

The State of Unpaid Caring in Leeds

Annual Survey 2024/2025 findings



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:

- Advice 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 for more information and resources.

Email

advice@carersleeds.org.uk



Carers Advice Line
0113 380 4300

Introduction

At the end of 2024 and the beginning of 2025, we surveyed unpaid adult and parent carers in Leeds for the third year running. Our aim was to understand what carers were most concerned about, their experiences and what matters most to them.

This report, based on the findings of the survey, covers four areas: health and wellbeing; social life and relationships; access to support; work, money, and finances.

As well as highlighting what matters most to unpaid carers in Leeds this year, we'll also compare some findings with previous years' surveys. In doing so, we aim to show where things have changed for carers—and where they haven't.

At its core, our State of Caring report will unfortunately show that many challenges and concerns remain ongoing and unresolved. Our aim is to tell the real story of what it means to provide unpaid care in Leeds.

More than just amplifying the voices of unpaid carers, we hope the findings will drive real change—encouraging others to work with us to improve the lives of unpaid carers in our city.

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.

Contents

1	Introduction	8	Access to Support
2	Who responded to our Survey	9	Work
4	Health and Wellbeing	10	Money
6	Social Life and Relationships	12	Conclusion and Recommendations

Who responded to our survey

536 unpaid carers responded to our survey:

- Their ages ranged between 25 and 90 plus. Most carers were working age (61% were between 35-64 years old).
- 80% were women, 18% were men, 2% were transgender or non-binary.
- 86% were white British, 14% were from Black, Asian and other ethnically diverse groups.
- 81% were heterosexual, 2% lesbian, 1% gay man and 2% bisexual.
- 34% considered themselves to have a disability.

Unpaid carers were given the option to skip questions if they wanted to. So, in some cases, there were slightly fewer than 536 responses to a question.

In terms of caring responsibilities:

- 75% of respondents were caring for one person, 20% were caring for two people and 5% were caring for three 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 2-4 years (20%), 5-9 years (22%) or 10-14 years (17%).
- Hours a week of care ranged from 0-9 hours to 90 hours or more. 37% were providing 90 hours or more care – the highest proportion in any of our surveys so far. 12% were providing between 20-34 hours and 16% were providing between 35-49 hours.

The top 3 concerns for unpaid carers

These echo the top concerns from our previous annual carers surveys. These are perennial issues for carers and reflect what we know from national surveys over the years.

- 1** My own health & wellbeing needs (60%)
- 2** The changing needs of the person I care for (48%)
- 3** Money and the cost of living (30%)

The positive things about caring

Some carers struggled to find anything positive to say about caring, with many saying that they wished they 'could just be a daughter, parent or spouse'. For those who could find the positives, some common themes were:

- The act of caring itself, is a positive.
- Spending time and building a closer relationship with the person you care for.
- A sense of privilege and duty to care for those who cared for you or love you. To give back for care you received as a child or as part of the commitment you made to a spouse.
- Knowing that the person you love is well cared for.
- Ensuring that the person you care for can stay in their own home, rather than going into a care home.
- A sense of purpose, reward and a 'job' well done.
- Making you a 'better' person: kinder, more patient and empathetic because of caring.
- The positives of receiving additional help and support from family and friends; paid carers and other professionals; Carers Leeds and peer support from other carers.

“Knowing my children are cared for ‘properly’ and their needs are being met. Although incredibly demanding, I have peace of mind.”

Unpaid Carer

Health and Wellbeing

For the third consecutive year, unpaid carers in Leeds identified 'their own health and wellbeing' as their top concern, with even more carers than last year expressing worries about this. The results of this year's survey once again underline the significant impact that caring has on both physical and mental health.

On a scale of 0-10 (0 being no impact and 10 being a significant impact), 62% of carers reported that caring had a negative impact on their physical health (scoring 6 or more), with 37% reporting this as significant (scoring 8 or more). This is an increase on last year's survey findings.

