



# I care

## Carers Week report on unpaid carer identification



June 2023

[carersweek.org](https://carersweek.org)

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In 2023, Carers Week is made possible through Carers UK working together with six other major charities: Age UK, Carers Trust, Motor Neurone Disease Association, Oxfam GB, Rethink Mental Illness and The Lewy Body Society.

# Executive Summary

Carers Week charities commissioned YouGov to carry out polling of the general public, including adults who are currently providing unpaid care. The polling, which was carried out with over 4,000 people, found that:

- 1 in 5 people (20%) are currently giving unpaid support or care to someone. Based on this polling, we estimate that there are now 10.6 million unpaid carers in the UK.
- 30% of people are not currently providing unpaid support or care but have done so in the past. This means that 50% of the public have provided unpaid support or care at some point in their life.
- Nearly three quarters of people (73%) who are providing, or have provided, unpaid care said they do not identify as, or call themselves, a carer. This suggests that a significant number of people providing unpaid care may not be receiving information, advice or support to help them with their caring role. Based on this polling, we estimate that 19 million people in the UK have provided unpaid care or support but not identified themselves as a carer.



**1 in 5**

people (20%) are currently giving unpaid support or care to someone

**73%**

of people who are providing or have provided unpaid care do not identify themselves as a carer



**50%**

of the public have provided unpaid support or care at some point in their lives

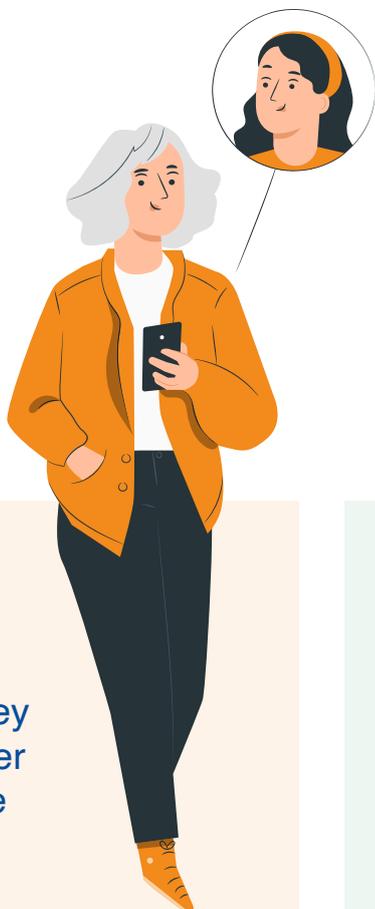


- 29% of people who did identify or call themselves a carer took up to 1 year to do so, with another 29% taking over a year. This suggests it may take people some time to understand what support they may be entitled to.
- The most common way in which people realised they were a carer was through the help of a family member or friend (29%). 22% said that a healthcare professional identified them as a carer. 11% said that a carer organisation or charity identified them as a carer.

- Females are significantly more likely to be providing unpaid care than males, and also more likely to identify as or call themselves as a carer. People aged over 65 are significantly more likely to be providing unpaid care than people in younger age groups, including the 18-24 category, and more likely to identify themselves as a carer through a healthcare professional.

**29%**

of people who did identify as carer took over a year to do so



**29%**

of people realised they were a carer through the help of a friend

**20%**

of people aged 65 plus said they were currently caring



- Nearly half of those who took longer to identify themselves as a carer (46%) said they missed out on financial support as a result of not knowing they were a carer.
- Nearly a third (31%) of those who have provided unpaid care said their health and wellbeing had suffered. Women were more likely than men to say their health and wellbeing had suffered (35% vs 25%).



**46%**

of those who took longer to identify as a carer missed out on financial support as a result



**31%**

of those who have provided unpaid care said their health and wellbeing had suffered as a result of their caring role

# Introduction: who are unpaid carers and why is identification important?

Millions of people in the UK are providing unpaid care or support to a family member, friend or neighbour. However, a significant proportion of those people do not identify as or call themselves a carer.

There are often several reasons for this: some people may not want to be labelled a carer because they feel it depersonalises their relationship with the person they care for; others may feel it just part of their duty as a family member; some may not think that the amount or type of care they are providing is sufficient to call themselves as carer.

Even those who do identify as or call themselves a carer often take several months, or years, to do so, and may be missing out on accessing support from an early stage. Carers UK State of Caring survey 2022 found that half of carers (51%) took over a year to recognise themselves as a carer. For many people, caring is just a part of life.

It's important to recognise that not everyone will want or need to identify as a carer. However, one of the risks of people not doing so is that they may not be aware of the financial or practical support they are entitled to, from benefits such as Carer's Allowance to support with caring through a Carer's Assessment or Adult Carers Support Plan (Scotland). Carers also have access to support, information and advice from national charities like Carers UK, or local carers organisations and organisations across the UK, such as those provided by Carers Week supporters.

Research suggests that providing unpaid care can impact on health and wellbeing, finances and employment. Carers UK's State of Caring survey 2022 found that nearly a third of carers (30%) said their mental health was bad or very bad, over a quarter (29%) said they felt lonely often or always, and over a quarter (27%) said they were struggling to make ends meet. Three quarters of carers in employment (75%) said they worry about juggling work and care. It is therefore vital that carers are aware of, and able to access, the support they may need to address some of these challenges.

In this polling of the general public, conducted by YouGov, we asked people whether they are caring, whether they identify as a carer, how they identified themselves as a carer, what impact late identification may have had, and what impact providing unpaid care may have had.

# Data analysis (UK)

## How many people identify themselves as carers

YouGov polling results suggest that half of the general public (50%) have provided unpaid care at some point:

- 20% said they are currently giving unpaid support or care.
- 30% said they are not currently providing unpaid support or care but have done so in the past.
- 43% of people said they do not give unpaid support to anyone and have not done so in the past.

This polling suggests that 1 in 5 people in the UK are currently providing unpaid care or support. Based on ONS population data, we estimate this is 10.6 million people.

This estimation is higher than the number of people providing unpaid care in the Census 2021. Census data suggests that 5.7m people in the UK are providing unpaid care: a decrease since 2011.<sup>1</sup> ONS have stated that factors affecting the decrease in the proportion of people identifying as providing unpaid care in England and Wales may include a change in how the question on unpaid care was worded, as well as other factors such as changes in the nature of caring during the pandemic and the timing of the Census.

