

# **The State of Unpaid Caring in Leeds**

## **Annual Survey 2026 findings**



# Introduction

At the end of 2025 and the start of 2026, we carried out our fourth annual survey of unpaid adult and parent carers in Leeds. The survey aimed to explore carers' main concerns, understand their experiences, and identify what matters most to them.

This report highlights the issues that matter most to unpaid carers in Leeds this year and compares some findings with the responses from our previous annual carers surveys.

This helps us understand the extent to which carers' experiences are changing over time. Sadly, this year's State of Unpaid Caring report shows that many of the challenges facing carers remain unchanged and in some cases, are greater than previous years.

Alongside telling the real story of what it means to provide unpaid care in Leeds; we will use the findings to help drive meaningful change in our city so that more carers are identified and get the recognition and support they need.

If you wish to discuss any of our findings in more detail or want to know more about our work, please email [comms@carersleeds.org.uk](mailto:comms@carersleeds.org.uk)

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# About Carers Leeds

## Who are we?

Carers Leeds offers free support and information to unpaid carers across Leeds. A carer is someone who, without payment, provides support to a family member or friend, who, due to illness, disability, dementia, mental health issues or an addiction, cannot manage without their help.

## We can help you through our:

- Support Line – someone to talk to, information and guidance.
- 1:1 support – in person or on the phone.
- Support groups – meet with people who have similar experiences as you.
- Information to help you in your caring role.

We can support you to manage your own health, wellbeing and relationships, as well as your caring role. We can also offer guidance on managing money and practicalities, and how to get time to yourself.

## Get in touch

**Call Us**    **0113 380 4300**  
Mon, Wed, Thu, Fri: 9am - 4.30pm  
Tue: 9am - 6.30pm

**Webchat**    Click the webchat icon on our website to speak with a member of our team.

**Website**    Visit [carersleeds.org.uk](https://carersleeds.org.uk) for more information and resources.

**Email**    [support@carersleeds.org.uk](mailto:support@carersleeds.org.uk)



Support Line  
**0113 380 4300**

# Who responded to our survey

## 492 unpaid carers responded to our survey:

- Their ages ranged between 18 to over 90. Most carers were in the 55-64 age range and 68% of respondents were 55 or older.
- 82% were women, 17% were men, 1% were transgender or non-binary
- 88% were white British, 12% were from Black, Asian and other ethnically diverse groups
- 90% were heterosexual, 3% gay or lesbian, 2% bisexual, 1% preferred to self-describe and 4% preferred not to say
- 54% considered themselves to have a disability

## In terms of caring responsibilities:

- 71% of respondents were caring for one person, 23% were caring for two people and 6% were caring for 3 or more people.
- The time respondents had been caring for ranged from less than a year, to over 15 years. Most respondents had been caring for between 5-9 years (26%) or 15 or more years (33%).
- Hours a week of care ranged from 0-9 hours to 90 hours or more. 63% of respondents were providing 90 hours or more care per week – the highest proportion in any of our annual carers surveys so far.

## The top 3 concerns for unpaid carers

The top two concerns for carers in Leeds right now, mirror the finding of our three previous annual carer surveys. This year the third concern is focused on health and care services.

- 1** My own health & wellbeing needs (68%)
- 2** The changing needs of the person I care for (48%)
- 3** Services not being able to meet my needs/the needs of the person I care for (34%)

Money and the cost of living ranked fourth, with 31% of carers listing it among their top three concerns. This is the first time in four years it has not featured in the top three, likely reflecting growing worries about public services rather than improved financial security.

## The positive things about caring

We asked carers about the positives of caring. Some respondents struggled to find any positives, particularly if their situation was in crisis, they had little or no support or things had worsened over time. For those carers who could find the positives, the main themes were:

- The knowledge that that someone was well looked after at home, by someone who understood and could best meet their needs
- The act of making a difference or improving the quality of life of someone else, providing meaning and purpose to your own life
- Spending more time together, building a trusted, loving relationship
- Giving back for care you received as a child or fulfilling your wedding vows
- Being appreciated and thanked by the person you care for
- Improving your knowledge about a health condition or learning new skills including patience, empathy and compassion
- Getting support from Carers Leeds and peer support from other carers

**“It is not about positive or negative, it is a fact of 58 years of marriage.”**

**Unpaid Carer**

# Health and Wellbeing

For the fourth year running 'my own health and wellbeing' was the number one concern for carers in Leeds, with even more carers than last year reporting concerns about their health and wellbeing (68% compared with 60%). Our survey findings mirror national and international evidence of the impact of caring on carer's physical and mental health.

