



Carers Speak Out

Making sure the voices of people looking after a family member or friend are heard

More than three in five of us will be a carer

It is vital all our voices are heard



**Caring
Together
Charity**

November 2023

No unpaid carer in crisis

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Who cares?

“It is important we raise the importance of what carers provide.

Some care for duty, some care out of love.

In the end we all may provide unpaid care.
So it is important to say 'I Care'.

Matthew, carer

Who is an unpaid carer?

An unpaid carer is any of us, including children, who look after a family member, partner or friend who needs help because of their illness, disability, mental health problem or addiction, and would struggle to cope without support.

Our new strategy (2023–2026) sets out how we at Caring Together are determined to reach and help more unpaid carers. It is the voices of carers that have shaped our priorities, our ways of working and our vision. As well as wider conversations with, and feedback from carers, the input of our Carer Council and the messages from carers using the Carers Speak Out platform (caringtogether.org/carers-speak-out) have been invaluable in ensuring that the needs of carers are at the heart of all we do.

Our vision is this:

We believe no unpaid carer should be in crisis, isolated or struggling alone.

And we believe that together we can make this vision a reality.



Introduction

Caring for someone is something which will affect every one of us at some point in our lives. As a carer, being cared for, or with someone very close to us being a carer or cared for.

Too often the role of caring and challenges faced by carers are not recognised or understood.

In fact, almost three in four people who are or have been carers don't recognise or call themselves a carer. This is a huge barrier to the needs of carers being recognised or them getting the support they need.

In this report we share the voices of carers, as they need to be heard.

We also include numbers to show the scale of the situations facing carers in our communities. But the voices of carers are essential, every number is a person who is affected by being a carer.

There are more than 150,000 carers across Cambridgeshire, Peterborough and Norfolk. We support all carers including young carers, working carers, carers in education, parent carers, retired carers and those who have given up work or education to care full-time.



It is essential more people who are caring are recognised, reached with the support that they need, and that more is done to help them.

This is something we all must play a role in.

That is why in 'The difference you can make' section we are speaking to everyone. Whether someone is an MP shaping legislation or a child being the first person to recognise a classmate is a young carer, we can all make a difference.

If you have not experienced being a carer already, it is likely that one day you will. So please do what you can.

Miriam Martin, Chief Executive

Note

Where we have heard carers say they are not getting the help they need, we have contacted them to discuss how we can help them in their situation.

Caring affects us all

In our lifetimes we will all encounter caring

Some of us will look after a family member or friend who is ill or disabled.

Some of us will be the person who needs that help.

Some of us will have a family member – perhaps even our own partner or spouse – who becomes a carer.

Whether it happens suddenly, due to an accident or sudden diagnosis, or we gradually slip into caring as someone's health deteriorates, our lives will change immeasurably if we become an unpaid carer.

Looking after someone with a disability or long-term illness is very common. Across Cambridgeshire, Peterborough and Norfolk over 150,000 people are doing just that.¹ Yet we rarely hear their voices and few of us understand what being a carer is like.

Carers Speak Out is an online platform for carers to talk about their experiences. This report draws on what carers have been telling us over the past year on this platform, and through wider feedback to Caring Together Charity.

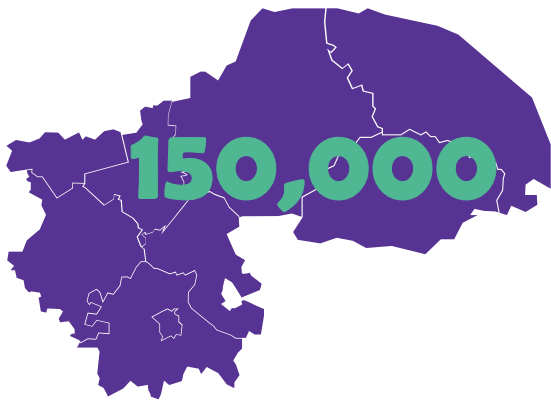
"When I was working full-time there was doctors' appointments, hospital appointments, Parkinson's nurse appointments and 'can you just do this?', and 'can you just do this?' and it's just like, 'well, I'm working!'"

