

# The State of Unpaid Caring in Leeds

## Annual Survey 2023 findings

# **About**

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# **Carers Leeds**

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**3 in 5 of us will provide unpaid care at some point in our lives.**

**Carers Leeds believes all care counts.**

## **What is an unpaid carer?**

**An unpaid carer is someone who provides help and support to a family member, friend or neighbour who couldn't manage without their help. This could be due to illness, disability, mental health problems or substance misuse.**

**Established in 1996, Carers Leeds is a charity that provides information, advice and support to unpaid adult and parent carers across our city.**

**This includes our Advice Line, carers support groups, one to one support and support in hospitals. Some of our services are universal – open to all carers – and some are targeted at specific groups of carers. Our services are provided to communities throughout Leeds.**

**We work in partnership with others to deliver our services and to influence them to act to benefit unpaid carers. This involves those working in health, social care and employers.**

# Introduction

At the end of 2023, we surveyed unpaid adult and parent carers in Leeds for the second 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; and money, work and the cost of living.

Alongside telling the story of what is important to unpaid carers in Leeds this year, we will draw some comparisons with last year's survey results.

In some cases, this will illustrate what has changed for unpaid carers.

In the main, sadly, it will highlight which issues and concerns remain persistent. We want to tell the real story of what it means to provide unpaid care in our city.

This report is not simply about giving greater voice to the experiences of unpaid carers.

We want to use the findings to influence others to work with us to help improve the lives of those providing unpaid care in 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).*

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# Who responded to our Survey

679 unpaid carers responded to our survey.\* This included carers of different ages, gender, ethnicity, sexual orientation, and carers with disabilities.

Our 2023 survey had significantly more male respondents, carers from ethnic minority communities and LGBTQ+ carers, than our 2022 survey. Of course, there is more work to do to ensure that in future years this survey truly reflects the diverse carer population in Leeds.

Most respondents cared for one person (63%), 26% cared for two people and 11% cared for 3 or more people. We asked respondents to complete the survey based on the person they did the most caring for. For 32% of respondents this was a partner or spouse, 30% cared for a parent, 26% for their child and 5% for a sibling.

The conditions or disabilities of the person cared for were incredibly diverse. The most common responses were physical disability (36%) and a mental health condition (32%).

Unpaid carers also varied in the length of time they had been caring, hours of caring per week and where the person they cared for lived.

## Caring responsibilities and the cared for person

- The length of time care had been provided ranged from less than one year to 15 years or more – most frequent responses were between 2-4 years (26%) and between 5-9 years (24%).
- Hours of caring per week ranged from less than 10 hours to 90 hours or more, with 29% providing 90 hours or more unpaid care per week.
- 62% of unpaid carers lived in the same house as the person they cared for and 22% of the people cared for lived in their own home. The remaining cared for were in supported accommodation, a care home, hospital or other.



*\*Unpaid carers were given the option to skip questions if they wanted to. So, in some cases, there were slightly fewer than 679 responses to a question.*



# Who responded to our Survey

## Key stats

### Age

The age range of our respondents was between 16 and 90.

This year most respondents were working age (aged between 25-64) and the largest age group was 55-64 (which is the most common age nationally to have caring responsibilities).



### Ethnicity

74% White British

19% from Black, Asian and other ethnic minority groups



### Sexual Orientation

81% heterosexual

6% lesbian

4% gay man

2% bisexual

### Gender Identity

68% female, (which reflects national carer data)

23% male

5% transgender, non-binary or wanted to self-identify



### Disability

34% consider themselves to have a disability



## THE TOP 3 CONCERNS FOR CARERS

These echo the top concerns from last year's survey. These are perennial issues for carers and reflect what we know from national surveys over the years.

- 1 My own health & wellbeing needs (51%)
- 2 The changing needs of the person I care for (37%)
- 3 Money and the cost of living (34%)