**20%**

of the public said they are currently giving unpaid support or care



<sup>1</sup> This estimation by Carers UK is based on Census 2021 data for England and Wales, Census 2021 data for Northern Ireland, and Census 2011 for Scotland, along with ONS mid-year population estimates in June 2021

## How long it takes people to identify themselves as a carer

Nearly three quarters of people who are providing/have provided unpaid support or care (73%) said that they do not call themselves or identify as a carer. This suggests that a significant number of people providing unpaid care may not be receiving information, advice or support to help them with their caring role. Only 25% of people giving unpaid support or care said that they identified as or called themselves a carer. Based on this YouGov polling, we estimate that 19 million people in the UK have provided unpaid care or support but not identified themselves as a carer.

38% of people who had identified themselves as a carer said they had done so immediately. 29% said it had taken up to a year, and 29% said it had taken over a year. This suggests that it can take a considerable amount of time for people to realise that they are caring, and to access the support they are entitled to.

This polling reiterates the results of Carers UK's State of Caring 2022 survey which also found that many people do not identify themselves as carers. The State of Caring survey found there are a range of barriers that can prevent people from recognising they are caring.

For example, 71% of carers who took a while to identify themselves as a carer said that seeing themselves primarily as a family member or friend was a barrier to identification. Some carers may feel that identifying themselves as a carer de-personalises or devalues their relationship with the person being cared for. Others may feel that caring is their duty, and not a specific role that is separate to their existing responsibilities.

*“It’s hard to view myself as a carer when it’s my own child I’m providing the care for – it just feels like something any parent would do for their child.”*

*“I was doing what I thought any wife should be doing. I still don’t see myself as a carer after 15+ years.”*

*“At the start I felt I was offering support to my parents rather than care, but when my father died I realised I was now the primary carer for my mother.”*

**“It’s hard to view myself as a carer when it’s my own child I’m providing the care for – it just feels like something any parent would do for their child.”**



The State of Caring 2022 survey found that 53% of carers who took a while to identify themselves as a carer said that this was because taking on their caring role was a gradual process. If the condition of the person being cared for deteriorates over time, some carers may find that their caring responsibilities increase. Other barriers identified in the State of Caring survey included carers being too busy to realise the role they were undertaking (40%), not feeling like the amount of support being provided was enough to be identified as a carer (35%), and no-one advising them that they were a carer (32%).

*“It starts as a normal parental role but then because of disabilities the parental duties don’t evolve or reduce as they normally would. In fact caring increases.”*

*“I started so young that it was normal to me. I’ve never known a different life, except for a few short months, in over 60 years.”*

*“I was primarily focussed on my own job, and saw taking on ever increasing caring duties as just another fact of life.”*

**“I started so young that it was normal to me. I’ve never known a different life, except for a few short months, in over 60 years.”**



## How people identify themselves as a carer

A higher percentage of people said that a friend or family member helped them to identify themselves as a carer (29%) than a healthcare professional (22%). 14% said they found information online, and 11% said a carer organisation or charity identified them.

Other ways in which people identified themselves as a carer included through a social worker (9%), their employer (7%), another carer (5%), the media (5%), social media (5%), and this poll (2%). Some carers also said that they worked it out for themselves.

**22%**

of respondents said a healthcare professional helped them to identify as a carer



## The impacts of not identifying as a carer

We asked people who took time to identify themselves as a carer what support they felt they missed out on, as a result of not identifying themselves as a carer. The majority of carers had missed out on some kind of support. Only one quarter (25%) of unpaid carers said that they had not missed out on any kind support.

Nearly half (46%) felt they missed out on financial support. There are many different forms of financial support that carers may be entitled to, including Carer's Allowance and Universal Credit, as well as help with health and care costs.

This group also felt they had missed out on other types of support:

- 35% said they missed out on practical support.
- 33% said they missed out on carers' breaks.
- 23% said they missed out on support at work.
- 22% said they missed out on support from family or friends.



**35%**

of respondents said they missed out on practical support by not identifying as a carer

## The impacts of caring

We asked people who have provided unpaid support or care what, if any, negative impacts they had felt as a result of providing this support. Research suggests that providing unpaid care can impact on finances, employment, and health and wellbeing and nearly a third (31%) said that their health and wellbeing suffered.

*"I lost my career, home, friends and family, something inside me broke."*

**31%**

of respondents said their health wellbeing had suffered due to their unpaid caring role



This reflects findings from the Carers UK State of Caring 2022 survey, in which unpaid carers identified health and wellbeing as their biggest area of need. In the State of Caring survey, 62% of unpaid carers said they needed support with health and wellbeing, and 30% said their mental health was bad or very bad.

YouGov polling results suggest that providing unpaid care, now or in the past, can have other negative impacts:

- 19% said that their relationships with their friends and family suffered.
- 16% said it had affected their job or ability to work.
- 13% said it had affected their savings.
- 8% said the person they cared for was impacted.
- 6% had got into debt.

*“Looking after my widowed mother caused long-lasting damage to my marriage.”*

*“I had to stop work for a year to help out and am likely to have to again in the near future.”*

*“I used to care for my neighbour... this affected my social life as I had to work round her needs and be on call...”*

Whilst 47% of people with current or past unpaid caring experience said that caring had not had a negative impact, the proportions of carers who do experience impacts are a concern.



**“Looking after my widowed mother caused long-lasting damage to my marriage.”**

# Zoe's story

Carer's story provided by

Zoe met Mike on Channel 4's First Dates in early 2020, where they hit it off but decided to be friends. After continuing to talk daily throughout lockdown, they realised they had feelings for each other. At the same time, Mike was diagnosed with MND. Their relationship blossomed after lockdown lifted, and in August 2022 they got married. Zoe self-identified as a carer early on in their relationship.

“ I did a lot of research in the early stages of our relationship, as Mike was diagnosed with MND just before we became a couple. I remember reading some MND Association information which said that, while carers may not identify themselves as such, it's a term that the government recognises and it laid out some of the things that carers do. I read that and thought 'that's me'.