Alison, adult carer



Caring affects us all - the wider picture

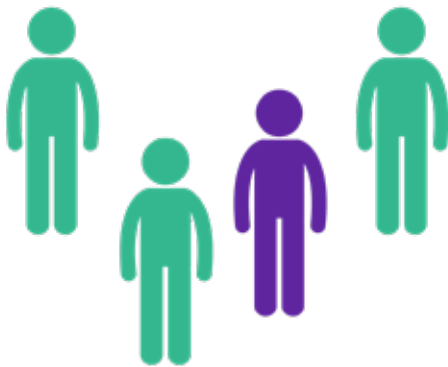
What carers say in this report gives human voices to what research shows it is like to be a carer



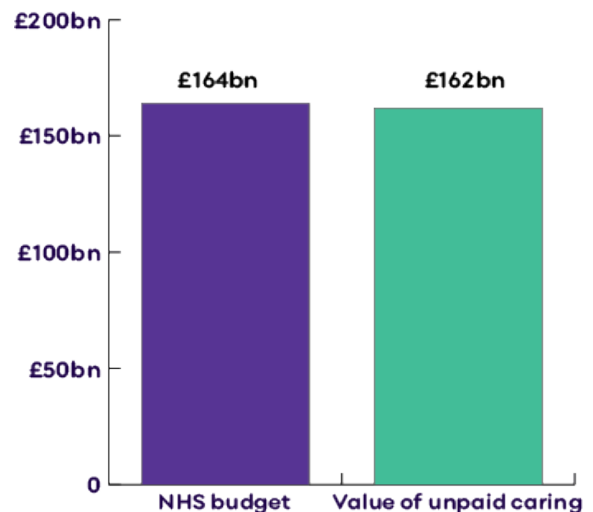
Number of unpaid carers in Cambridgeshire, Peterborough and Norfolk.¹



More than three in five of us will care for someone during our adult life.²



Three in four of us who are/have been a carer don't call themselves a carer.³



Carers provide a hugely valuable service, especially when compared to the NHS budget in England and Wales.⁴

1 Unpaid care by age, sex and deprivation, England and Wales: Census 2021. These numbers, taken during COVID restrictions, are likely to underestimate the number of carers.

2 Will I care? Carers UK, November 2019

3 I care: Carers Week report on unpaid carer identification, June 2023

4 Valuing Carers research report, Carers UK

What carers are saying

Caring and work

Carers say that trying to work, full or part time, while also caring for someone is incredibly demanding – practically, emotionally and financially.

Carers who work need support with all of these demands.

There needs to be a recognition that carers may be at work and unable to take phone calls from health and social care professionals during their working hours.

Too often caring means people are having to reduce the hours they work, feel limited in the jobs they can take and are exhausted from the demands of both working and caring.

Being in work means some carers are ineligible for financial support despite the hours they spend caring.

And working carers need recognition and emotional support.

"It's ridiculous that I don't qualify for any financial support with caring for my elderly mother because I work.

There are 168 hours in a week and because I work 30 of them, I am not entitled to anything.

Does she not need care for the remaining 138 hours?"

Rachel





...my life has changed in so many ways. I still work but can only do part time because mum has become very needy. My sister died so I'm the only person who can be there.

She has Parkinson's with Lewy body, is 85 and lives near me which can be stressful.

Financially giving up full-time work has hit us as a family hard. I have a partner, three grown up sons and two grandchildren. It's mentally draining trying to support everyone.

Alison, adult carer

What carers are saying

Caring and work - the wider picture

"...taking on care responsibilities often involves sacrificing paid work, whether by working fewer hours, accepting a lower-paid job, or leaving employment altogether."

