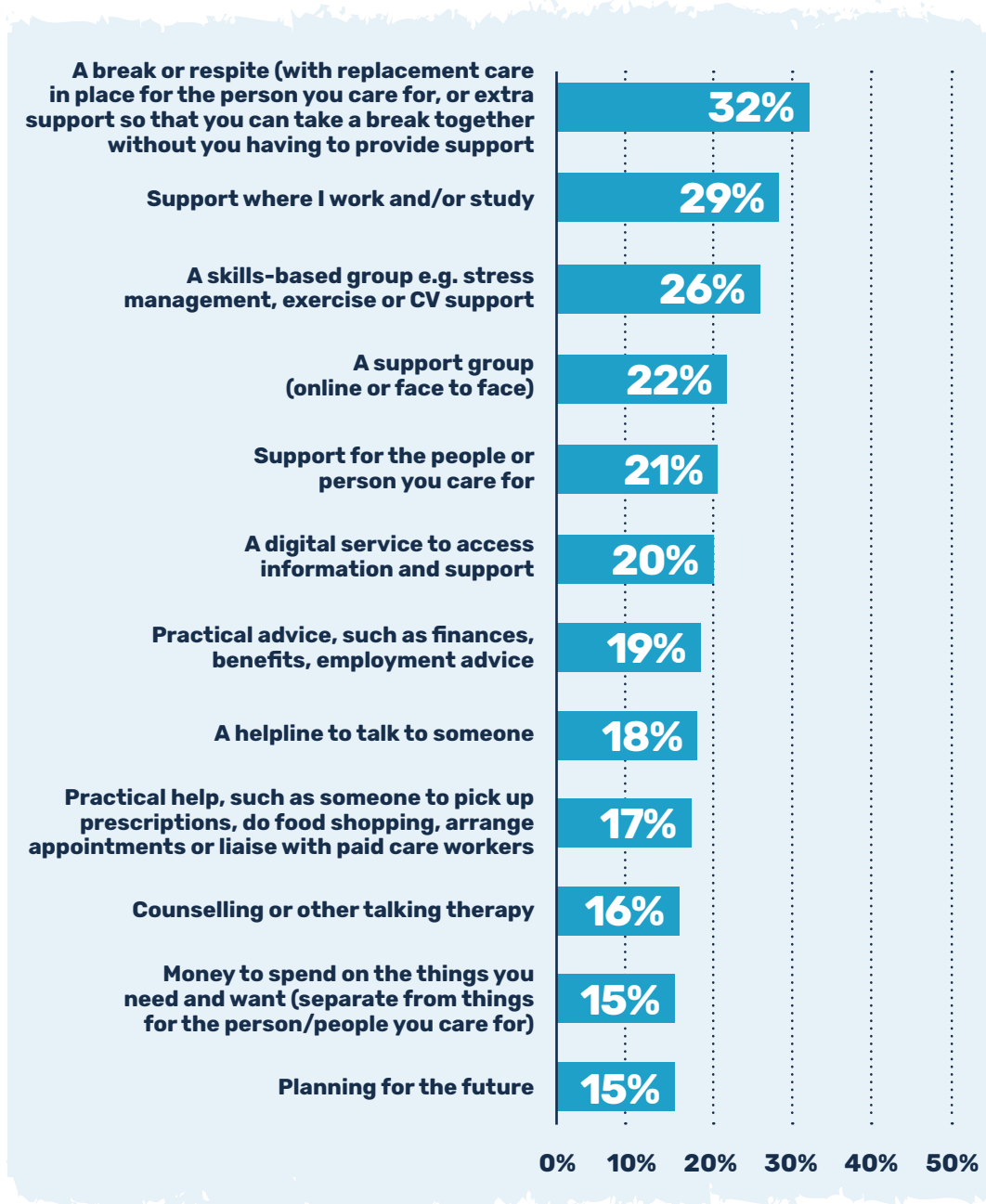


⁹ These experiences are all too familiar for unpaid carers. As part of the [Survey of Adult Carers in England](#), the percentage of unpaid carers saying there had been no discussions about support or services provided to the person they care for in the last 12 months increased from 31% in 2018-19 to 36% in 2021-22. Furthermore, of unpaid carers who reported never feeling involved or consulted, 4% felt extremely satisfied with the support received.

When asked about availability and access to support, unpaid carers told us which services they could access whenever needed and that they use. **Only 32% of respondents said they could use and get a break whenever needed.** No support service was being accessed by more than one-third of our survey respondents. This data shows that many unpaid carers are still not getting access to or using the help they need.



Figure 7: 'I use this support, and I can get it whenever I need to' to the question 'What support have you used in your local area?' (variable n)





The Directors of Adult Social Services [2023 Spring Survey](#)¹⁰ found that unpaid carer burnout was the number one reason directors gave for the breakdown in unpaid carer arrangements. Breaks can be crucial in helping local authorities meet their legal duties, promoting unpaid carers' wellbeing and preventing their needs from escalating¹¹. However, only a small percentage of unpaid carers can take a break from their caring role, and the percentage reporting that they can take a break has reduced over time¹².