As a carer, I've been able to access support from the MND Association, such as money towards driving lessons so that I could pass my test and take over the driving from Mike. I still work full-time so I don't access Carer's Allowance or any other benefits. Since identifying myself as a carer at work I've found out that a few colleagues are also carers, so we now have a bit of emotional support and visibility between us, and I'm now able to work from home most of the time.

When I wake up, I get Mike out of bed and wash and dress him. I give him his medication, flush his feeding tube and then we have breakfast before I start work. While I'm working, I get anything for Mike that he needs as he can't use his arms to reach things, I scratch his nose if he has an itch.

If he needs the toilet, I will move him to the toilet or commode. On my lunchbreak I prepare his lunch and give that to him, along with more medication. Then I go back to work, making up any time I've lost through helping Mike. After work, I'll make us dinner, get Mike changed again and do any creams or medication, clean his teeth and get him into bed. Overnight, I am on call to help Mike with whatever he needs, like repositioning. That is just a regular day with no appointments, phone calls or journeys outside.

It's so important that the government recognises carers. Without unpaid carers there'd be an even bigger strain on services and a lot more care workers would be needed. Carers do what they do because they love the person they care for, but it is really hard. They don't want millions of pounds or a pat on the back, but they do want people to understand what caring is like and put accommodations in place for them to get by. Something has to give at some point, and Carer's Allowance is not enough to live on.

”

**“Since identifying myself as a carer at work I've found out that a few colleagues are also carers, so we now have a bit of emotional support and visibility between us.”**



# Lizzie's story

Lizzie shares her experience of caring for her father who had Lewy Body Dementia.

“ Roald Dahl's Danny the Champion of the World, which Dad used to read to me, says *“What I've been trying so hard to tell you all is simply that my father...was the most marvellous and exciting father...”*”

Danny, mine too and despite the best efforts of Lewy Body Dementia (LBD), it'll never take away his greatness. Caring for him was one of the greatest privileges of my life and one of the toughest.

I moved back in with Mum to help take care of Dad and confess I had no idea about what caring for someone involved. It's A LOT.

Meal times were now a task; we prepared one 'softer meal' for Dad and one for us. Mum, the real hero of the story, gave him his breakfast, his medication, prepared lunch and dinner, all of which took time. Body clocks were out of sync – I called it 'Daddy time'. When we winding down for the evening Daddy was awake. When we didn't want to get up at 3am, Daddy could be calling out. He was often asleep when grandchildren arrived, sorry to have missed them.

Dad suffered from hallucinations which can be part of LBD – we hid from bullies, pretended to ring the fire brigade and fought in WW2. I tried dismissing them, being there with him, and reassuring him. *“Hello Daddy”, “hello little one”*, he replied before scrunching up the bedsheet and stopping a chimney falling down. The mind is a powerful thing.

Also no one tells you about the amount of stuff. Strange equipment became a logistical challenge. Prescriptions had to be ordered, medicines selected, pads counted, bags dated, fluid charts completed – it was a constant rhythm.

I'd work remotely next door to Dad and would get up sometimes to hold his hand whilst he was having a vision, returning to my zoom call often trying not to cry.

There were lighter moments of course: Dad humming The Dambusters whilst being hoisted across the room; 'Bed-bound catch' was fun. We'd both start laughing, my face being the perfect target at the foot of the bed; *“Dad make sure you're moving your fingers”* – wagging them with vigour, he turned Raynauds into Beethoven.

As mentioned, I didn't know much about caring but I want to say to any fellow carer, you're doing a fantastic job – please remember that.

I'm sorry to say we lost Dad a few months ago so please allow me to end with a tribute to him. Daddy, I hated seeing what this horrible illness stole from you but you were so dignified, kind, gentle and selfless until the very end, it is a lesson. I feel lucky that I could spend precious time with you, holding your hand like you have always held mine. Just because we can't see you now, doesn't mean that you're not with us. ”

**“I didn't know much about caring but I want to say to any fellow carer, you're doing a fantastic job – please remember that”**

# Differences by demographic factors

## Gender

More women than men are giving unpaid support or care to someone. 21% of women said they are currently caring, compared to 18% of men. This is a statistically significant difference, and reflects the findings of the Census 2021 which showed that women are more likely to provide unpaid care than men.

Of those who said they are providing/have provided unpaid care or support, women were more likely than men to identify themselves or call themselves a carer. 27% of women who are providing/have provided unpaid care said they identified as a carer, compared to 23% of men. This is a statistically significant difference. This highlights the need for local authorities and health commissioners to consider how they proactively identify carers who have protected characteristics in their areas.

When asked how they identified themselves as a carer, both male and female carers were most likely to say they did this with the

help of family or friends, followed by a healthcare professional. However, male carers were more likely than female carers to say they identified themselves by finding information online, through the media, social media, and this poll.



**21%**

of women said they are currently caring, compared to 18% of men

How did you identify as a carer?	Men	Women
Family or friends	29%	29%
A healthcare professional	20%	23%
Online information	18%	11%
Media	9%	3%
Social media	9%	3%
This poll	5%	0%

Table includes statistically significant differences between men and women in how they identified as a carer, and so does not add up to 100.

Of those who took a while to identify themselves as carers, both female and male respondents were most likely to say they missed out on financial support as a result of not knowing they were a carer. 51% of women and 40% of men said they missed out on financial support.

When asked what, if any, negative impacts there had been as a result of providing unpaid care, both male and female respondents were most likely to say that there had been no negative impacts. 48% of men providing unpaid care said there had been no negative impacts, and 47% of women providing unpaid care said there had been no negative impacts.

Female carers were significantly more likely to say there had been an impact on their health and wellbeing (35%) than male carers (25%). This suggests that female carers may need specific and targeted support with health and wellbeing. However, it is also possible that male carers are less likely to admit that they are struggling with health and wellbeing. Research has shown that men are less likely to talk about mental health.<sup>2</sup>

**51%**

of women said they missed out on financial support, compared to 40% of men



**35%**

of female carers said providing unpaid care had had a negative impact on their health and wellbeing, compared to 25% of male carers

<sup>2</sup> <https://www.mentalhealth.org.uk/explore-mental-health/a-z-topics/men-and-mental-health>

## Sue's story

“ I started caring over 20 years ago initially for my daughter, but in 2010, my son suffered mental health issues and was also diagnosed with autism. My son was under the Early Intervention team and they were very supportive of us both. When he moved onto adult mental health services, I was supported by Julie from Rethink Mental Illness I don't know how I would've managed without Julie. She's seen me monthly and has been so supportive and understanding of my son's issues. In 2010, my husband had a work related accident and a heart attack, needing a quadruple heart bypass. My mother also had a stroke, so I had to juggle caring for four.

