

A photograph of three elderly people sitting together and smiling. On the left is a man with a long white beard and a white turban. In the center is a woman with long, wavy brown hair wearing a yellow top. On the right is an older woman with white hair wearing a light green turtleneck. They are in a room with white bookshelves filled with books in the background.

The State of Unpaid Caring in Leeds

Annual Survey 2022 findings

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About Carers Leeds

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 service and to influence them to act to benefit unpaid carers. This involves those working in health and social care and employers.

Introduction

At the end of 2022, we surveyed unpaid adult and parent carers in Leeds.

Our aim was to understand what unpaid carers were most concerned about; their experiences as unpaid carers 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.

Our plan is to use the findings from

this survey to improve the services provided by Carers Leeds and to influence decision makers in our city to do more to improve the lives of unpaid carers.

When asked to what extent they feel that what they do as an unpaid carer is recognised, understood, and valued, 44% of respondents said rarely or never, 25% said sometimes.

As a minimum, we hope this report and the findings of the survey, go some way to ensuring that unpaid carers in our city feel more recognised, understood, and valued.

The top 3 concerns for unpaid carers in Leeds

- 1** My own health & wellbeing needs (57%)
- 2** The changing needs of the person I care for (44%)
- 3** Money and the cost of living (38%)

Who responded to our survey

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

Most respondents cared for a parent (33%), a partner or spouse (33%) or their child (26%).

The conditions or disabilities of the person cared for were incredibly diverse including physical disabilities, mental health conditions, learning disabilities, multiple long - term conditions and dementia.

Demographics of our respondents

- *The age of respondents ranged from 18 to 89, most were in mid and later life (aged between 35-74) and the largest age group was 55-64*
- *Respondents were predominantly female (78% female to 21% male), with 1% of respondents who were transgender, non-binary, or preferred not to say*
- *84% were White British, with 15% from Black, Asian and other ethnic minority groups*
- *87% were heterosexual, 5% lesbian, 0.2% gay man and 3% bisexual*
- *33% of respondents considered themselves to have a disability*

Caring Responsibilities

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.

- *The length of time care had been provided ranged from less than one year to 15 years or more. The most frequent responses were 15 years or more (29%) and between 5-9 years (26%)*
- *Hours of caring per week ranged from less than 10 hours to 90 hours or more, with 37% of respondents providing 90 hours or more unpaid care per week*
- *62% of unpaid carers lived in the same house as the person they cared for, 27% of the people cared for lived in their own home, the rest were in supported accommodation, a care home, hospital or other.*

"I have spent my life caring for others. Now I am 66 and I don't find any positives in this role, in my retirement years. And unpaid, as I don't get Carers Allowance since receiving my state pension, which makes me feel angry and undervalued by society."

Unpaid Carer

*Unpaid carers were given the option to skip questions if they wanted to. So, in some cases, there were slightly fewer than 523 responses to a question.



Health & 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.

Unpaid carers reported having little time to prioritise their own health and wellbeing, 45% say they always or mostly miss out on this. When asked if they felt supported to look after their own health and wellbeing, 47% said rarely or never.

Caring is having an adverse effect on the physical health of unpaid carers in Leeds.

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 34% reporting this as significant (scoring 8 or more).

The picture is even more stark when it comes to mental health. 73% of unpaid carers indicated that caring had a negative impact on their mental health (scoring 6 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 2021-22).

We found that the wellbeing of unpaid carers was considerably worse than that of the general adult population of Leeds:

- *6.6% of unpaid carers reported very high levels of life satisfaction, for the Leeds adult population it is 25.3%.*
- *15.5% of unpaid carers reported feeling strongly that the things they do in life are worthwhile, whereas 30.9% of adults in Leeds report this.*
- *The percentage of unpaid carers reporting they felt very happy was 11%. It is 27.8% for Leeds adult population.*
- *11.2% of unpaid carers reported very low levels of anxiety, for adults in Leeds it is 30.9%.*

Day to day impact of caring

The day-to-day impact of caring on physical and mental health can be huge.

with feelings of guilt and resentment, can take both a physical and emotional toll on unpaid carers.

It is not difficult to imagine how poor sleep, low mood and stress, coupled



- 60% of unpaid carers reported having disturbed, disrupted or poor sleep always or frequently.



- 62% of unpaid carers reported always or frequently feeling stressed, overwhelmed or anxious.



- 52% of carers reported feelings of guilt always or frequently.

"I have looked after my partner for 13 years through his mental health and without any availability of help in his diagnosis, with too many closed doors. My own health has deteriorated."