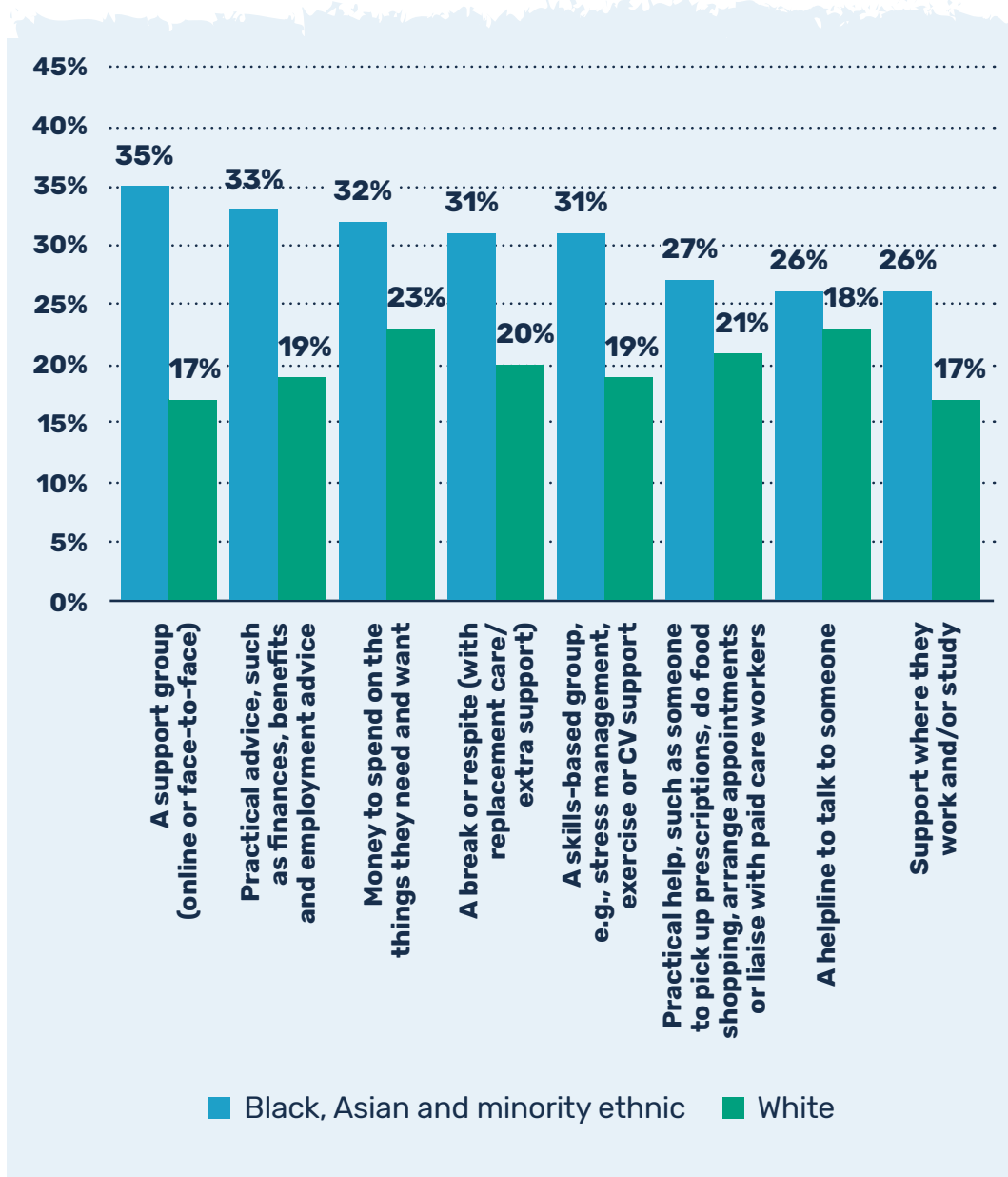
¹⁰ Directors of Adult Social Services (2023) *Spring Survey 2023*

¹¹ Carers Trust and Carers UK, as part of the Health and Wellbeing Alliance, supported by the Department of Health and Social Care, published a report *Time Away from Caring: Good practice in carer breaks*, which highlights the evidence on the importance of breaks for unpaid carers and highlights good practice in providing breaks. This includes exploring what works for unpaid carers from Black, Asian and minority ethnic communities and diverse LGBTQ+ communities which can face additional barriers in accessing support and breaks.

¹² Nuffield Trust (2022) *Falling short: How far have we come in improving support for unpaid carers in England*

Availability and access to particular types of support were challenging across diverse groups of unpaid carers. Statistically significant differences between demographic groups included:

Figure 8: 'I would like to use the following services but I can never get access to them when needed' to the question 'What support have you used in your local area' by demographic group





Overall, our findings from this survey reinforce conclusions repeated across research, such as the Kings Fund [report](#)¹³, supported by local carer organisations that called for:

1. Support to be tailored to unpaid carers' situations and not create extra work for unpaid carers to attend support or take a break.
2. Health and social care systems to be as integrated as possible to reduce the burden on unpaid carers.

This report highlights that certain demographics of unpaid carer groups are facing additional challenges in accessing support compared to others.