- Unpaid carers experience an average pay penalty of £487 per month (nearly £6,000 per year) reaching £744 per month (nearly £9,000 per year) after six years of providing unpaid care.
- By the end of the sixth year, unpaid carers will have foregone over £40,000.
- These penalties are driven by carers leaving paid work and reducing their hours after they start providing care, set against the increases in pay that they would have otherwise experienced.⁵
- Carer's Leave Act 2023 received Royal Assent in May 2023 and the law will be enacted in 2024. This gives carers the right to a week of unpaid leave per year. However, carers facing financial difficulties may be unable to take this.
- 19% of people in paid employment said they are currently providing unpaid care and support.⁶

⁵ The caring penalty, Joseph Rowntree Foundation, July 2023

⁶ I care: Carers Week report on unpaid carer identification, June 2023

"It's just as well I no longer go to work as my wife could not cope on her own.

I think the government has tin ears as far as carers are concerned. I dread to think what the cost to the economy would be without us."

Geoff, adult carer





I care for my mum and work full-time. It's hard work and I have no support from any other services.

Sometimes I just want to break down, but I can't because my mum's dementia is deteriorating quickly. I'm working towards keeping my mum's wishes to staying at home.

I'm a dementia champion in a care home so my days are long, challenging but very rewarding.

Sometimes I just need to know I am doing a good job with everything.

Katherine, adult carer

What carers are saying

Demands of caring

For carers of any age looking after someone can be a very demanding role. But many of us who look after someone do not even see ourselves as a carer.

This means many of us are not aware we are eligible for help.

And even when people do realise they are a carer, the health and social care systems can be challenging and difficult to navigate or work with. At times they do not recognise the roles of carers, including young carers.

Carers have financial worries, or find they struggle to get the support they want. This is why it is all the more important people get early support, and good advice and help to get what is available to them.

Carers can be children and young people trying to cope at school, college or university while caring.

"When mum was in hospital, no-one was listening to me.

She was having medication changes that wasn't being communicated to her so that was stressing her out - I couldn't get anything out of the hospital because they said I wasn't next of kin.

She called me at midnight on a school-night in floods of tears because no-one was listening to her - I lost all faith in the hospital. No matter how many times I said I was the main carer, nothing happened."

James, young adult carer





I'm a carer, get Carer's Allowance, [and] care for [my] autistic non-verbal son.

What I find overwhelming is the amount of paperwork, now he's in his teens, plus housework and other stuff has to be done when he's at school, so I can pay full attention when he's in.

Getting time for me is sometimes a problem too. We have respite once a fortnight for two hours, sometimes it would be nice to just have someone there for help or advice with the paperwork alone, especially now I am on my own coping since hubby passed.

Maria, adult carer

What carers are saying

Coping with change

Carers' circumstances also change. This can be due to changes in the condition of the person being cared for, changes in the carer's circumstances, or due to the cumulative impact of caring for someone over a long period of time.

Sometimes people who have previously been able to help are no longer able to do so. This includes when someone has passed away meaning a carer is trying to cope with bereavement at the same time as an increasingly demanding caring role.

Other changes are also hard. If someone has been a carer over a long period the person they care for moving into a home can bring another time of practical and emotion change which is hard to cope with.

And for many, the end of their caring role is bereavement as the person they care for passes away.

"As my partner becomes less physically able, blind and his mental capacity reduces, I find myself less able to fulfil my own needs mentally physically or emotionally.

I am exhausted and very low in mood. I get help and support from the local services but feel at a loss as to how to maintain my own self."

Carol, adult carer





My husband has recently been diagnosed with Vascular Dementia after a stroke in June last year. Care is a big worry.

We are self-funding but this won't last long.

If there was at least some free care for dementia sufferers this would be one less thing to worry about.