Mental ill health is the hardest to deal with. It's very draining trying to keep upbeat and positive, when the person who's being cared for is depressive and negative. After several inpatient stays, my son found a placement in a local Mind. Before this, my son had self-harmed on several occasions, and I had to sit with him all night in the hospital to be seen the next morning. In the early days, when sorting out his medication, there were times when he couldn't dress or feed himself. He was in a zombie-like state. Because of his self-harm, we were always flagged when needing emergency services. On one occasion, when my son was sectioned, we had 19 policemen and paramedics surrounding our house.

You feel guilt because of this. No one knows what life's like as a carer, unless they've walked in your shoes. Many people are ignorant of how mental illness affects the person suffering, but also the people who have to deal with it every day.

Initially, I didn't think of myself as a carer. I didn't know anything about Carer's Allowance or any benefits, until I became a postmistress. People I knew were claiming to look after their children and getting all sorts of benefits.

I didn't really think any more about it, until we had an appointment with a paediatrician. She asked me what benefits I was getting for my daughter and myself. I told her I wasn't on any and she told me what we'd be entitled to. But it's my daughter! No, she said, you're an unpaid carer and your daughter is entitled to DLA (Disability Living Allowance). You must get assessed. I used to go to a carers group and did a 'Caring With Confidence' course, where I made some friends. We went on to become the Gang of Four. I stopped going when my caring responsibilities expanded, but I still keep in touch with two friends from the gang on social media. I have a brilliant friend who is also a carer. She obviously understands the issues carers have.

The government and people in general don't realise what it's like being a carer. I only get one lot of Carer's Allowance, even though I care for three adults. I don't get any relief for my glasses or dental work. I don't think what's involved in being a carer is appreciated. It's not just the hands on care, it's the admin; dealing with finances and juggling everyday issues.

My son and husband feel guilty that I have to care for them. My daughter doesn't know any different, but I wouldn't change a thing. Through caring, I've met some tremendous people and made some genuine friends. Caring has changed me and my life. I had to give up my job to be a full-time, non-paid carer. I've had to fight to get what is needed for the people I care for. Follow your gut, rather than just accepting what you've been told. Keep on fighting as no-one else will. ”

**“No one knows what life's like as a carer, unless they've walked in your shoes.”**

## Employment

19% of people in paid employment said they are currently providing unpaid care and support, 25% of people in part-time employment are giving unpaid support, and 17% of people in full-time employment are giving unpaid support. 44% of people who are not working or who are unemployed are providing unpaid care, and 22% of retired people are providing unpaid care.

22% of people who are unemployed are providing unpaid care, 22% of those who said they are not working for another reason are providing unpaid care.

Of those who are providing/have provided unpaid care, people working part-time were more likely to identify themselves as a carer (28%) than people working full time (21%).

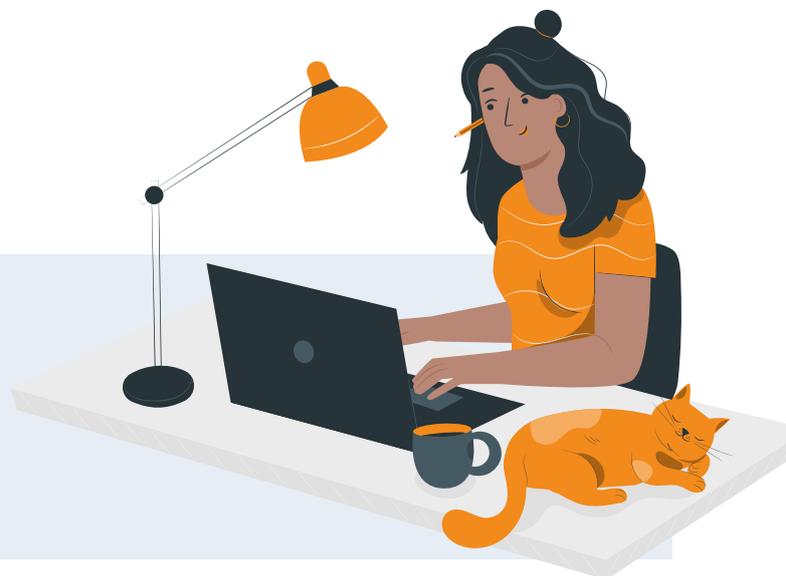
Like all carers, carers in employment were most likely to identify themselves as a carer through family or friends (32%). Unsurprisingly, they were more likely to identify themselves as a carer through their employer (12%), compared with all carers (7%).

When asked what support they missed out on as a result of not knowing they were a carer, people in employment were most likely to say they missed out on financial support (43%). Again, a higher proportion of people in employment said they had missed out on support at work (31%) than all carers (23%).

45% of employed people who are providing/have provided unpaid care felt that there was no negative impact of providing care or support. 31% said their health and wellbeing had suffered, the same proportion as all carers. However, employed people who are providing/have provided unpaid care were slightly more likely to say that caring affected their job or ability to work (19%) compared to all carers (16%). They were more likely to say that caring affected their savings (14%) compared to people in retirement who are providing unpaid care (9%).

# 19%

of of people in paid employment said they are currently providing unpaid care and support



# Rachel's story

Carer's story provided by  
We Care campaign, in  
collaboration with Oxfam GB



Rachel lives in Northumberland and had to give up her job teaching to provide full-time care for her daughter Betsy, who has Down's Syndrome and was born premature. Rachel didn't identify as an unpaid carer straight away, she explains why.

“ I think it took me a year to identify as something more than Betsy's mum. It was when I was fighting to get Betsy Disability Living Allowance (DLA). It took me that length of time because up until that point life was one endless stream of health appointments and trips in and out of hospital. This understandably took up all my time and energy.