As with previous years, the mental health of unpaid carers is faring even worse than their physical health. 76% of unpaid carers indicated that caring had a negative impact on their mental health (scoring 6 or more), with 47% of unpaid carers reporting a significant impact (scoring 8 or more), another increase on previous findings.

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). Results were generally comparable with last year, with carers in Leeds reporting much lower levels of life satisfaction, happiness and feeling the things they do in life are worthwhile.

Carers also reported much higher levels of anxiety than the general adult population in the city. The contrasts between levels of happiness and levels of anxiety are particularly stark.

“24 hour care every day is slowly eroding my health and mental capacity.”

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	23.2
Low levels of feeling the things you do in life are worthwhile	3.7	19.5
Low levels of happiness	9.1	37.5
High levels of anxiety	20.1	44.6

Some of the ways caring impacts on health and wellbeing are day-to-day things which accumulate over time.

Many carers reported one or more of these impacts. 63% of carers reported having disturbed, disrupted or poor sleep all or most of the time. 65% of carers reported feeling stressed, anxious or overwhelmed always or frequently.

Over half (55%) reported feeling guilty all or most of the time, and under half (46%) said they experienced low mood or depression always or frequently.

As with previous years, the survey findings illustrate that whilst caring can have an impact on your physical health, it is often the emotional toll of caring which is felt so deeply. It is not difficult to see how a cumulation of poor sleep, stress, anxiety and overwhelm can lead to poor mental health outcomes for unpaid carers.

Although 'my own health and wellbeing' was the number one concern for unpaid carers in Leeds for the third year running, 52% of carers reported that they didn't have time to prioritise their own physical and mental health.

Social life and relationships

Taking a break from caring – doing something you enjoy or with others you care about – can be challenging for unpaid carers.

53% of respondents to our survey said they were always or mostly missing out on time for themselves. This included spending time with friends and family, participating in hobbies or going on holiday. Only 27% of respondents felt connected to or part of their community and just 21% regularly participated in social activities.

When talking about some of the things they missed because of their caring role, respondents shared that it could be hard to be spontaneous, given the need to find alternative care arrangements. Others said it was equally hard to commit to future plans, given the risk of having to cancel due to a caring emergency.

Many carers said that they had very little to look forward to, when it came to a social life.

Some respondents said they missed being able to leave the house feeling carefree and being able to switch off when away from home. Some talked about the pressures of always being on call or feeling guilty about being out and that they had to rush back. Others longed for some time at home to relax by themselves.

When it comes to supporting carers to have a better social life and more time for themselves, carers had the following suggestions for things that would help:

- Better recognition from local services of my needs as a carer (51%).
- Support with paid care for the person I care for (36%).
- Accessible activities for myself, and the person I care for, to attend together (34%).

“My husband and I are both full time carers, so we never get to go out together as a couple. We have no family or friends for support; it’s just us and the children we care for.”

Unpaid Carer

“The parent/daughter role has reversed almost completely and the pressure of having a full-time job on top, is causing a lot of stress in the relationship.”

Unpaid Carer

On the subject of closer relationships, 49% of respondents said they had people close by they can call on and 41% said they had enough meaningful contact with family and friends.

This means that over half of respondents don't have enough support for their caring role or meaningful contact, which could help their own wellbeing. It is not surprising then that 38% of unpaid carers reported they were often or always feeling lonely.

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, 20% said their relationship had got worse, and 39% said their relationship hadn't changed. 26% said it had changed in other ways.

A common theme when reflecting on relationships was that respondents now felt more like a carer than a family member or friend. Or that they felt the parent/child relationship had been reversed.

Some spoke positively about relationships, which had always been good or had improved by having more time together to talk, building relationships and become closer.

Others said that they had never been close or had always had a difficult relationship with the person they now cared for.