Unpaid Carer

Social Life & Relationships



Missing out

We know that unpaid carers can miss out on doing things that matter to them, such as social activities.

Many carers find it difficult to take a proper break from care and for some, caring can have a negative impact on their relationship with the person they care for or with family and friends.

Through the survey, unpaid carers told us they were particularly missing out on:

- *Time for myself and taking a break (44% were always or mostly missing out on this)*
- *Participating in hobbies or spending time doing things I enjoy (39% were always or mostly missing out on this)*

Only 26% of unpaid carers felt connected to, or part of their community.

Only 21% regularly participated in social activities. The picture was more positive when it came to having people close by who you can call on (52%) and having enough meaningful contact with family and friends (47%).

However, this still leaves around 50% of unpaid carers reporting that they didn't have this level of support and contact. Based on these findings, it is not surprising that 31% of unpaid carers reported feeling lonely often or always.

When asked whether their relationship with the cared for person had changed since they started caring, 21% reported that their relationship had got worse, 20% reported that their relationship had got better and 35% stated that their relationship had not changed.

A further 23% reported that their relationship had changed in other ways. For those caring for a parent, a common feeling was that the parent/child roles had been reversed and they were acting more like a parent now.

Amongst those caring for a spouse or partner, a significant number of unpaid carers reported a negative impact on their sexual relationship and communication as a couple, with unpaid carers stating they felt more like a carer than a spouse or partner.

Suggestions from carers



Unpaid carers suggested a few things that would help them have a better social life or time for themselves. The most common responses were:

- *Better recognition from local services of my needs as a carer (50%)*
- *Support with paid care for the person I care for (35%)*
- *Accessible activities for myself and the person I care for, to attend together (35%)*
- *Support from my family and friends (34%)*

"Caring is still a lonely task, and no matter how many people are around you can still feel very sad at times, lost."

Unpaid Carer

Access to support



Barriers to services

Having the right information, advice and support for themselves and the person they care for, has a huge impact on the quality of life of unpaid carers.

We know that without this, unpaid carers' own health and wellbeing, social life and relationships can suffer.

35% of unpaid carers reported that they always or mostly had good quality information and advice which was relevant to them. 42% said they had this sometimes, 23% reported they had this rarely or never.

In terms of levels of satisfaction with the support the person they care for receives, 43% were always or mostly satisfied, 28% were sometimes satisfied and 29% rarely or never satisfied.

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

- *I don't know about the services that are available (41%)*

- *Getting appointments at a time that suits me or the person I care for (34%)*
- *I am unable to find care and support services in my area that meet our needs (27%)*
- *The cost is too high (24%)*

The second most common thing that unpaid carers were concerned about is the changing needs of the person they care for. Therefore, overcoming these barriers to accessing support services is vitally important.

"I referred myself for counselling and I am on a waiting list, which is currently 8 months. I hope I will be seen in the next month or two. It is difficult to meet all my caring responsibilities when I am struggling with my own mental health."

Unpaid Carer

Digital Barriers

52% of unpaid carers in our survey had a digital device and felt confident using technology.

This still means that 48% of unpaid carers either don't have access to a device, don't feel confident using technology or both.

Unpaid carers cited a range of barriers to being online which included affordability, poor internet access, the cared for person not wanting to use technology and carers not feeling that digital services would meet their needs or the person they care for.

The positive things about being an unpaid carer



A small, but significant, number of unpaid carers 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.

Lack of support, the toll on their mental and physical health and lack of recognition, all influenced the way they were feeling. But many unpaid carers did reflect on the positives. The most common of these were:

- *Spending quality time with the person you care for*
- *Experiencing your relationship with the cared for person, grow and develop*
- *Giving back for the care you received as a child*
- *Making a positive difference to someone else's life*
- *Giving meaning and purpose to your life*
- *Developing knowledge, skills and personal qualities*
- *Support from others including professionals and other unpaid carers*

Money, work and the cost of living



Rising costs and worries

Unpaid carers in Leeds are worried about money and the cost of living. It was the third most common concern for unpaid carers.

Of the unpaid carers who responded to our survey, 25% were in receipt of Carers Allowance, 12% received Attendance Allowance and 8% Universal Credit. 54% were not in receipt of any benefits. Just over half of the carers surveyed were in work (full time, part-time or self-employment) and 22% were full time unpaid carers.

Whilst a third of carers felt able to manage their monthly living costs, many were not so lucky. 20% were struggling to make ends meet and 52% were worried about monthly living costs and whether they can manage in the future. A quarter were struggling to afford the cost of food or utility bills (24%). 14% were, or had been, in debt because of caring.