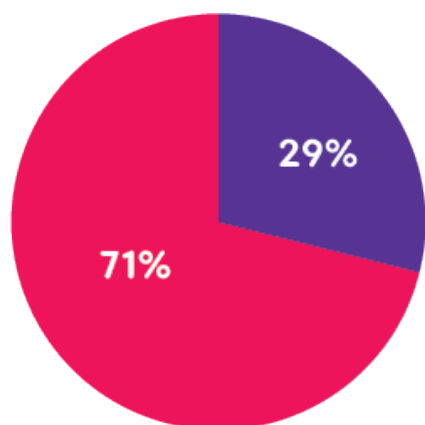
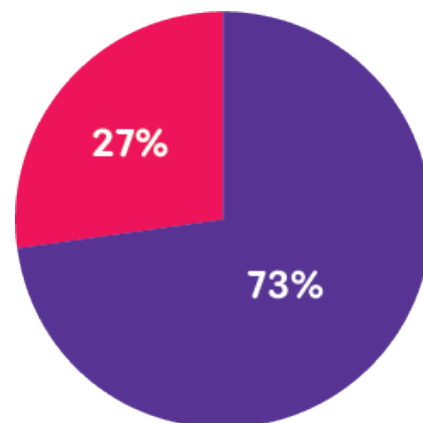
I am already exhausted both mentally and physically.

Jenny, adult carer

What carers are saying

The wider picture

73% of people in the UK who are providing, or have provided, unpaid care in their lifetime have not identified themselves as a carer.



29% of people who did identify or call themselves a carer took up to one 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%).

As a result of not knowing they were a carer, almost half missed out on financial support, they also missed out on practical support, carers' breaks, support at work, and support from family or friends.⁸

⁸ I care: Carers Week report on unpaid carer identification, June 2023

"Being a young carer and going to school is hard.

It's just the worry and anxiety you have with you being at school and not at home day-to-day. You never know what will happen while you are not there."

Erin, young carer





“After caring for my wife through disability, brain surgery and advancing dementia there was an inevitable sense of relief when she moved into care.

She is close by and I try to visit her every two days. Yet two years later, on days when I have no commitments, no visitors, or no phone calls, a sense of loneliness and sadness is very real.

This is especially true when there has been little response during the hour I have spent with my wife.

It needs to be understood that carers also need care.

Steve, adult carer

The difference you can make

Will you take one small step to support carers?

We are encouraging people from across the community to take action to support unpaid carers, and to encourage others to do the same.

Even seemingly small acts can have a huge impact on the lives of carers – one carer getting the support they need could be life changing for them and the person they care for.

And some of us may be in a position to do something that has a much bigger impact.

If you are willing to do any of the actions mentioned in this report, or are acting to support carers in any other way, please do sign up to show you too are taking action to help carers.

Go to caringtogether.org/pledge



YES, I will!



Tell a friend



Follow and share



Speak out



Stay informed



In your workplace



Join our
Carer Council

See page 22 for full details. And sign up at caringtogether.org/pledge

The difference you can make

Do you have a say in policy, services or support for carers?

You may be involved in:

- shaping policy at a local, regional or national level
- deciding what services are available and how they are delivered. This may be services for carers, the people they care for, or other services where what is delivered and how has a direct impact on carers.

Those of us who are in positions where we can shape policy or services for carers have a vital role to play in changing the experiences of carers.

Too often carers are forgotten when decisions are made that affect them.

The awareness and support of decisions makers is essential to changing the experiences of carers.



Action is needed nationally

Essential changes are needed

At national level three areas in urgent need of review are:

- Carer's Allowance – which needs to be increased and the eligibility criteria overhauled.
- Homecare – this must be more widely available to help carers and the people they care for. And, therefore, it must be adequately funded.
- Carer identification and recognition – This must be put in place across health and social care settings in consistent and effective ways.

Given the financial pressure on carers, lack of breaks available and failure of carers being identified early enough or involved in decisions affecting the person they care for, these actions are already urgently needed.