Many more said that relationships were worse or different. Several carers described relationships which were claustrophobic or suffocating, particularly where someone was completely reliant on you. This meant few breaks from each other and very little meaningful contact with other people.

Respondents spoke about relationships which felt very 'one way' in terms of love and care and the challenges of not being able to share the load or decision-making, with the person you cared for.

Some carers felt that they had to keep their own emotions in, and as a result couldn't truly be themselves with the person they cared for.

Others described how frustration on both sides caused tension and arguments, or the strain of living with someone whose condition leads to anger, verbal abuse, or depression. Several carers reflected on how their relationship fluctuated—'the good days and bad days'—or how it had improved or worsened over time.

Access to support

This year, 'services not being able to meet my needs or the needs of the person I care for' was fourth place in the top concerns for carers right now, with just under 30% respondents stating this as a top concern.

Carers are all too aware of the pressures on public services, such as cuts to funding and increased waiting times.

When asked whether they felt that health and care services in Leeds delivered the 3Cs for carers: communication, compassion and co-ordination (a benchmark for services in our city) it was a mixed picture:

- Communication with carers – 41% of respondents said it was poor or very poor, 30% said it was acceptable and 29% said it was good or very good.
- Compassion for carers – 31% said it was poor or very poor, 40% said it was acceptable and 32% said good or very good.
- Co-ordination of care – 42% said it was poor or very poor, 37% said acceptable and 21% said it was good or very good.

Carers talked about being offered services that don't materialise, being told someone will call them back and not receiving the call. They spoke about the impact of high levels of staff turnover and the frustration of being passed from one service to another.

The common barriers to accessing support services for the person they cared for, cited by respondents, were:

- I don't know about the services available (39%)
- Getting appointments at a time that suits me (33%)
- Not having an allocated social worker (38%)

Several carers said the person they cared for was a barrier to accessing services, with examples such as refusing to accept help from paid care workers or engage with health and care professionals.

Other carers spoke about the additional barriers faced by people who were neurodivergent or who had sight or hearing loss.

This year, 54% of respondents felt confident using digital devices. Among the 46% who didn't, the main barrier was the person they care for being unwilling to use technology. To less extent, some carers also lacked confidence or awareness of available digital and technology services.

Work

41% of respondents to our survey were in some form of employment, while 38% were retired. Most of the remaining 21% were not working due to their caring responsibilities or their own health conditions.

Alongside the financial benefits, work can provide further meaning and purpose to life – 80% of respondents who were working carers said that work gave them a purpose outside of, or a break from, their caring role. 25% of carers who were not in work, would like to be.

When talking about their experiences of balancing unpaid care and paid work, over half of respondents (56%) said their employer was understanding about their caring role and 65% said they felt comfortable talking about their caring role at work. These are slight increases on last year but indicate that we still have some way to go to ensure that all workplaces in Leeds are 'carer friendly'.

70% of carers reported that they had given up opportunities at work because of caring.

Balancing work and care can take an emotional toll on working carers. 78% of carers said they often felt anxious about caring while at work, with 77% saying they often felt tired at work because of caring.

These factors make it even more important to have workplaces which can support working carers and to have social care services which can provide additional care to help enable carers to work.

Work and unpaid care

When asked what would help them juggle work and care, the top three suggestions from carers were:

- An understanding line manager/employer (45%)
- Ability to take time off - unpaid or paid Carers Leave (45%)
- My employer being more flexible (36%)

Money

We know that unpaid carers are more likely to experience poverty than someone who doesn't provide unpaid care.

Many of the respondents to our survey were in receipt of welfare benefits. 25% received Carers Allowance, 16% received Universal Credit, 15% received Attendance Allowance (themselves) and 13% received a Personal Independence Payment (themselves). 41% of respondents to our survey were not in receipt of any welfare benefits.

When talking about their financial situation, 41% of carers were worried about monthly living costs and whether they could manage in the future. 15% said they were struggling to make ends meet.