On a scale of 0-10 (0 being no impact and 10 being a significant impact) 69% of carers reported that caring had a negative impact on their physical health (scoring 6 or more), with 44% reporting this as significant (scoring 8 or more). This is an increase on previous years' survey findings.

Carer mental health fares even worse than carer physical health. 80% of unpaid carers indicated that caring had a negative impact on their mental health (scoring 6 or more), with 54% of unpaid carers reporting a significant impact (scoring 8 or more). Again, this is an increase on previous years' survey findings.

Carers are substantially more likely to report lower levels of wellbeing, than the general Leeds population.

Our survey uses the ONS measures of personal wellbeing, so we can compare the survey data with the most recent data on the adult population of Leeds (ONS 2022-23).

The contrast between these sets of figures is stark, with the largest gaps being in life satisfaction and happiness. Over half of carers reported high anxiety, compared to 1 in 5 in the general Leeds population.

When asked about the way caring impacts on their day-to-day health and wellbeing, there was a high prevalence of sleep problems and stress, anxiety and overwhelm – 70% of carers reported experiencing these all or most of the time. Over half of carers reported feelings of guilt and low mood and depression all or most of the time (59% and 53% respectively).

**“I feel so stressed and I get migraines due to the stress. My own health is deteriorating.”**

**Unpaid Carer**

Personal wellbeing measures	Adult population of Leeds (%)	Unpaid carers in Leeds (who responded to our survey) (%)
Low levels of life satisfaction	3.8	42.9
Low levels of feeling the things you do in life are worthwhile	3.7	34
Low levels of happiness	9.1	46.8
High levels of anxiety	20.1	54.1

Although 'my own health and wellbeing' was the number one concern for unpaid carers in Leeds for the fourth year running, 55% of carers reported that they did not have time to prioritise their own physical and mental health.

Over the four-year period we have been conducting an annual carers survey in Leeds, the prevalence of the negative physical and mental health impacts of caring has increased year on year. The very act of caring – particularly if intensive, over time and without support – is damaging the health of carers in our city.

The findings provide evidence of a cohort of carers who, despite experiencing significant emotional and psychological impacts of caring, continue to care for family members and friends.

Increased concerns about services not being able to meet carers needs or the needs of the person they care for (now a top three concern for carers in Leeds) suggests that carers could be taking on even more, to help fill the gap of statutory services, at an even greater cost to their physical and mental health.

# Relationships and social connections

Taking a break from caring to do something you enjoy, or spend time with people who matter to you, can be difficult for unpaid carers.

We know that caring can have an impact on the relationship between the carer and the person being cared for. When we asked carers whether their relationship with the person they cared for had changed since they started caring, 15% said that their relationship had got better, 21% said their relationship had got worse, and 34% said their relationship hadn't changed. 26% said it had changed in other ways.

When describing any changes to their relationship with the person they care for, people talked about the positives: how their relationship had got stronger, closer and to a deeper level of mutual understanding. Some carers talked about the benefits of spending more time with the person they care for and what the act of caring can bring to a relationship:

*"There is a closeness that develops from having to physically care for someone, that is different from what was there previously. It feels like an acknowledgment of being human and that frailty will come for us all. It is also a privilege in many ways, to feel trusted and able to show love in this way. It's a deeper, gentler, kinder relationship than before."*

It was more common for carers to talk about changes to the relationship between them and the person they care for in more negative and challenging ways. Many carers described the grief they felt for the relationship they had pre-caring and how, in some cases, they missed intimacy, emotional connection and meaningful conversation.

**'The person I care for has regular mood swings so one day they might be in an aggressive mood, the next they might be okay. I never know what to expect.'**

Unpaid Carer

**'I have people who check-in on me, celebrate the successes with me, ask how they can help. One family member regularly has my son to stay over to give me a break.'**

## Unpaid Carer

For some, whilst they were spending more time with the person they cared for than before they began caring, this was more focused on the caring routine than quality time together. In these situations, caring was the overriding part of the relationship, the thing that eclipsed all other areas. Others spoke of how roles had been reversed or changed – feeling more like a parent than a child, or more like an employee than a family member. Some of those caring for partners, said they didn't feel like equals anymore.