Sources of support for unpaid carers

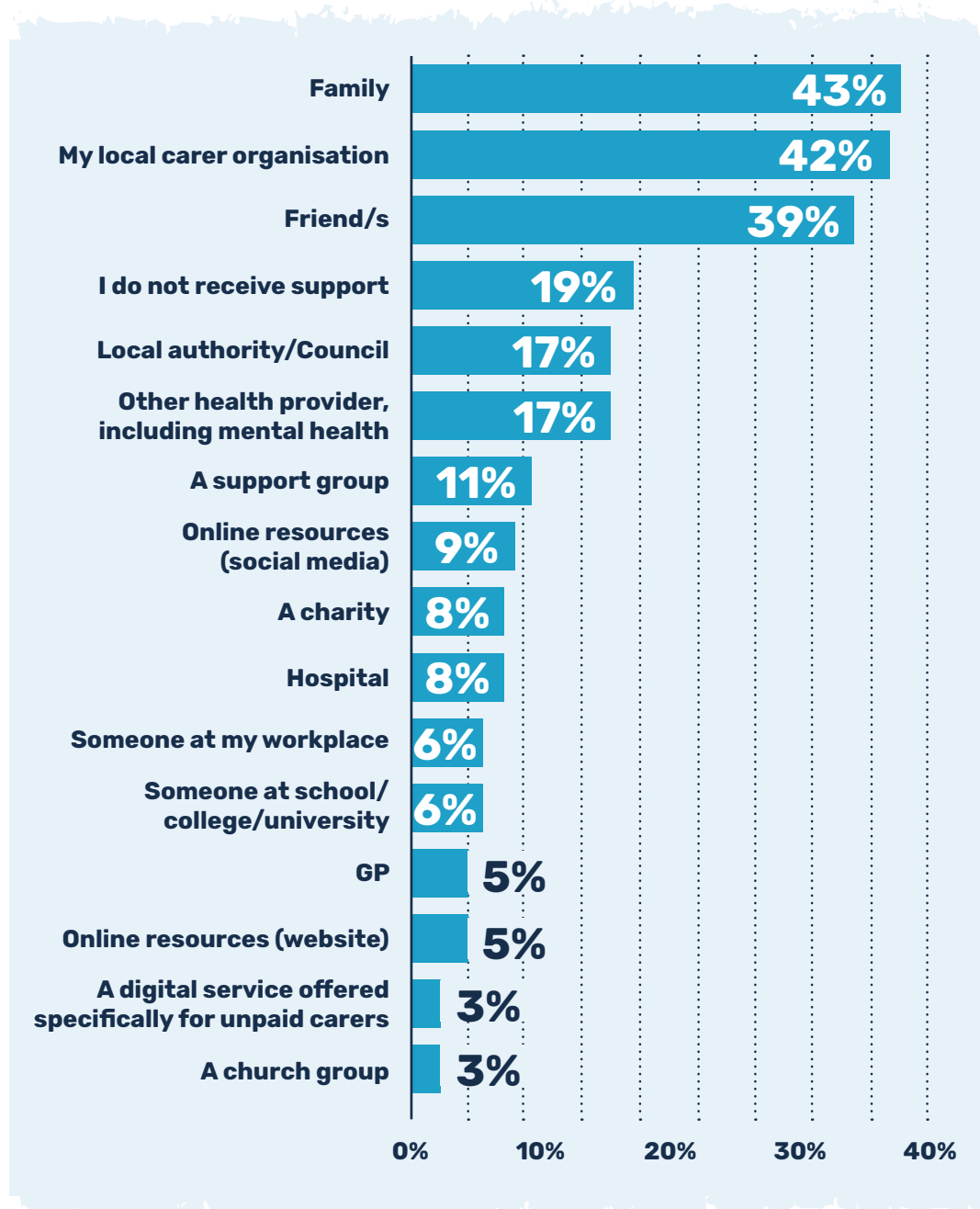
19% of respondents stated they receive no support at all. Most respondents said they received support for being an unpaid carer from their family (43%). This was followed by support from their local carer organisation (42%) and friends (39%).

Many unpaid carers in contact with their local carers organisation described this support as a 'lifeline'. However, conversations with unpaid carers highlighted the need for more funding and for staff to ensure that unpaid carers across all areas have equal access to high-quality, accessible support from local carer organisations¹⁴.

¹³ Kings Fund (2023) *Caring in a complex world: Perspectives from unpaid carers and the organisations that support them*

¹⁴ It is important to highlight that many unpaid carers are not in receipt of support from a local carer organisation. The [Survey of Adult Carers in England \(2021/22\)](#) reported that in England, 66% of unpaid carers surveyed said that they had not used support from local carer groups or someone to talk to in confidence to help them as an unpaid carer in the last 12 months.

Figure 9: 'Where do you receive the most helpful support to be a carer' (n=3368)



Amongst different demographic groups of unpaid carers there was a diverse range of responses in relation to where they receive support. For example, in this survey:

Age: The top three sources of support for unpaid carers varied according to age groups. For instance:

- **18 to 25 year-olds:** 1. Friends 2. Local carer organisation 3. Someone at my school/college/university
- **25 to 30 years old and 30 to 40 years old:** 1. Friends 2. Family 3. My local carer organisation
- **40 to 50 years old:** 1. Family 2. Friends 3. I do not receive support
- **50 to 65 years old and 65 years plus:** 1. I do not receive support 2. My local carer organisation 3. Family