You can help by:

- Recognising the challenges and needs carers experience as summarised in this report.
- Speaking to carers and organisations that support carers before making decisions that directly affect carers.

We can help put you in touch with carers, help you know how to identify carers who will be affected, and share relevant research with you.

The right to carer's leave

We welcome the Carer's Leave Act which will mean unpaid carers are entitled to a week of unpaid leave.

This statutory right may also mean more people becoming aware that they are carers. But action is needed by employers for them to be ready for the Carer's Leave Act to come into effect.

We believe that in future carer's leave should be paid.



The difference you can make

Your business or organisation can help

Each business and organisation in the community can play a valuable role in ensuring carers are supported. With more than 120 organisations holding our Carer Friendly Tick Award, it shows that there is a growing awareness of the importance and value of recognising and supporting carers.

You can act so:

- your business is ready for the Carer's Leave Act to come into effect next year
- your organisation is able to identify and support the carers you come into contact with, whether in an education, health and social care, community or business setting.

We can support you

Our free resources can ensure you are ready for the Carer's Leave Act to come into effect.

We have an awareness video and Carer's Leave fact sheet available at caringtogether.org/companies

You can email companies@caringtogether.org

We have toolkits and support available so you can achieve our Carer Friendly Tick Award accreditation. This is available for employers, and organisations involved in health, communities or education.

Please email carerfriendlytick@caringtogether.org or call us on 01480 499090



We can all make a difference

All of us have a role to play, and by each of us doing what we can, we can change the experiences of carers where we are.

People who are looking after someone not seeing themselves as a carer, or realising support is available leads to carers being in crisis, isolated or struggling alone.

We can each make a difference.

Someone has to act. The 'someone' has to be each of us

What you can do

Tell a friend

If someone you know is working hard to help a family member due to illness, disability or frailty:

- Tell them about the free information and advice Caring Together provide. They may have no idea they don't have to do this by themselves.
- Talk to them about their caring role – feeling heard and being listened to can be hugely important.



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Follow and share

By sharing our posts on Facebook, Instagram, Twitter/X and LinkedIn you can help more people who need a bit of help know about the support available to them.



You can also use social media to share your own experiences as an unpaid carer, and comment on topics that affect you and other people who are caring for someone.

Speak out

If you have ever looked after someone, and know what it's like to be an unpaid carer (the good and the bad), please share your experiences at caringtogether.org/carers-speak-out – it's easy to do and helps us raise awareness and campaign for better support for carers.



See page 19 for what you can do if you have a say in policy, services or support for carers. But all of us can speak up if we are ever in a situation where we can raise the importance of carers being recognised and supported.

Can you suggest that your organisation considers working towards the Carer Friendly Tick Award? (See Page 23).

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Stay informed

You can make sure you have up to date information for carers, for your own use and so you can share it with others.

- Caring magazine is our free quarterly magazine for unpaid carers.
 - Inside news is our free email newsletter which comes out monthly, with special editions also covering important topics.
 - You can sign up at caringtogether.org/keepintouch
-



In your workplace

Check your employer is aware that the Carer's Leave Act comes into effect next year.

You can request a free carer awareness video and fact sheet about the Carer's Leave Act at caringtogether.org/companies

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Could you join our Carer Council?

Our Carer Council ensures the voices of carers are heard throughout the work of Caring Together, and further afield. It meets quarterly, often by video call.



If you would be interested in knowing more about joining and having your say in this way, contact the chair of the Carer Council, Steve Acklam, at steve.acklam@caringtogether.org

You are not to blame

I am recovering from carers breakdown. It has been so traumatic and as a Carers Ambassador I never felt this could happen to me.

I could tell my story of caring over the past 10 years but apart from our personal stories some long held views need to change I think.

Talk about your caring role. Care as long as you can. When you cannot, accept it. When you are no longer coping say so. You are not to blame.

Joy, adult carer



No unpaid carer in crisis



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