When I did identify as a carer, I was able to apply for Carer's Allowance. I was called into my GP surgery to receive my flu and Covid vaccines earlier than I would have otherwise. This was important to keep Betsy well.

Parents as a group don't understand they can have a carer's assessment for themselves and not just a child needs assessment. I was able to access family parent carer organisations and I run one of these myself in Northumberland where I live.

There seems to be a lot of stigma, particularly around parents identifying as carers. Many don't want this identity. I still haven't had a carer's assessment for myself, although I asked for one.

What I got was a child needs assessment which isn't about me and my caring role, it's about Betsy. I'm hoping to get my assessment soon.

It's important to say parent carers do way more than a parent of a typical child. Coordinating Betsy's care is a full-time job in itself. Getting a break is also impossible, as there is overnight care to consider. Betsy has a condition called silent aspiration which means she can't drink liquids. It's quite dangerous and means she needs supervising closely. It's a lot to ask of family or friends, alongside how to communicate with her.

It's important that carers are recognised by government and NHS and wider systems but recognition isn't enough. Actions are needed and these actions need to be meaningful. Too many systems which are supposed to support carers in different situations are worthless.

”

**“There seems to be a lot of stigma, particularly around parents identifying as carers. Many don't want this identity”**



## Socio-economic status

People from the lower social economic groups (CD2E) were slightly more likely to provide unpaid care or support (21%) compared with people from the higher socio-economic groups (19%). Those from the higher socio-economic groups were significantly more likely to say they had never provided care (47%) compared to people from the lower social economic groups (39%).

Of those who are providing/have provided unpaid care or support, people from the lower social economic groups were significantly more likely to say they identified themselves as a carer (29%) than people from the higher social economic groups (23%).

All carers were most likely to say that they identified themselves as a carer through support from family or friends, regardless of social grade. However, a significantly higher proportion of those from the lower socio-economic groups said they had identified themselves as a carer with the help of family or friends (33%), compared to people from the higher socio-economic groups (24%).

People from the higher social economic groups were more likely to identify themselves as a carer by finding information online (18%) than people from the lower social economic groups (10%).

This may be because people who are financially vulnerable are more likely to be digitally excluded.<sup>3</sup>

When asked what support they missed out on due to not identifying as a carer, all current and former carers were most likely to say that they missed out on financial support, regardless of social grade. 44% of people from the higher socio-economic groups said they missed out on financial support, and 49% of people from the lower socio-economic groups said they missed out on financial support.

Impact on health and wellbeing was the highest reported negative impact (30% of those from the higher socio-economic groups and 32% of people from the lower socio-economic groups). However, people from the lower socio-economic groups were significantly more likely to say that they had got into debt as a result of caring (8%) than people from the higher socio-economic groups (5%).

# 29%

of people from the lower social economic groups were significantly more likely to say they identified themselves as a carer, than those from higher social economic groups (23%)



<sup>3</sup> [https://www.ofcom.org.uk/\\_data/assets/pdf\\_file/0022/234364/digital-exclusion-review-2022.pdf](https://www.ofcom.org.uk/_data/assets/pdf_file/0022/234364/digital-exclusion-review-2022.pdf)

## Young adult carers (18-24)

Young people were significantly less likely to be providing unpaid care or support compared to people in older age groups, including 65 plus. 11% of young people (aged 18-24) said they were currently providing care. This figure is more than double the number of young adult carers identified in the 2021 Census, where the figure was just 4.6%. 22% said they were not currently providing care but had done so in the past.

Of those who are providing/have provided unpaid care or support, a fifth (21%) had identified themselves or called themselves a carer.

Just under a quarter (24%) said their health and wellbeing had suffered. Young carers were significantly more likely to say they had got in debt (8%) than carers aged 55-64 (4%) and carers aged 65 and over (2%). Young adult carers were also significantly more likely to say the person being cared for was impacted as a consequence of being a carer (12%) compared with carers aged 55-64 (6%) and carers aged 65 and over (6%).

**Only**  
**21%**  
of young people  
who are providing  
or have provided  
care identified or  
called themselves  
a carer



# Chelsea's story

Chelsea Wheeler, 23, from Plymouth, is an unpaid carer for her dad Ron, 52, who has Motor Neurone Disease.

Paralysed from his waist down, Ron is confined to his bed. He can no longer write and uses an eye gaze to communicate. It all means that Chelsea has to organise everything for her dad during the day while her mum, Karen, is out at work. She makes sure he's set up for the day, including setting up his catheter bag for his toilet needs. She makes sure that Ron gets his food and medication which have to be taken through a tube. And she needs to be there for his regular appointments with dieticians and nurses, as well as to help him with his cough machine and breathing machine.

Chelsea said she was never even aware of the terminology "carer" until the age of 15, when her dad was diagnosed two years into his illness.

She said: "The financial support at the time was bare minimum as I was in full-time education and trying to find a support group aimed at my age group was near enough impossible. In the first couple years of becoming a carer my dad had not received a formal diagnosis and gaining any benefits was difficult so as a family we struggled a bit until we found a diagnosis in London."

After realising she was a carer, Chelsea was eventually able to get help from several charities and now attends a local support group for 18 to 25-year-olds run by Improving Lives Plymouth. She said: "I'm very grateful for this group as, in a year of being part of it, I've achieved and experienced so much more in life than I would have if not given the support."

She said: "I think it's important to be recognised as a carer in general as not only does the person with the condition get affected but their families also. Due to the cost of living going up in this day and age most families are unable to pay for live in carers so family members are stepping up to take on this role and many are still within school age. It is not a responsibility we feel forced into as we would do anything for loved ones but to be recognised by the government and other systems would open up several doors to support that many people still don't know about."

**"I'm very grateful for this group... I've achieved and experienced so much more in life than I would have if not given the support."**



## Older carers (65+)

Older people were significantly more likely to be providing unpaid care or support compared to people in younger age groups, including 18-24. A fifth (20%) of people aged 65 plus said they were currently providing care. 41% said they were not currently providing care but had done so in the past.

Of those who are providing/have provided unpaid care or support, just over a quarter (27%) had identified themselves as or called themselves a carer.