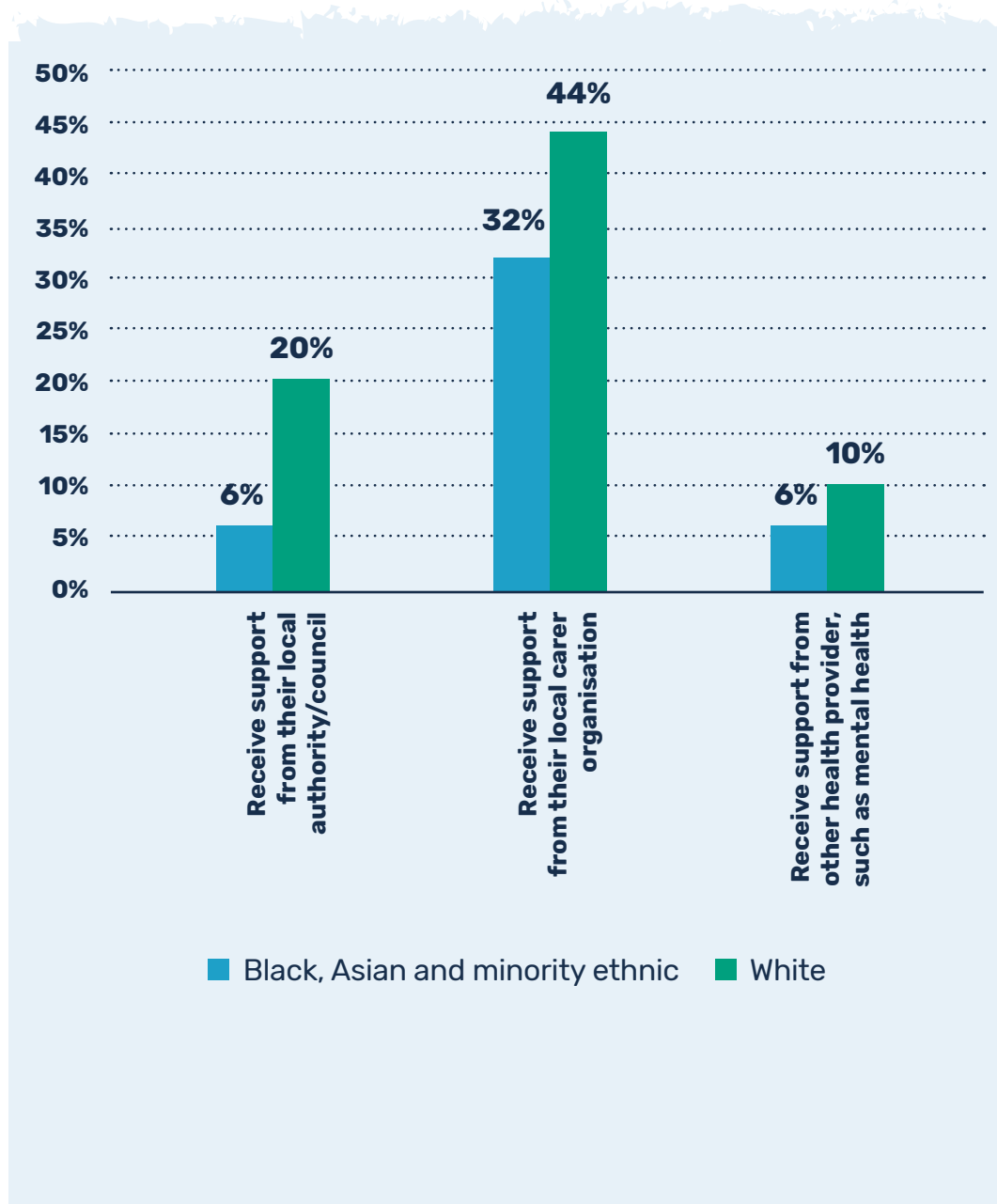
This data shows a particular need to improve the provision of support for unpaid carers aged 40 or over, where the answer 'I do not receive support' featured in the top three responses we heard.

Furthermore, digital resources, such as online resources or digital services, featured in the least-accessed support across older groups of unpaid carers. This shows that there is a need to better understand the reasons as to why certain groups of unpaid carers do not want to access support online, or if they require additional support to access digital support.



Statistically significant differences across demographic groups also included:

Figure 10: 'Where do you receive the most helpful support to be a carer' by demographic group



This data shows the importance of improving reach, ensuring inclusivity, and tailoring relevant support across the system for seldom-heard groups of unpaid carers. Particularly of note are unpaid carers from Black, Asian and minority ethnic communities and LGB+ unpaid carers having a statistically lower percentage receiving support from statutory services, and from their local carer organisations (this was also the case for unpaid carers from lower socioeconomic backgrounds).