In terms of ways of coping with financial struggles, the most common strategies were:

- Cutting back on hobbies and leisure activities (29%).
- Using my own savings (24%).
- Cutting back on seeing family and friends (18%).
- Cutting back on essentials like food and heating (15%).
- Using bank overdraft, loan or credit card (14%).

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:

- Had cut down on the size of meals or skipped meals (17%)
- Being unable to keep my home warm (16%)
- Not had essential dental treatment done (14%)
- Unable to repair or replace broken major electrical appliances (17%)

“I earnt 15p more than the allowed amount and had to repay six weeks of carers allowance. This was extremely stressful and degrading.”

Unpaid Carer

Carers Allowance Overpayments

Carer's Allowance overpayments occur when carers exceed the earnings limit for the benefit.

There is currently an independent review into Carers Allowance overpayments, to understand how these have occurred and how to prevent some of the problems (such as delays in communication, leading to large repayments for carers) happening in the future.

Of the respondents to our survey who were in receipt of Carers Allowance, 8% reported that they have had issues with overpayments. Just over half of these said that this has had no or limited impact on them.

For the remainder, the most common impacts were mental health distress and that the experience had stopped them claiming Carers Allowance. A smaller number said that the overpayment had caused them to go into debt. One carer said they had left work as a result.

Conclusion

Through this report, we want to tell the real story of what it means to provide unpaid care in Leeds. Too many unpaid carers in our city feel invisible and undervalued. Too many are at breaking point, caring at a cost to their own health and wellbeing, social connections and financial security.

Sadly, many of the findings from this year's survey echo what we have heard in previous years. There are also important differences: carers health and wellbeing fares even worse than last year, with mental health and wellbeing being particularly impacted.

Carers feel less supported by those around them than in previous years – both in their caring role and through meaningful relationships, which we know are so important for wellbeing.

Carers are all too aware of the pressures on health and care services and what it means for them and the people they care for. This year 'services not being able to meet my needs or the needs of the person I care for' narrowly missed being in the top three concerns for carers right now.

Yet again, the findings of our annual carers survey highlight long-standing, difficult to change, issues for unpaid carers. These are the things that we must continue to pay most attention to and work together as a city to address.

At Carers Leeds we want to make unpaid caring everybody's business. Not least because if you have people in your life who you love, or who love you, you are likely to provide unpaid care at some point.

Unpaid carers make a vital contribution to our city and without them our local health and care system would collapse. We must take urgent action, together, to improve the lives of unpaid carers in Leeds.

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.

Recommendations

These recommendations are based on the findings of this survey:

Improved carer health and wellbeing

Urgent action is needed to improve the health and wellbeing of unpaid carers in Leeds. Ensure that carers are a priority in city-wide health and care transformation projects and that this leads to improvements to carer health and a reduction in carer health inequalities.

Creating communities that care

Providing unpaid care is not a job for one person. Make the creation of 'communities that care' – ways in which people in local communities can develop networks of support, to help each other to care – a priority within neighbourhood approaches to health and care. Learn from similar initiatives across the UK.

Ensure financial security for carers

Focus on carers, as well as people with disabilities or long-term health conditions, in the forthcoming changes to welfare benefits and employment support. Ensure that carers are a priority group for benefits information and advice and tailor employment support. Work with Carers Leeds to increase the number of 'carer friendly' employers across our city.

Deliver the 3Cs for carers

Communication, compassion and co-ordination

Ensure that this benchmark for good health and care services – the 3Cs – is delivered for carers. Carers deserve good communication, care delivered with compassion and effective co-ordination of services, as much as the people they care for.



Carers Leeds

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

Need advice and support?

Call	0113 380 4300
Email	advice@carersleeds.org.uk
Website	carersleeds.org.uk

Socials

Bluesky	@CarersLeeds
Facebook	Carers Leeds

Scan to
subscribe to
our newsletter



Carers Advice Line
0113 380 4300