In general, people of all ages who identified themselves as a carer were most likely to say they did so through family or friends (29%). However, people aged over 65 were slightly less likely to identify themselves through family or friends (22%). In contrast, they were most likely to identify themselves through a healthcare professional (29%). This suggests that older people may have higher levels of trust in healthcare professionals, be more likely to use healthcare services than younger carers or that the image or expectation is that it's more likely that older people provide care.

When asked what support they missed out due to not identifying as a carer, carers aged over 65 were most likely to say they missed out on financial support (46%).

The greatest negative impact of caring experienced by carers over the age of 65, was impact on health and wellbeing. Over a quarter (26%) said their health and wellbeing had suffered.

# 20%

of people aged 65 plus said they were currently caring

41% said they were not currently caring but had done so in the past



# Norman's story

Norman gave up work to care for his wife Ros. This is their story.

“ I am often asked when I realised, I had become a “Carer”. My answer is it crept up very slowly and I did not take on board what was happening until I broke down physically and was taken to hospital. I had sought help trying to get help in looking after Ros as looking after Ros was impacting my ability to work. Initially no help was offered, but when I was incapacitated, help was provided via social services.

The balance scales were as Ros' health declined, my caring load increased, until I reached the above tipping point.

I/we had to decide, continue with my career, our main income source, or take on looking after Ros. It was at that point I was told “you are a Carer”, I did not want to be a “Carer”. I am Ros' husband. However, it was obvious if I did not look after Ros, she would have to go to residential care. She did not want that. So, we made the decision to adapt to a life where I supported Ros to live the best life she could.

However, it became obvious that being labelled a “Carer” had a meaning to the Health and Social Care System, in that you could get help via a Carers Assessment,

I then entered on my trip through the health and social care system to get treatment for Ros and support for the both of us. It is a job of work and absorbs a lot of time and a great deal of energy. Too much of both. The main support for “Carers” comes from the voluntary sector and other “Carers”.

My dearest wish is never to go to a meeting of “Carers”, where the words, fight, struggle, ignored are replaced with valued, supported and safe.

”

**“It was at that point I was told “you are a Carer”, I did not want to be a ‘Carer.’ I am Ros' husband... We made the decision to adapt to a life where I supported Ros to live the best life she could.”**

**Results in the nations**

# Caring in Scotland

A fifth of people in Scotland (20%) said they are currently providing unpaid care or support. 30% said they are not currently providing care but have done so in the past. 42% of people said they do not give unpaid support to anyone and have not done so in the past.

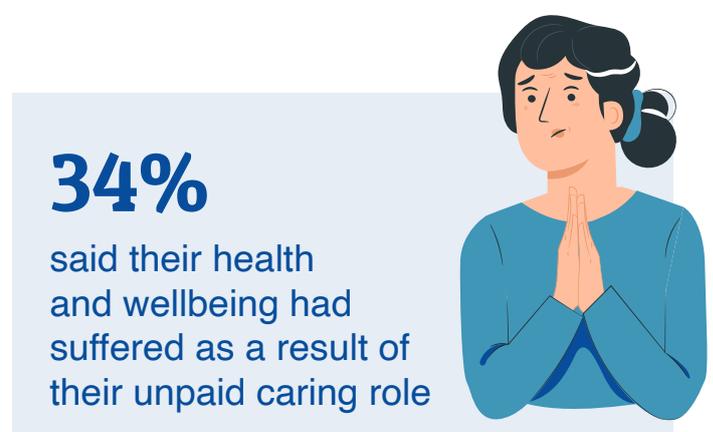
This YouGov polling suggests that 1 in 5 people in Scotland are currently providing care. To estimate the total number of unpaid carers in Scotland, Carers UK has extrapolated the polling results to the whole population in Scotland using ONS population data, we estimate this is just under 900,000 people. Whilst this is higher than Scottish Government figures which said in 2019 that there were around 700,000 to 800,000 (with latest figures showing an estimated total of around 685,000 carers living in Scotland, including 30,000 young carers), a separate standalone report from the Scottish Health Survey in 2020 showed a larger figure of 839,000 which excluded carers 18 and under.<sup>4</sup> Research by the Centre for Care published last year suggests that 6.4% of people in Scotland become carers every year.<sup>5</sup>

In this polling 68% of people who are providing/have provided unpaid support or care said that they do not call themselves or identify as a carer.

29% of people who have provided unpaid support or care said that they identified as or called themselves a carer. 32% of people who had identified themselves as a carer said they had done so immediately. 28% said it had taken up to a year. 34% said it had taken over a year. 5% said they didn't know.

People who identified themselves as a carer were most likely to say that a friend or family member helped them to do so. 30% said that they identified themselves as a carer through the help of a family member or friend. 22% found information online, 17% said a healthcare professional identified them, and 12% said a social worker identified them.

Over a third (34%) of people who have provided unpaid care said their health and wellbeing had suffered, and just under a third (30%) said their relationships with friends and family had suffered. Over a fifth (23%) said it had affected their job or ability to work.



<sup>4</sup> <https://www.gov.scot/publications/scotlands-carers-update-release-2/#:~:text=Published%2012%20April%202022&text=The%20number%20of%20carers%20living%20in%20Scotland%20is%20estimated%20to,Scotland%2C%20including%2030%2C000%20young%20carers.>

<sup>5</sup> <https://www.carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf>

# Caring in Northern Ireland

A quarter of people in Northern Ireland (25%) said they are currently providing unpaid care or support. 29% said they are not currently providing care but have done so in the past. 35% of people said they do not give unpaid support to anyone and have not done so in the past.

Based on this YouGov polling, and NISRA population data, we estimate that over 350,000 people are currently providing unpaid care or support in Northern Ireland.

Research by the Centre for Care published last year suggests that 6.8% of people in Northern Ireland become carers every year – or around 240 people per week.<sup>6</sup>

Carers UK's State of Caring 2022 survey found that many people providing unpaid care take a while to identify themselves as carers. 61% of carers in Northern Ireland took over 6 months to identify themselves as carers. A quarter of carers in Northern Ireland (75%) said that it had taken them a while to identify as a carer because they saw themselves primarily as a family member or friend. 49% said that taking on caring was a gradual process so it took them a while to realise they were caring.

*"I think of myself as a mother and was shocked to be considered a carer"*

*"In family you are expected to look after everyone and you automatically do it."*

In the polling with YouGov, we asked people who have provided unpaid care or support what, if any, negative impacts there had been as a result of providing unpaid care.