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

Over the past 12 months, a significant proportion of unpaid carers who responded to our survey have gone without one or more essentials. This is an indication that these unpaid carers may be living in poverty.

- 24% have been unable to keep their home warm
- 21% have cut down on the size of meals or skipped meals
- 18% have not had essential dental treatment done
- 14% have been unable to repair or replace broken major electrical goods

"Because of my daughter's needs, I can't have my house cold. I'd rather not eat and have a warm house for her"

Unpaid Carer

Balancing work and care

Of those unpaid carers not currently in work, education or volunteering, 29% would like to be in work (33% would like to be studying, 31% would like to be volunteering).

Being able to stay in or return to work, is one potential route to better financial security for unpaid carers. 47% of unpaid carers reported that work gave them a purpose or break from, their caring role.

We know that balancing unpaid care and work can be incredibly challenging. For example, 41% of unpaid carers reported that they felt anxious about caring whilst at work, 45% said they felt tired at work because of their caring role. Many unpaid carers (45%) said they had given up opportunities at work because of caring.

Alongside the challenges, unpaid carers did provide examples of things that help to balance unpaid care and paid work, based on their current and previous experience of employment.

The most helpful things were:

- *Ability to take time off, unpaid or paid Carers Leave (54%)*
- *An understanding line manager and/ or employer (47%)*
- *My employer being more flexible e.g. working from home (40%)*
- *Working Carers Passport (a document to record additional support needed for employees who have unpaid caring responsibilities) (38%)*
- *Affordable and accessible paid care for the person I care for (31%)*

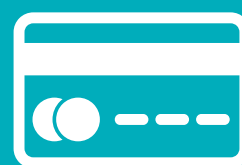
The impact of the cost of living



- 33% of carers told us they are cutting back on hobbies and leisure activities



- 23% of carers are cutting back on essentials like food and heating



- 17% of carers are using their bank overdraft, loans and credit cards to get by day to day

Conclusion

Our survey findings tell a story of unpaid carers who are deeply concerned about their own health and wellbeing.

Many are missing out on doing things for themselves, such as social activities or taking a break, because of their caring role. Too many unpaid carers in our city often or always feel lonely. A shocking number of carers who responded to the survey reported feeling exhausted, depressed, and overwhelmed all or most of the time.

This is compounded by serious worries about money and the cost of living. Too many unpaid carers in Leeds are struggling to make ends meet and are cutting back on essentials such as food and heating.

"As a carer I think we just carry on without support. It's our loved one and I suppose it's a choice we take."

Unpaid Carer

They are worried about the future. Our findings suggest that some may not be accessing the welfare benefits they may be entitled to and many who aren't in work, would like to be.

Whilst there are positives associated with unpaid care, a significant number of respondents to our survey struggled to see any positives. The daily struggles and pressures, combined with worries about the future, dominating their caring experience.

We can and we must do more in Leeds to support unpaid carers. If someone in our city is providing unpaid care for family, friends or neighbours, they must never do so at a cost to their own health and wellbeing, finances, or relationships.

We must ensure that unpaid carers in Leeds have the information, advice and support they need to undertake their caring role and are able to live fulfilling lives.

Recommendations

These recommendations are based on what unpaid adult and parent carers have told us through this survey:

HEALTH INEQUALITIES

Ensure that any policies, partnerships, and initiatives focused on population health or reducing health inequalities in Leeds, recognise that unpaid caring can have a negative impact on health and wellbeing.

SOCIAL CARE

Better quality and availability of social care, which can adapt to people's changing needs. Stronger recognition that good social care also has health and wellbeing benefits for unpaid carers, including supporting them to take a break or stay in work.

CAMPAIGN

Develop a campaign to reach more, and more diverse carers sooner with the right information, advice and support. Led by Carers Leeds and involving stakeholders from across health and social care, it should recognise that we all have a role to play in identifying and supporting unpaid carers.

INCLUSIVE SOCIAL ACTIVITIES

Greater availability of inclusive activities that an unpaid carer and cared for person can do together. Breaks are important for unpaid carers but we shouldn't assume that social or wellbeing activities should be focused on spending time apart.

MONEY AND WORK

Ensure that initiatives targeted at the cost of living or poverty reduction, include unpaid carers. We need tailored employment support services to help unpaid carers return to work and information, advice and support for employers to help keep unpaid carers in work.



Carers Leeds

Working together to support carers

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