# Health and Wellbeing

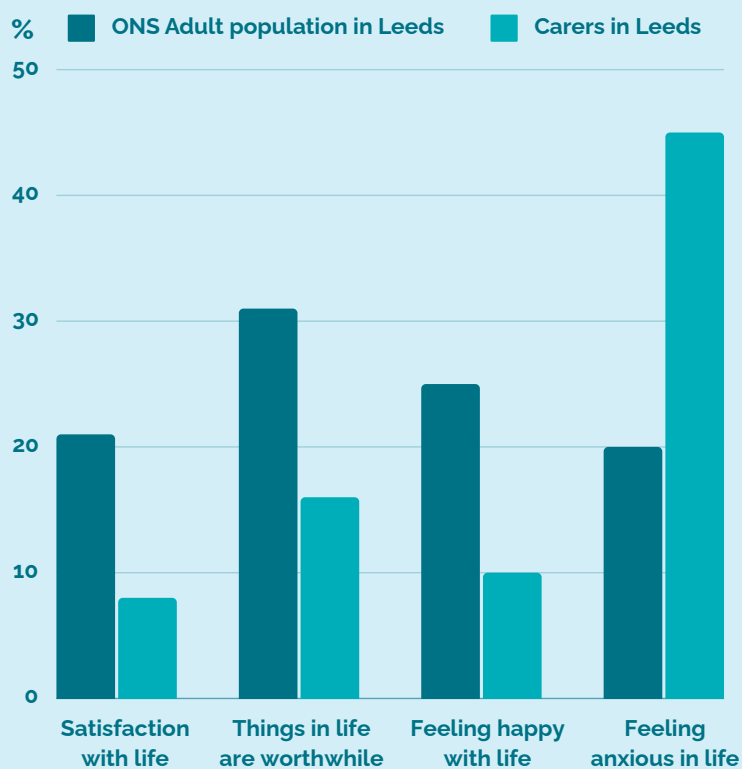
For many unpaid carers in Leeds, caring is having a negative impact on their health and wellbeing. It was the number one concern for unpaid carers in our survey for the second year running.

On a scale of 0-10 (0 being no impact and 10 being a significant impact) 56% of carers reported that caring had a negative impact on their physical health (scoring 6 or more), with 33% reporting this as significant (scoring 8 or more).

Carers' mental health is fairing even worse than their physical health. 70% of unpaid carers indicated that caring had a negative impact on their mental health (scoring 6 or more), with 45% of unpaid carers reporting a significant impact (scoring 8 or more).

We used ONS measures of wellbeing in our survey, so we could compare the wellbeing of unpaid carers, with the most recent data on the adult population of Leeds (ONS 2022-23).

The results were generally comparable with last year. Although, levels of anxiety were higher amongst the carers who responded to this year's survey (45.8% of carers reporting feeling very anxious, compared to 20.1% of the Leeds adult population):



## HEALTH AND WELLBEING

For many unpaid carers in Leeds, caring is having a negative impact on their health and wellbeing.



**70%**

of unpaid carers indicated that caring had a negative impact on their mental health



**56%**

of unpaid carers reported that caring had a negative impact on their physical health



**52%**

of unpaid carers reported always or frequently feeling stressed, overwhelmed or anxious.

Over half of carers reported having disturbed, disrupted, or poor sleep always or frequently.

A similar number also reported always or frequently feeling stressed, anxious, or overwhelmed. Just under half reported feelings of guilt about their caring role as well as low mood or depression.

We know the impact of these things is cumulative, with many carers reporting one or more of these impacts.

Whilst the impact on physical health can't be underestimated, the survey findings on overall carer health and wellbeing, alongside the day-to-day experiences of things like poor sleep, anxiety and guilt, highlight the considerable toll on carers mental health. This illustrates that unpaid care is not simply a set of tasks to do, it is emotional labour.

Furthermore, although my own health and wellbeing was, by far, the number one concern for unpaid carers, 43% of carers said they rarely or never feel supported to look after their own health and wellbeing.

## The positive things about being an unpaid carer



Just under 20% of respondents struggled to identify anything positive about being an unpaid carer, and this was more likely amongst those who had been caring for a long time and had little or no support.

Others described an ebb and flow of positives and negatives and how their feelings could change over time (at times, over the course of a day). 41% of respondents reported that they rarely or never felt that what they do as a carer is recognised, understood and valued.

Amongst those who did reflect on the positives, the most common themes were:

- *The act of care, being a good thing, in its own right*
- *Bringing you closer to the person you care for, being able to spend quality time together*
- *Giving back for care received or fulfilling a family duty*
- *The belief that someone will be properly cared for by someone who cares about them*
- *Improving someone else's day to day quality of life*
- *Learning empathy, compassion, and patience*



# Social Life and Relationships

Unpaid carers can find it difficult to take a break from caring. 38% of respondents to our survey said they were always or mostly missing out on this.

Others reported missing out on things that mattered to them. 39% were always or mostly forgoing opportunities to participate in hobbies or doing things they enjoy. Only 27% regularly participated in social activities.

There is good evidence about the relationship between social connections and good health and wellbeing. 36% of unpaid carers felt connected to, or part of their community which means many respondents to our survey do not have those community connections.

When it comes to those closer relationships with family, friends and neighbours, 48% say they have people close by who they can call on and 47% say they have enough meaningful contact with family and friends.

This is slightly down on last year and still means that just over 50% of unpaid carers report they don't have this level of support and contact which could help with both their wellbeing and their caring role.