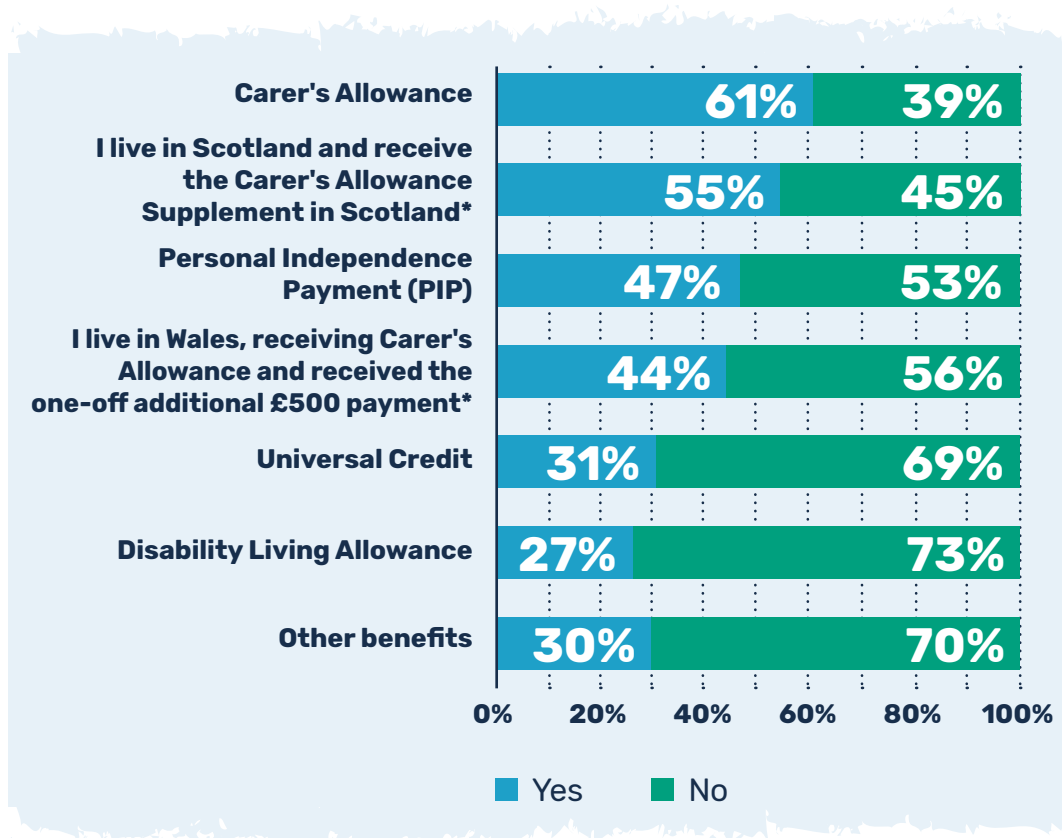
RIGHTS AND ENTITLEMENTS

Benefits received by unpaid carers

In this survey, Carer's Allowance was the benefit that the majority of respondents said they were claiming (61%).

According to the Department of Work and Pensions, in February 2022, 1.3 million people were claiming Carer's Allowance. Of the total number claiming Carer's Allowance, 30% were entitled to the benefit but did not receive payments. The [Kings Fund](#) (2023¹⁵) states that the number of unpaid carers receiving Carer's Allowance comprises a relatively small percentage of the 4.7 million unpaid carers in England identified by the 2021 Census.

Figure 11: 'Do you receive any of the following benefits' (variable n)



¹⁵ Kings Fund (2023) *Caring in a complex world: Perspectives from unpaid carers and the organisations that support them*

*This data is only showing figures for Scotland/Wales.

The main conditions leading to [eligibility for Carer's Allowance](#)¹⁶ are:

- 1.** The person you care for must receive **one of the following benefits:** Personal Independence Payment (the daily living component), Disability Living Allowance (the middle or highest care rate), Attendance Allowance, Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit), Constant Attendance Allowance (at the basic (full day) rate with a War Disablement Pension, Armed Forces Independent Payment, Child Disability Payment (the middle or highest care rate), Adult Disability Payment (daily living component at the standard or enhanced rate).
- 2.** You spend **at least 35 hours a week** caring for someone.
- 3.** Your earnings are **£139 or less a week** after tax, National Insurance and expenses.
- 4.** You're **not** in **full-time education**.
- 5.** You're **not** studying for **21 hours a week or more**.
- 6.** You cannot get Carer's Allowance if you **share the care of someone and the other carer is already claiming Carer's Allowance** for that person/ the extra amount of Universal Credit for caring for someone who gets a disability-related benefit for that person.
- 7.** You cannot get the full amount of both Carer's Allowance and your **State Pension** simultaneously.

Unpaid carers provided great detail about the challenges they experience with claiming Carer's Allowance and the above eligibility criteria. For instance, struggling to navigate and understand information about what is available and what they are eligible for, the interaction of benefits and frustration over the restrictive eligibility criteria.



¹⁶ GOV.UK (no date), *Carers Allowance*. Available at: <https://www.gov.uk/carers-allowance/eligibility>

The two main challenges we heard about were:

1. The income eligibility criteria of Carer's Allowance and the impact this has on unpaid carer's choices about employment¹⁷, and
2. The interaction of Carer's Allowance and State Pension:

“Carer's Allowance is so little with so many requirements. It's not a large enough amount that you can survive on it without working. The maximum salary threshold is below the minimum amount you need to have a standard quality of life generally – this is especially hard with inflation.”

“As I receive a pension, I can't get Carer's Allowance. It makes me feel worthless.”

When asked whether they felt social security benefits for unpaid carers were enough, only 38% of respondents said **Carer's Allowance was enough to make a meaningful difference to them. This was the lowest rating of all the benefits we asked unpaid carers about:**

“Carer's Allowance is pitiful. I've had to give up my full-time job, so my mum doesn't go into a care home, which would cost the Government thousands. Yet all I get is £76 a week?”

Scotland has provided extra assistance to unpaid carers through the Carer's Allowance Supplement. Unpaid carers in Wales who receive Carer's Allowance were made eligible to claim an additional £500 payment in 2022. However, despite these supplements, only 38% of unpaid carers in Scotland and Wales said the extra payments were enough to make a meaningful difference to them.

When asked about the amount needed for reform of Carer's Allowance, one unpaid carer told us this:

“How much would the Government need to replace us if we decided not to care anymore? How much would each service charge? That's your ballpark figure.”

¹⁷ Within [Wavehill's evaluation \(2022\)](#) of Carers Trust's Working for Carers partnership, 31% of unpaid carers reported that financial concerns, such as the loss of Carer's Allowance or other benefits, were a barrier to entering employment, education or training.

Notably our survey showed the percentage of **females** unpaid carers receiving benefits was lower than that for **male** unpaid carers. This included benefits such as:

- **Carer's Allowance** (23% compared to 39%)
- **Disability Living Allowance** (25% compared to 45%)
- **Universal Credit** (27% compared to 44%) and
- **Other benefits** (46% compared to 49%).

The eligibility criteria for Carer's Allowance must be reformed. Carer's Allowance should be increased to reflect the cost of caring and the fact that many unpaid carers have to give up work, reduce their working hours or spend their life savings to pay for expenses associated with caring.