For some, the changes in their relationship were influenced by the condition of the person they cared for, especially if that was dementia or a progressive illness. This could manifest itself in unpredictable behaviour and in some cases, not recognising you anymore. Others spoke about how the person they cared for slept much more and how there was little communication or emotional connection.

Some carers described their relationships as feeling 'one way' — giving more than they received. They spoke about the weight of supporting someone who now depended on them for decisions and tasks they once shared, such as household chores, finances and future planning. This often contributed to feelings of loneliness. Others described relationships marked by tension, conflict, frustration and resentment on both sides.

A huge part of this were feelings of exhaustion and entrapment – a byproduct of intense levels of caring with little support. This meant that tempers were frayed and patience was lacking. Carers spoke about the negative impact of feeling unappreciated and in the worst cases, examples of cruel, aggressive and violent behaviour at the hands of the people they care for.

We asked carers to what extent family members and friends supported them with their caring role. 24% said always or often, 32% said sometimes and 46% said rarely or never. We defined 'support' as helping to care, helping with other tasks or emotional support.

Some carers spoke of the benefits of having regular support, whether that was a listening ear or practical help with caring or domestic tasks. They spoke about family members stepping in when things become too much or on a regular basis to give them a break. Some described a network of family and friends who could be routinely called upon, others said that family were there in an emergency, or played a role (for example, helping with legal and financial tasks) from a distance. Others spoke more generally about family and friends showing appreciation for what they did.

Those carers who did not have much or any help from family and friends, spoke about feeling lonely and isolated. The most common reasons given for the lack of help and support were:

- I don't have family who live close by
- Family and friends have work or family commitments or their own health issues
- The person I care for will not accept help from anyone else
- I do not let others see how I am really feeling
- No-one else understands the condition of the person I care for or how to care for them
- Family and friends do not acknowledge my caring role or appreciate how hard it is
- People make general offers of help, that don't materialise

We asked carers about their wider social connections and the opportunities they had to take a break. Many carers reported that their caring responsibilities were a barrier to a social life.

Around 56% of respondents said they always or mostly missed out on time for themselves or taking a break, while 47% said they always or mostly missed out on spending time with friends and family.

Missing out on holidays was also common, with 54% reporting that they always or mostly missed out on going away. 46% said they regularly missed out on hobbies or activities they enjoyed.

41% of respondents agreed or strongly agreed that they had people close by they could call on for help, fewer felt connected to their community (23%). This means that most carers who responded to our survey did not have networks of support and felt disconnected from their wider community.

Over one-third of carers (39%) disagreed or strongly disagreed that they had enough meaningful contact with friends or family, and a significant proportion (61%) said they did not regularly participate in social activities.

Given these findings, it is not difficult to understand why loneliness was common among carers. 44% of respondents reported that they often or always felt lonely, and a further 36% said they sometimes felt lonely. Only one fifth of respondents (20%) said they rarely or never experienced loneliness.

Carers identified several areas where they felt additional support could enable them to take a break and feel more connected to their family, friends and community. The most common responses were better recognition from local services of my needs as a carer (51%) and support from family and friends (40%).

Over a third (34%) suggested support with paid care for the person they care for would be helpful, as would accessible activities for carers and cared-for people to attend together (31%). Around three in ten carers wanted support with paying for social or leisure activities (33%).



**“There is a closeness that develops from having to physically care for someone, that is different from what was there previously.**

**It feels like an acknowledgment of being human and that frailty will come for us all. It is also a privilege in many ways, to feel trusted and able to show love in this way. It’s a deeper, gentler, kinder relationship than before.”**

**Unpaid Carer**

# Access to support

Accessing services was one of the top three concerns in this year's survey, with carers worried about services not being able to meet their needs or the needs of the person they care for.

Some of this may be a result of a lack of knowledge about health and care services (beyond mainstream NHS services) or be borne from previous, negative experiences of seeking help from health and care services.

The most used services by respondents and the people they care for were mainstream NHS services. 86% used primary care services such as GPs, dentists and pharmacists, 60% used hospital services for planned or emergency treatment or mental health care, 35% used community health care services such as district nurses or recovery hubs and 27% had support from paid care workers at home. 37% of respondents had used Carers Leeds services. Use of short breaks and respite services was considerably lower, with only 15% using day services and 14% accessing other short breaks or respite support.