Based on these findings, it is not surprising that 32% of unpaid carers reported feeling lonely often or always.

**“I feel that I am now less of a partner, more of a detached carer.”**

Unpaid Carer

Providing and receiving unpaid care, can impact on the relationship between the unpaid carer and the person with care needs.

When asked whether their relationship with the cared for person had changed since they started caring, 22% reported that their relationship had got worse, 25% reported that their relationship had got better and 34% stated that their relationship had not changed. A further 18% reported that their relationship had changed in other ways.

Some carers described distressing situations involving verbal abuse and violence, others talked about the impact of mood swings and arguments.

Some carers mourned how their relationship used to be. This took different forms: those caring for a parent talked about a role reversal; those caring for a spouse or a partner talked about the lack of intimacy or conversation.

Some reflected that their relationship felt one way (they gave and did not receive) whereas others talked about reciprocal relationships, where they helped each other in different ways. One carer described their relationship as 'better and worse, in different ways' which reflected the response from many other carers.



## Suggestions from Carers

Unpaid carers suggested a few things that would help them have time for themselves, an opportunity to do things they enjoy and better social connections.

The most common responses were:

**41%**

Better recognition from local services of my needs as a carer.

**39%**

Support from my family and friends.

**36%**

Support with paid care for the person I care for.

**36%**

Accessible activities for myself and the person I care for, to attend together.

**32%**

Support with paying for my social or leisure activities

# Access to Support

We conducted this year's survey at a time of huge challenges for public and voluntary sector services. Demand for these services continues to rise, whilst funding for these services is more and more squeezed.

On the issue of access to support, our survey presents a mixed picture. Just over a third of carers remain happy with the quality of the information and advice they receive and feel listened to and included by the team planning care for the person they care for.

36% of unpaid carers reported that they always or mostly had good quality information and advice which was relevant to them. 40% said they had this sometimes, 24% reported they had this rarely or never.

37% report that they are always or mostly listened to and feel part of the team planning care for the person they care for. 30% of respondents feel this sometimes and 25% feel this rarely or never.

In terms of levels of satisfaction with the support the person they care for receives, this was down by 5% on last year's survey findings. 38% were always or mostly satisfied, 30% were sometimes satisfied and 27% rarely or never satisfied.

This is a worrying finding given that, for the second year running, the changing needs of the person I care for, is one of carers top three concerns.

We understand the importance of having the right support, at the right time both for carers themselves and for the people they care for. This can support carers to continue to care and have a positive impact on carer health and wellbeing.

41% of unpaid carers in our survey had a digital device and felt confident using technology, which is a around 10% lower than last year. This means that 59% of unpaid carers report barriers to using technology or digital devices.

The most common barriers were the person I care for doesn't want to use technology or digital services; I don't feel confident using technology or digital services or I don't know what services are available online. This is at a time when digital services or digital ways of accessing services (such as online booking systems, email or text communication) are on the increase.





## MOST COMMON BARRIERS

The most common barriers to accessing support services cited in the survey were:



33%

Don't know about the services that are available



30%

Getting appointments at a time that suits me or the person I care for



30%

I am unable to find care and support services in my area that meet our needs



30%

The cost is too high

COVID-19

21%

Are worried about the person they care for catching COVID-19

“It makes me realise that the care sector is grossly undervalued.”

Unpaid Carer

# Money and the cost of living

We know that for too many people in our city, worries about money and the cost of living still loom large. Unpaid carers are no exception. As with last year's survey, it is in the top three concerns for unpaid carers in Leeds right now.

Of the unpaid carers who responded to our survey, 32% were in receipt of Carers Allowance, 19% received Attendance Allowance, 14% received Universal Credit and 13% received Housing Benefit.

19% of unpaid carers were struggling to make ends meet and 37% were worried about monthly living costs and whether they can manage in the future. Just over a quarter were struggling to afford the cost of food or utility bills (26%). 14% were, or had been, in debt because of caring.

Over the past 12 months, too many unpaid carers have gone without one or more essentials. An indication that these unpaid carers may be living in poverty.

## 21%



of unpaid carers have been unable to keep their home warm.

## 20%



of unpaid carers have cut down on the size of meals or skipped meals

## 20%



of unpaid carers have have not had essential dental treatment done

## 13%



of unpaid carers have visited a food bank.

## 14%

of unpaid carers have been unable to repair or replace broken major electrical goods including necessary equipment and white goods.



These findings reflect what carers told us last year and, in some areas, things have got worse. Compared with last year's survey results, twice as many respondents have visited a food bank and an increased number of carers report not having essential dental treatment.