Carers Trust is one of 90 organisations that support the [Joseph Rowntree Foundation's Campaign](#)¹⁸ urging the Government to adopt the Essentials Guarantee. This would ensure the basic rate of Universal Credit would at least cover life's essentials, such as food, utilities and vital household goods with support never being pulled below that level.

Assessment, reviews or reassessments

Unpaid carers can ask for a carer's assessment (in England or Wales) or an adult carer support plan (in Scotland) to see what might help make an unpaid carer's life easier. It is free and is usually undertaken by the council or a local carers organisation working with the council. To get a carer's assessment/adult carer support plan, an unpaid carer can contact the social work team at their local council or contact their local carers organisation for further information.



¹⁸ Joseph Rowntree Foundation (2023) *More than 90 charities unite behind a powerful call on party leaders to guarantee essentials for low-income households amid rising hardship*. More information available at: <https://www.jrf.org.uk/press/90-charities-unite-behind-guarantee-essentials>

Not even half (43%) of survey respondents said they had had an assessment, review or reassessment in the last year. Again, similar to findings on benefits for unpaid carers, this is a higher response than is prevalent in the national picture for unpaid carers. [According to Short and Long Term \(SALT\) data¹⁹](#) on unpaid carers, there has been an overall decline in the number of unpaid carers supported or assessed/reviewed by local authorities in England. In 2021-22, in England, only 380,725 carers were supported or assessed/reviewed by local authorities, down 2.1% since 2020-21.



We asked those who had not received an assessment or review in the last year why they hadn't received one. **39% of respondents told us that they weren't offered one, 30% said that they didn't know they could have one,** and 6% said that when they asked for one, they were told they didn't need it and that it wouldn't make a difference to them. An additional 7% said they didn't receive an assessment or review because they didn't want one. Within this, unpaid carers told us about some of the challenges they experienced resulting in them not wanting a carer's assessment/adult carer support plan. These include fear and distrust of services, concerns about the process of assessments being intrusive and having to negotiate a stressful assessment experience.

Furthermore, similar to our previously reported findings on benefits, it is essential to note that within this survey, a smaller percentage of females providing unpaid care said that they had had an assessment, review or reassessment of their needs over the past year: **41% reported not having an assessment, review or reassessment compared to 31% of males.** Our findings have shown that, despite the Census in England and Wales identifying larger numbers of females providing unpaid care, a lower percentage of the sample of females we heard from reported having access to support, benefits, or an assessment.



¹⁹ NHS Digital (2022) *Adult Social Care Activity and Finance Report, England 2021-22*

SUPPORT WITH HEALTH AND WELLBEING

Unpaid carers need support for their own health and wellbeing. Still, we heard from unpaid carers that it often feels impossible to prioritise their own wellbeing or access appropriate support being a carer themselves.

In this survey, we heard from many unpaid carers who had health conditions themselves: **60% of respondents said they had a physical and/or mental health condition that affected their daily lives**²⁰. An additional 27% of our respondents were on hospital or mental health treatment waiting lists.



Experiencing challenges with their health and wellbeing puts additional strain and stress on unpaid carers, with several unpaid carers saying it makes their caring role more challenging and, often, overwhelming to balance. As the recent ADASS [Spring Survey 2023](#)²¹ references, *'it makes no sense for unpaid carers to sacrifice their own health and eventually cost the NHS more'*. The health needs of unpaid carers must be a key priority; otherwise, they risk being unable to continue with their caring responsibilities.

Unpaid carers highlighted challenges around prioritising and accessing support for their own wellbeing, which would add even further pressure onto already strained NHS and Social Care resources. Some of the difficulties they told us they were experiencing included:

1. Hospital discharge of the person in receipt of care.
2. Balancing medical needs with caring and worrying about being able to carry out their caring role in the future.
3. Mental health support not feeling relevant.

²⁰ Findings from the [Survey of Adult Carers in England](#) found that on a national level, the percentage of unpaid carers with a mental health problem or illness rose from 11% in 2018-19 to 13% in 2021-22. Furthermore, findings from the [2021 Census multivariate data](#) found that the percentage of unpaid carers reporting bad or very bad health has increased from the 2011 Census in England and Wales and that the percentage of those reporting bad or very bad health was higher for unpaid carers providing more hours of care per week.

²¹ Directors of Adult Social Services (2023) *Spring Survey 2023*

“**My mum was in hospital. Three days into her stay, she called me saying the nurses told her she was coming home that day. Thankfully my local carer support service gave me advice and support regarding the discharge procedure. However, the staff kept insisting she’d be coming home that day- they didn’t involve me in the plan. This continued for two weeks. I ended up in A&E myself with stress and later pneumonia, which prevented me from caring for my own children, my mum and myself- I’m totally burnt out. Every day I’m battling with services, and I get nothing.**”

When we asked about unpaid carers' opinions on the NHS, **36% disagreed or strongly disagreed that the NHS understands their caring responsibilities and that they have received appropriate support.** This was particularly felt by females who provide unpaid care (39% compared to 24% of males providing unpaid care) and those from lower socioeconomic backgrounds (54%). Unpaid carers told us about the challenges they had experienced in getting NHS staff to recognise their expertise:

“**It feels like unpaid carers have to become healthcare experts in so many areas without training or support. When a professional asks how everything is going, my mother says everything is fine, but the professional doesn’t ask my opinion. I’m left picking up the pieces. I wish professionals would speak to carers - this would help me feel listened to as an unpaid carer.**”



CONCLUSION

This report has provided a snapshot of the experiences of unpaid carers, mapping the journey of 3,400 unpaid carers through the system to highlight the challenges many are experiencing across identification, awareness, and access to appropriate support. It points to the critical need for more support for unpaid carers so they can continue their valuable and highly challenging work.