We asked carers to rate their experiences of communication, compassion and co-ordination across a range of health, care and voluntary sector services.

The 'Three Cs' as they are referred to locally, are part of a person-centred approach to measuring and improving the quality of joined up health and care in the city, which has been adopted by the Leeds Health and Wellbeing Board.

Local charities received the highest ratings in all three domains. Communication from local charities was rated as good or very good by 43% of respondents, slightly higher than primary care services at 41%. Compassion from local charities received the strongest positive ratings overall, with 45% rating this as good or very good, compared with 42% for primary care services. Co-ordination was also rated highest for local charities, with 40% reporting good or very good experiences, substantially higher than other services.

These findings suggest that carers perceive voluntary sector organisations in Leeds more positively than statutory services, particularly in relation to communication, co-ordination and compassion.

**'The person I care for has regular mood swings so one day they might be in an aggressive mood, the next they might be okay. I never know what to expect.'**

Unpaid Carer

We asked carers about their awareness and uptake of carers assessments – a social care assessment, under the Care Act 2014, to identify a carer's needs and determine what support may help them maintain their wellbeing while caring. Social care services carry out needs assessments for people with care needs.

Around one-third of respondents said that the person they care for had received a needs assessment (35%), with 24% reporting that they had had a carers assessment. A similar proportion said they had not been offered a carers assessment (36%). 3% of carers had been offered a carers assessment but declined it.

There was a lack of awareness of needs and carers assessments amongst the carers who responded to our survey. 29% said they did not know what a carers assessment was and 24% didn't know what a needs assessment was. This suggests that although some carers are engaging with social care assessment processes, there remains a substantial proportion who either have not been offered a carers assessment or are unaware of carers assessments.

Accessing services was one of the top three concerns in this year's survey, with carers worried about services not being able to meet their needs or the needs of the person they care for. Some of this may be a result of a lack of knowledge about health and care services (beyond mainstream NHS services); lack of services; long waiting times or be borne from previous, negative experiences of seeking help from health and care services.

Carers experience significant barriers when trying to access support services for the person they care for. The most common barrier, reported by 40% of respondents, was not knowing what services are available. Around a third of carers reported difficulties accessing appointments at suitable times, while over a quarter of carers said they were unable to find care and support services in their area that met their needs.

Concerns about cost were reported by 24% of carers and 16% felt the quality of care available was not good enough. Only 14% stated that they experienced no barriers to accessing support. These findings suggest that information about services which could support carers, still isn't reaching all who need it. Furthermore, that carers continue to face practical, financial and system-navigation challenges when seeking support from health and care services.

While many carers were confident using digital technology, a significant minority still faced barriers to accessing online services. Just over half of respondents (56%) had a digital device and felt confident using technology. The most common barrier (25%) was that the person they care for did not want to use technology or digital services. Other key barriers included a lack of confidence using technology, limited awareness of available online services, and concerns that online services did not meet their needs. Some carers also reported affordability issues, lack of suitable devices, or unreliable internet access. These findings suggest digital exclusion is driven more by confidence, awareness, accessibility and caring circumstances than simply having access to digital devices.

# Money

**We know that you are more likely to experience poverty as a carer than if you are someone who doesn't provide unpaid care. Concerns about money and the cost of living have featured strongly in our previous surveys, and this year's survey is no exception.**

Many respondents to the survey were receiving financial support through welfare benefits. Universal Credit with the Carer Element was the most reported benefit (40%) followed by Attendance Allowance for the cared-for person and Carer's Allowance (both at 18%).

Over one-third of carers were worried about monthly living costs and whether they could manage in the future (35%). Financial hardship was affecting some carers' ability to meet basic needs, an indication that they are living in poverty.

Those worried about money and the cost of living used a range of coping strategies to try and manage financially. The most common responses included cutting back on hobbies or leisure activities (29%), using personal savings (23%), and cutting back on seeing family and friends (19%).

Around one in six carers said they were cutting back on essentials such as food and heating, while others reported using credit, borrowing money, or falling into arrears with household bills.