- Nearly a third (32%) said their health and wellbeing had suffered.
- Just over a quarter (27%) said their relationships with friends and family had suffered.
- Nearly a quarter (23%) said it had affected their job or ability to work.

This reflects the results of Carers NI's State of Caring survey in which over a quarter of carers in Northern Ireland (27%) said their mental health was bad or very bad.



We estimate over

**350,000**

people are currently providing unpaid care or support in Northern Ireland

**32%**

said their health and wellbeing had suffered as a result of their unpaid caring role



<sup>6</sup> <https://www.carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf>

# Caring in Wales

Just under a fifth of people in Wales (18%) said they are currently providing unpaid care or support. This is lower than the proportion of people providing care in the UK. 28% said they are not currently providing care but have done so in the past.

To estimate the total number of unpaid carers in Wales, Carers UK has extrapolated the YouGov polling results to the whole population in Wales using ONS population data, we estimate that nearly 450,000 people are currently providing unpaid care or support in Wales.

Research by the Centre for Care published last year suggests that 6.9% of people in Wales become carers every year.<sup>7</sup>

Our State of Caring 2022 survey found that many people providing unpaid care take a while to identify themselves as carers. 59% of carers in Wales took over 6 months to identify themselves as carers. 69% of carers in Wales said that it had taken them a while to identify as a carer because they saw themselves primarily as a family member or friend. 50% said that taking on caring was a gradual process so it took them a while to realise they were caring.

*“Being a mum you do what is necessary”*

*“He’s my son so I just saw it as being his parent”*

The following polling findings were the most significant negative impacts from people who have provided care:

- 35% said their health and wellbeing had suffered.
- 21% said unpaid caring had affected their job/ability to work.
- 18% relationships with family and friends had suffered.
- 14% said it had affected savings.
- 7% had got into debt.
- 5% said it had affected their pension.

This reflects the results of the Carers UK State of Caring 2022 survey in which over a third of carers in Wales (34%) said their mental health was bad or very bad.

We estimate nearly  
**450,000**  
people are currently  
providing unpaid care  
or support in Wales



**35%**  
said their health and  
wellbeing had suffered  
as a result of their  
unpaid caring role



<sup>7</sup> <https://www.carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf>

# Mark's story

Carer's story provided by 

Mark has cared for Michael, his adult son, for his whole life. Here he shares how the impact of the pandemic and the cost of living crisis has made his unpaid caring role even more challenging.

“ I'm a carer in Caerphilly and I care for my 43 year old son Michael, who has complex needs and needs round the clock care. I have cared for him all his life, and know how important it is that carers are recognised and know how to get support.

Being recognised as a carer would mean being acknowledged as someone who needs specific support and information in order to make the right decisions for my son.

I care for my son with my wife, both alongside paid employment. This means that support services are critical in allowing us to be able to care. However, we just do not have the support that we need or that used to be in place.



Before the pandemic my son could attend day services for thirty hours a week, now it is only six. This is a huge reduction and puts more obligation on myself and on other unpaid carers in my area.

In addition, my son cannot regulate his own temperature and is incontinent. This means that we have to keep the house at a consistent temperature, no matter the weather.

We also have to use the washing machine two or three times a day, as well as the tumble drier in the winter. As a result, our heating bills have risen substantially over the last year. This is a substantial extra cost that we have no way of cutting down. We need to keep my son healthy and safe, but it is essential that we receive proper support to do so.

It is vital that carers like me know where to turn for support, and that an adequate level of services are provided for those of need of them. This includes proper signposting, and making sure that carers know what they are eligible to claim and how to access it.

Caring can be stressful and all-encompassing, so it is essential that councils and local organisations recognise the challenges. ”

**“We need to keep my son healthy and safe, but it is essential that we receive proper support to do so.”**

# Conclusion

Whilst caring is part and parcel of life, it can have a significant and profound impact on many different aspects of someone's life.

Not everyone wants to call themselves a carer or needs to be labelled as a carer, but recognising the role can lead to a pathway of support and this can help prevent some further challenges in the future – loss of income, reduced pensions, poor health and loneliness.

We have a 50:50 chance of providing care by the time we are 50 years old, and a 2 in 3 chance of providing care in our lifetime.<sup>8</sup> Despite caring being very prevalent in our lives, it still remains a hidden issue. In consultation and engagement with carers, they often place themselves at the back of the queue, putting the needs and wishes of the person they care for first.

When there is such clear evidence of the positive benefits of identifying unpaid carers earlier, why don't public services and employers, services, friends, family and the community do so? As well as still being a hidden issue, these structures and mechanisms may not be in place to encourage awareness and support or they may be under-utilised. However, there are also a number of opportunities to increase awareness of unpaid carers.

There is more to do to consistently improve understanding and commitment to carers throughout the NHS, data collection is patchy and the legislation for the NHS regarding carers is weaker than in social care legislation.

Local authorities who are strapped for cash and other public bodies may also be concerned about demand for services, which may, in turn reduce willingness in some areas to reach out to unpaid carers and to offer support.

It may also not feel like a priority when they are dealing with other pressing issues. This may also be true for some voluntary sector services which are over-stretched.

Awareness amongst employers about unpaid carers in their workforce is improving and data from the NHS staff survey which shows that one third of their staff and colleagues are unpaid carers, and the Carer's Leave Bill which is currently passing through the Westminster Parliament are important mechanisms which have the potential to raise awareness.

In terms of carers' finances, there is no doubt that caring can impact financially and the work carried out by different organisations shows that this can be significant.