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

Our survey findings highlight how difficult it can be for carers to break free from the constraints of poverty, given their circumstances

Poverty can restrict carers options, leaving them in impossible situations like choosing to heat their homes or put enough food on the table. These constraints also impact on the coping strategies available to them.

## CARER FINANCES

The most common ways unpaid carers were coping with financial struggles:



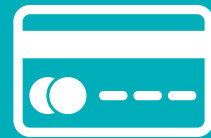
**28%**

of unpaid carers have cut back on hobbies and leisure activities



**27%**

of unpaid carers have used their savings



**18%**

of unpaid carers have used their bank overdraft, loan or credit card



**18%**

of unpaid carers have cut back on essentials like food and heating



**17%**

of unpaid carers have borrowed money from family and friends



# Work

More working age carers responded to our survey this year, than last year. Of those unpaid carers not currently in work, education or volunteering, 41% would like to be in work (40% would like to be studying, 38% would like to be volunteering). This is a significant increase on last year's figures.

57% of the carers surveyed were in work (full time, part-time or self-employed), with 63% of those saying work gave them a sense of purpose or a break from their caring role.

Over half of carers (54%) said their employer was understanding about their caring role. 51% said they were comfortable talking about their caring role at work.

These are higher percentages than last year but indicate that we still have some way to go when it comes to 'carer friendly' workplaces in Leeds.

But there are practical actions employers in Leeds can take right now. The most common recommendation provided by unpaid carers was offering Carers Leave (paid or unpaid), closely followed by an understanding line manager or employer.

Over a third of respondents suggested that all employers should offer a Working Carers Passport (a document to record additional support needed for employees who have unpaid caring responsibilities).

This kind of document is a practical way of demonstrating understanding and encouraging conversations about caring at work. It can also support reasonable adjustments such as flexible working.

## UNPAID CARERS AT WORK

We know that balancing unpaid care and work can be hard. Working carers reported significant challenges in this year's survey.



**54%**

of unpaid carers reported that they felt anxious about caring whilst at work.



**58%**

said they felt tired at work because of their caring role.



**55%**

said they had given up opportunities at work because of caring.



**“Carers need more financial support, if they’ve had to give up work. The financial strain is huge and adds to the stress.”**

Working age carer.

# Conclusion

This report tells the true story of what it means to provide unpaid care in Leeds. Not 'unsung heroes' just people, living in our city, who have found themselves in this position. Too many unpaid carers are feeling invisible and undervalued and living in circumstances which are leaving them at breaking point.

The findings of this year's survey bring to the fore stubborn issues which are difficult to change, and the things we must pay most attention to, if we are really to make a difference to the lives of unpaid carers. These include carers' own health and wellbeing and financial security.

The survey highlights the importance of work, not just financially but for the wellbeing and social benefits it can bring to unpaid carers, if they are properly supported in the workplace. The findings remind us that many carers who are not in work, would like to be.

Whilst many of the findings echo what we heard last year, there are some important differences: carers report feeling more anxious this year and lower levels of support from the people around them. They are also less satisfied with health and social care services in Leeds. This is, in part, due to increased challenges with accessing these services.

This year's survey findings highlighted a reduction in the proportion of carers feeling digitally confident, at a time when digital support and digital access to services is on the increase.

These insights and carer experiences are of course, set in the context of a continued cost of living crisis, a squeeze on public sector finances and increasing pressure on health and care services.

Now, more than ever, we need to pay attention to what unpaid carers are telling us and act to ensure all carers in Leeds are recognised, valued and supported to live a fulfilling life.

## 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:

## Public sector funding cuts

Include unpaid carers in equality impact assessments used to inform decisions to fund or cut health and care services, so that the risk of dis-investment - increased costs and demand for services (from the carer *and* the person with cared need) - is fully understood.

## Health and wellbeing

Unpaid carers are now a priority within the Leeds Health and Wellbeing Strategy. Ensure that this results in action to address carer health inequalities, with a focus on transformation and strategic Health and Care projects in Leeds (e.g. Healthy Leeds Plan priority projects and Home First).

## Money and the cost of living

Leeds initiatives targeted at the cost of living or poverty reduction should include unpaid carers. Local organisations to join with Carers Leeds to support a national campaign to reform the benefits system to better support carers. This should include raising the level of Carer's Allowance, increasing its earnings limit, and introducing a taper.

## Work and Unpaid Care

Design and deliver a tailored Leeds based employment support programme to help unpaid carers who want to work, return to work. Work with Carers Leeds to increase the number of 'carer friendly' employers across our city'. Ensure that work and unpaid care is visible in other local employer initiatives, such as the Fair Work Charter.



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# Impact Report 2022/2023

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# Carers Leeds

Working together to support carers

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