Our survey findings tell a story of unpaid carers who are unrecognised, feel undervalued and are not receiving the support they need to do their caring role despite the incredible value of care they provide. Unpaid carers desperately need help understanding and navigating the services available in their local area. They must be able to access good quality support throughout the UK from local carer organisations and wider services.

This report highlights the need for increasing attention to the diverse experiences of unpaid carers across ethnicity, sexual orientation, sex, gender and age to identify the spaces in which seldom-heard groups of unpaid carers are experiencing additional barriers. Key findings from this report add value to the existing evidence base on unpaid carers, highlighting:

- Where diverse groups of unpaid carers are not being identified as effectively as they might be across the system and where improvements can be made.
- The haphazard nature of availability of support for diverse groups of unpaid carers and where improvements can be made.
- The differences between diverse groups of unpaid carers as to whether they felt like they are receiving the support they need to carry out their caring role.
- The types of support diverse groups of unpaid carers would like to access and the challenges preventing them from accessing this support.

Our findings from this report show that we must improve the provision of inclusive and accessible support that caters to unpaid carers' differing needs. Findings also show how research conducted on a national scale must prioritise understanding the diverse experiences and challenges of unpaid carers.

METHODOLOGY

3,430 unpaid carers aged over 18 completed our survey. Respondents came from across the UK. The survey ran from 12 May 2023 to 11 June 2023.

This survey was designed with a group of Lived Experience Advisors who co-designed the survey questions and provided expertise, critique and challenge throughout the report process. This survey was anonymous; no identifying data about unpaid carers is held. Survey completion was voluntary and unpaid carers could choose which questions they did and did not answer and could stop completing the survey at any time.

Respondents self-identified as unpaid carers aged over 18 before completing the survey; a short definition of unpaid carer was provided in the survey's introductory text.

We promoted the survey via Carers Trust Network Partners, other charities and external organisations we partner with and on our social media channels.

We ran quality assurance checks on the data to check for invalid responses.

Within the report, Carers Trust has undertaken a comparative analysis of unpaid carers' experiences across different demographic characteristics- ethnicity, differences between females and males, LGB+ unpaid carers, age and socioeconomic background. We have highlighted where there are statistically significant variations between demographic groups.

Unfortunately, we could not include an analysis of statistically significant differences and the experiences of non-binary or transgender unpaid carers due to the small sample size we received as part of this survey. However, we are looking at this data and learning from more in-depth research about the experiences of LGBTQI+ unpaid carers in our work.

These survey results have not been weighted by demographics and are not necessarily nationally representative. However, they provide a valuable snapshot of unpaid carers' experiences and views across the UK. They highlight the need to improve data collection and understanding of diverse experiences across the UK.

APPENDIX

Of those who provided information regarding their demographic characteristics and information regarding their caring role, the following presents a breakdown of the unpaid carers we heard from as part of this survey:

Relationship to carer	Number of respondents
39% were caring for their partner/husband/wife	1,336
37% were caring for a child under 18	1,277
37% were caring for a parent	1,261
19% were caring for a child aged 18 or over	654
11% were caring for a grandparent	380
11% were caring for a sibling	373
7% were caring for other relative/s	243
6% were caring for a friend	199
2% were caring for a neighbour	81

Support needs	Number of respondents
50% were caring for someone with a long-term health condition	1,755
46% were caring for someone with a mental health condition	1,600
45% were caring for someone with a physical condition	1,580
37% were caring for someone with frail/elderly needs	1,278
36% were caring for someone with a learning disability	1,266
21% were caring for someone with a neurodevelopmental condition (e.g., autism and/or ADHD)	717

Support needs	Number of respondents
18% were caring for someone with dementia	628
12% were caring for someone with a sensory impairment	418
7% were caring for someone with a life-limiting condition	241
6% were caring for someone with substance misuse or other addiction/ recovery issues	239

Ethnicity	Number of respondents
Unpaid carers from Black, Asian and minority ethnic communities (total)	551
0.1% Asian/ Asian British: Bangladeshi	5
0.4% Asian/ Asian British: Chinese	13
1.0% Asian/ Asian British: Indian	34
0.5% Asian/ Asian British: Pakistani	16
0.3% Asian/ Asian British: Any other Asian background	11
0.4% Black/ African/ Caribbean/ Black British: African	14
0.5% Black/ African/ Caribbean/ Black British: Caribbean	17
0.2% Black/ African/ Caribbean/Black British: Any other Black/African/ Caribbean background	6
1.0% Mixed/ Multiple ethnic groups: White and Asian	35
0.3% Mixed/ Multiple ethnic groups: White and Black African	11
0.3% Mixed/ Multiple ethnic groups: White and Black Caribbean	10
0.7% Mixed/ Multiple ethnic groups: Any other mixed/ multiple ethnic backgrounds	25
1.0% White Gypsy or Irish Traveller	33
3.7% White Irish	125