<sup>8</sup> <https://www.carersuk.org/media/warllcph/carersrightsdaynov19final-2.pdf>

# Recommendations

## Governments

- Step up cross-Government action to support better identification of carers and ensure carers get the support they need, e.g., by establishing a cross-Departmental Working Group focussed on unpaid carers, and in England, honouring the £25m commitment to fund service innovation that supports unpaid carers.
- Work towards developing a National Strategy for Carers in England, and delivery in Wales, Scotland and Northern Ireland.
- From a UK Government perspective, set up a programme to review and improve the mechanisms which drive greater identification of carers within the NHS to deliver robust and measurable outcomes at all levels.
- Improve and update NHS legislation to place a duty on the NHS to identify carers and to promote their health and wellbeing. Establish a programme to improve the mechanisms which drive greater identification of carers within the NHS to deliver robust and measurable outcomes at all levels.
- Improve data sharing to ensure that carers are identified and that support and entitlements are not missed.
- Improve support and identification for carers at key transition points from children's to adult's services.
- Improve the funding of social care to ensure that unpaid carers get the support they need once they have been identified.
- Review carers' financial support and benefits, including Carer's Allowance, to ensure that they are fit for purpose and prevent financial hardship.
- Build on carers' rights in the workplace and deliver the future Carer's Leave Act, and enhanced rights to flexible working.



## Specific recommendations for Governments: Scotland

- Implement and monitor the recommendations from the Scottish Carers Strategy including delivering the intended cross departmental actions. Ensure that actions link with those in other relevant key strategies including on mental health and dementia.
- Work with NHS Scotland and education bodies to develop and deliver ambitious plans (set out in the Carers Act 2016) to improve identification of carers within the NHS and primary health care and importantly during hospital discharge.
- Deliver transformational investment in social care as part of the development of a national care service. Increase social care funding in advance of this development to ensure that support for carers, disabled and older people does not wait for structural change.
- Scottish Government must create a dedicated National Outcome on Care, and then ensure it drives the new action that's needed to fully value and invest in care right across Scotland. <https://ascotlandthatcares.org/>
- Deliver the new Carer Support Payment which will replace Carer's Allowance and set out a timetable for further improvements from launch and after transfer.
- Recognise the financial hardship experienced by carers and those they care for and provide additional support to alleviate the challenges of the cost of living including a carer cost of living fund, energy payments and removing care charges.

## Specific recommendations for Governments: Northern Ireland

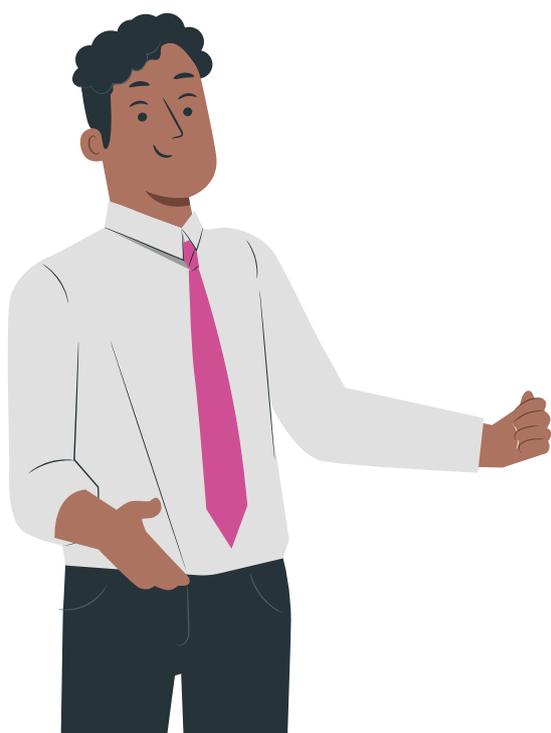
- Delivery of a new cross-departmental Carers Strategy for Northern Ireland – to provide the support carers need in the realms of health and social care, social security, employment, housing and more.
- Creation of a regional Carers' Register, with training for all Health and Social Care staff, and other relevant public sector workers, trained to identify carers and add them to the Register.
- Meaningful progress on the reform of adult social care and prioritisation of the carer-related recommendations within that.

## Specific recommendations for Governments: Wales

- The Welsh Government must ensure the needs and voices of unpaid carers are prioritised in their social care reform programmes, including the Rebalancing Care programme and work on the proposed National Care and Support Service.
- The Welsh Government should swiftly set out clear and measurable steps it will take to respond to the findings and recommendations of the Welsh Government-commissioned IMPACT evaluation of the Social Services and Well-being (Wales) Act 2014. The evaluation, published in March 2023, found significant gaps between the support for carers promised in the legislation and the reality for carers across Wales.

## Health, local authorities and public bodies

- Make a commitment to the I CARE campaign.
- Ensure a clear strategic direction in the NHS at a national level to raise awareness of unpaid carers and deliver appropriate support.
- The NHS and all associated parts of the NHS need to systematically and routinely identify unpaid carers and ensure that they are supported, including an awareness campaign to help identify unpaid carers.
- All parts of the NHS should routinely identify unpaid carers on patient records – their own as well as the person they care for to increase awareness, identification and pathways to support.
- Utilise mechanisms in the NHS to help identify unpaid carers e.g. Carer Passport schemes in England in acute care and Triangle of Care in England NHS Mental Health Trusts.
- Integrate data systems between the NHS and local authorities to help identify carers across different services with clear identification mechanisms.
- Public bodies need to identify carers in their systems and processes where someone is acting on behalf of someone else who has a disability.



## Employers

- Take positive and pro-active steps to raise awareness of unpaid carers within the workforce – by taking part in the I CARE campaign.
- Prepare for the implementation of the future Carer's Leave Act in England, Wales, and Scotland, linking up with Employers for Carers.
- Benchmark practice against nationally recognised schemes such as Carer Confident in the UK and Carer Positive in Scotland.

## Local carers and community organisations

- Continue to work to raise awareness of unpaid carers their needs and support.
- Encourage other organisations locally to engage in Carers Week and take part in the I CARE campaign.

## All of us – our family and our friends

We all have a role to play in helping family and friends understand and recognise the role they play as an unpaid carer and access the support available to them.

- Take steps to familiarise yourself with trusted places for information and advice for unpaid carers, both national and local and talk to family and friends about unpaid caring.
- Encourage family, friends and colleagues to take part in the I CARE campaign – whether they are unpaid carers or not, helping to spread awareness and help identify carers.





## About Carers Week

Carers Week is an annual awareness campaign to recognise the vital contribution made by unpaid carers across the UK.

In 2023, Carers Week is made possible through Carers UK working together with six other major charities: Age UK, Carers Trust, Motor Neurone Disease Association, Oxfam GB, Rethink Mental Illness and The Lewy Body Society.

[Find out more and get involved at carersweek.org](https://carersweek.org)



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