## The real cost of caring

Over the past 12 months, too many carers have gone without one or more essentials. This is an indication that they may be living in poverty:

- Being unable to keep my home warm (17%)
- Had cut down on the size of meals or skipped meals (16%)
- Gone without essential dental treatment in the previous 12 months (13%)

# Work

**We know unpaid carers are more likely to face barriers to work, study and volunteering. This year's survey highlights some of the challenges of juggling paid work and caring, while also showing the value work can bring to carers' lives.**

Over one-third of respondents were retired (37%) and 27% identified as full-time unpaid carers. Around 30% were in paid employment, 14% working full time and 16% working part time. A further 12% reported being unable to work due to their own health issues, indicative of the relationship between unpaid caring and poor health outcomes.

Of those carers not in work, education or volunteering many would like to be. Around 28% said they would like to be working, and a similar proportion would like to study (27%). Interest in volunteering was also evident, with 29% saying they would like to volunteer.

The survey findings highlight the impact that caring responsibilities can have on work. 42% agreed or strongly agreed that

they felt anxious about caring while working and 42% felt tired at work because of their caring role.

Nearly half (46%) said they had given up opportunities at work because of caring responsibilities. Despite these challenges, many carers also identified positive aspects of employment, with 47% agreeing that work gave them a purpose or break from the caring routine.

There was some evidence of carer-friendly employers in the city. 29% of respondents agreed that their employer was understanding about their caring role. Around a third of respondents (31%) felt comfortable talking about their caring role at work.

**“I know I can support my Mum, but I find it difficult working full time and often I'm not well.”**

**Unpaid Carer**

# Conclusion

**Through this report, we wanted to tell the real story of unpaid caring in Leeds to help ensure that carers are more visible and valued, so that carers in our city get the support and recognition they deserve.**

Most respondents to this year's carers survey were in mid to later life, which is often described as 'peak caring'. Many were providing high levels of care, for years, often with no or limited support from friends, family or health and care services. This is damaging their health and wellbeing, with the emotional and psychological impacts of caring being the most shocking. Carers are all too aware of the cost to their own health and wellbeing. It was their number one concern, for the fourth year running. Despite this, they continue to care.

Many carers are not aware or are not accessing health and care services which could support them in their caring role. When carers do seek help for themselves or the person they care for, many services are failing to offer the communication, co-ordination or compassion they need. Concerns about services not being able to meet their needs or the needs of the person they care for, it is now in the top three concern for carers in Leeds for the first year. This suggests that carers could be taking on even more, to help fill the gap of statutory services, at an even greater cost to their health and wellbeing.

Whilst money and the cost of living dropped out of the top three concerns for carers right now, over a third were worried about monthly living costs, alongside whether they could manage in the future. Around one in six were cutting back on essentials (including food and energy) an indication that they are experiencing poverty.

Only a third of respondents said they felt comfortable talking about their caring role at work and said they had an understanding employer. Carers also face real barriers to joining or rejoining the labour market, but many do want to work. Just under a third of carers who are not in work, would like to be.

## Carers Leeds

If you wish to discuss any of our findings in more detail or want to know more about our work, please email [comms@carersleeds.org.uk](mailto:comms@carersleeds.org.uk).

# Recommendations

These recommendations are based on the findings of this survey:

## City wide conversation about caring

We need a city-wide conversation about caring – involving citizens and Leeds institutions and organisations – to shine a spotlight on unpaid carers, what it means to provide unpaid care in Leeds and how we can work together to improve the lives of carers in our city.

## Improved carer mental health

Urgent action is needed to improve the mental health of unpaid carers in Leeds. Ensure that carers are a priority in mental health strategies, transformation projects and initiatives across the city, and that this leads to improvements to carer mental health and a reduction in carer health inequalities.

## Deliver better outcomes for carers, within health and care services

Ensure carers receive health and care services that are well communicated, compassionate and coordinated. Improve the number, quality and outcomes of Carers Assessments, and place carers at the centre of transformation projects, particularly neighbourhood health services.

## Ensure financial wellbeing for carers

As a city, we need to shine a light on the financial hardship experienced by unpaid carers alongside the people they support. Ensure that carers are a priority group for financial guidance (welfare benefits advice and wider support to reduce costs and maximise income) and tailored employment support. Work with Carers Leeds to increase the number of 'carer friendly' employers across our city.

# Impact Report

## 2024/2025



**Read on our  
website**



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unpaid carers in Leeds.  
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a difference.**

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donate**





## Carers Leeds

Mill 6, Ground Floor One  
Mabgate Mills,  
LS9 7DZ

## Need support?

Tel 0113 380 4300  
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