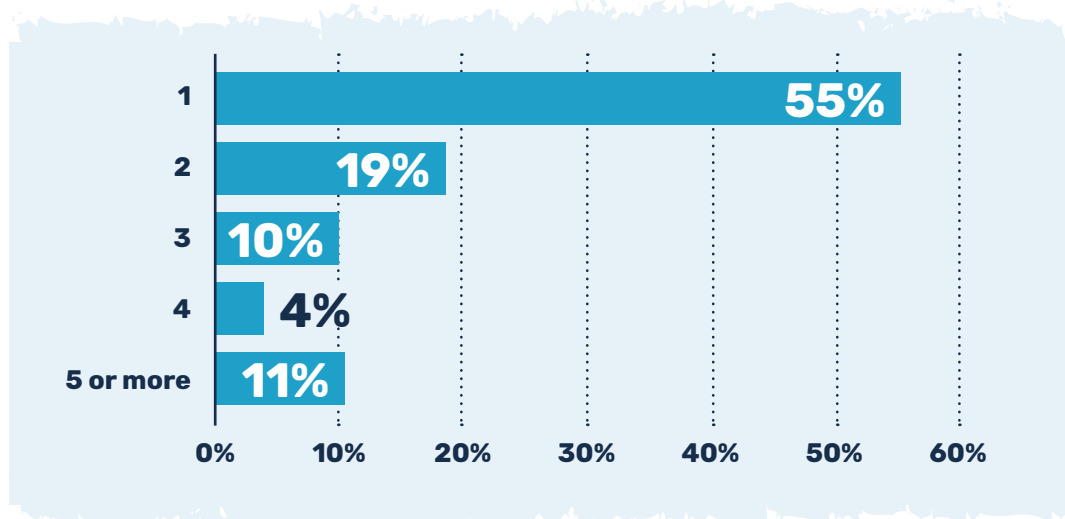
Ethnicity	Number of respondents
1.1% White Roma	38
0.0% Any other ethnic group: Arab	1
0.7% Any other ethnic group (Other)	24
83.6% White English/ Welsh/ Scottish/ Northern Irish/ British	2,812
No data available	67

Age	Number of respondents
2% were 18-25 years old	70
8% were 25-30 years old	259
37% were 30-40 years old	1,218
15% were 40-50 years old	503
22% were 50-65 years old	729
15% were 65+ years old	493

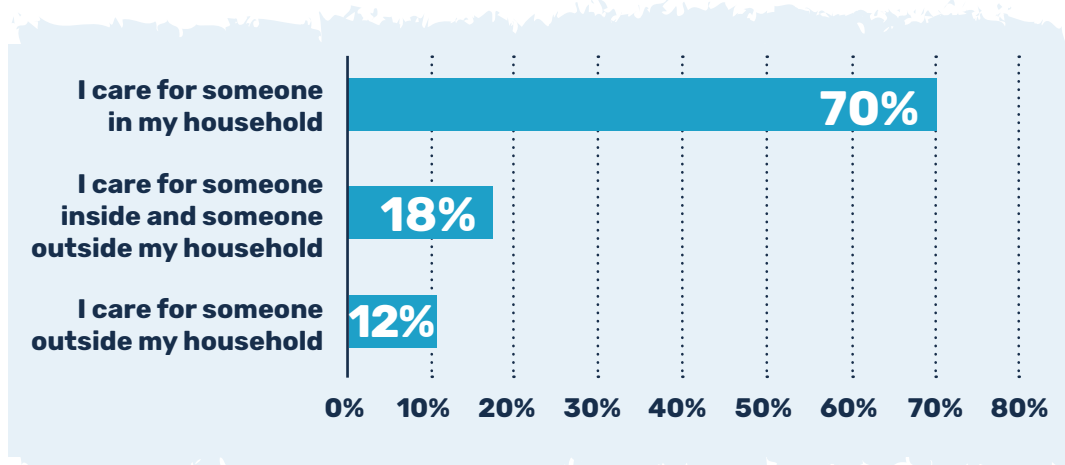
Sex	Number of respondents
76% females providing unpaid care	2,591
23% males providing unpaid care	775
1% non-binary unpaid carers	24

Sexual orientation	Number of respondents
93% heterosexual identifying unpaid carers	3,019
7% LGB+ identifying unpaid carers	230

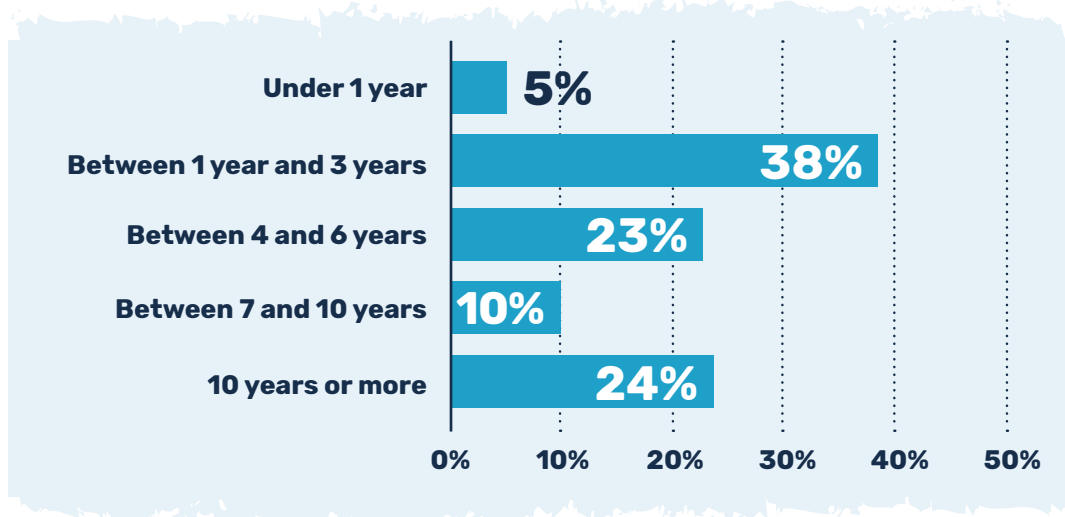
How many people do respondents care for?



Are respondents living with the person in receipt of care?



How long have respondents been providing unpaid care



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