



Carers Speak Out

The voices of unpaid carers
across Cambridgeshire,
Peterborough and Norfolk



May 2025

No unpaid carer in crisis

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Many of the challenges experienced by carers locally require change at a national level. We will pass a copy of this report to Carers Trust (of which Caring Together Charity is a network partner) and Carers UK, to support their advocacy for unpaid carers at a national level.

All information in this report is accurate at the time of publishing, May 2025.

Front cover image: Natalia and Amina from the Julaybib Project, a group for mothers of children with disabilities or additional needs in Peterborough.

Welcome

I am delighted to be asked to introduce this important and timely report focusing on the often-harrowing lived experience of unpaid carers across Cambridgeshire, Peterborough, and Norfolk.

As a carer myself I understand their frustrations, their worries and fears, and that overwhelming sense of helplessness as the challenges of caring increase, seldom accompanied by any obvious source of assistance. So, I volunteer with Caring Together, chairing their Carer Council, hoping to add value to the impact the charity delivers on its mission to leave no unpaid carer in crisis.

Clearly, though, achieving this goal requires the support of all those in positions of influence, whether as employers, as medical professionals, or politicians - national or local.

Please take on board the messages carers have left on the Carers Speak Out online platform, and do everything you can to bring about beneficial change.

Sincerely, with thanks

Steve

Steve Acklam
Chair of the Carer Council



About Caring Together Charity

Caring Together Charity works across Cambridgeshire, Peterborough and Norfolk supporting unpaid carers. Unpaid carers are people looking after a family member or friend with a disability or long-term illness such as dementia, Parkinson's disease, cancer, schizophrenia, multiple sclerosis (MS) or autism. Some carers support someone who is elderly, frail and unable to manage without support.

An unpaid carer can be any age. The youngest carer we support is four-years-old, the oldest is over 100! You don't have to live with the person you look after, or care for a certain amount of hours a week, to be an unpaid carer or use our services.

Our services include an Advice Line which can be accessed by phone or email, breaks for carers, emergency planning help, support groups, counselling and specialist support for children and young people who are carers.



What is Carers Speak Out?

Carers Speak Out is an online platform where any unpaid carer can express their views in a public forum¹. To visit the website go to caringtogether.org/carers-speak-out. Scroll down to view all entries (the most recent are at the top).

The messages left on Carers Speak Out are regularly reviewed by our team as they help shape our services and campaigns, along with feedback from carers using our services and our dedicated Carer Council which ensures the needs of carers are at the heart of all we do.

Make your voice heard

If you are an unpaid carer, you can add your voice to Carers Speak Out. Go to caringtogether.org/carers-speak-out to add your message. Scroll down on the Carers Speak Out page to view the over 100 other messages left by carers.

¹ When someone leaves a message, they provide their email address. If it is a valid address, and we feel we can offer some advice or support (e.g. if a question has been asked or someone is clearly in need of a listening ear), our Advice Line team contacts them by email to offer help.



Introduction to our carers' voices

“

It's heartbreaking

”

“

*It is extremely
difficult and
frustrating*

”

“

*They just
dumped him*

”

“

*Things are
getting harder
each day*

”

Every day, whether on the phone to our Advice Line, in person at one of our hubs, or online in a comment on our 'Carers Speak Out' online platform, we hear directly from unpaid carers living in Cambridgeshire, Peterborough and Norfolk. Many carers tell us that daily life is a struggle. There isn't enough support either for them or the person they look after. They feel abandoned, left to cope on their own, and taken for granted. Some carers are struggling to make ends meet with rising energy costs and low incomes. Many feel that the introduction of means testing for the Winter Fuel Payment is another blow on top of the continuing high cost of living. Unpaid carers say that the benefits system is unfair when they are giving so much yet are forced to survive on less than the minimum wage².

This report sets out what unpaid carers have been telling us in 2024 and early 2025, mainly on our Carers Speak Out online platform. We explore the challenges they are facing in not having enough support, accessing care from GP surgeries, and managing financially. We also highlight the things that are making a difference, and making life a little easier.

Whilst as a charity supporting unpaid carers, we at Caring Together work tirelessly to help carers, the reality is that much that needs to improve is beyond our control. We therefore call upon the NHS, local authorities, employers and others to step up and play their part in supporting carers across Cambridgeshire, Peterborough and Norfolk.

² Comparing Carer's Allowance at a rate of £83.30 a week in April 2025 (if you care for someone at least 35 hours a week and they are on certain benefits), totalling £2.38 per hour compared to minimum wage at April 2025 of £12.21 per hour. Unpaid carers can sometimes claim additional benefits such as Universal Credit but if you also claim Carer's Allowance, Universal Credit will be reduced by an amount equal to your Carer's Allowance payment.

There's not enough support

My 91-year-old mum lives on her own in the next road with vascular and mixed dementia. Navigation of the whole process of getting help has been challenging. 42 weeks for the memory clinic to do an assessment to gain a formal diagnosis. Three months for the social to assess to go into a home for her own safety. Now we wait for the process to gather information to help with funding. In the meantime, it's a struggle keeping a confused lady safe and calm. It's heartbreaking.



"My husband has early onset Alzheimer's and I had to give up [full-time] work as a result. I am still working 3 days per week and desperately seeking a companion - not a carer - who can take Mark out for a cuppa & a slice of cake one afternoon per week. Prepared to pay but stipulating middle aged male so as not to draw attention. It is proving extremely difficult and frustrating. I can't be the only one."

My husband has dementia and I'm caring for him. I have osteoarthritis, fibromyalgia and depression, and I can't get much help.

The experience of being an unpaid carer can be one of sadness, isolation and frustration.

Many carers feel emotional distress as they witness the deteriorating health or poor quality of life, of someone close to them. In addition, they can face many challenges getting that person the practical support they need which is tiring and frustrating. This often adversely affects the mental health and well-being of carers.

Carers UK recently found that over a third (35%) of the carers who completed their annual State of Caring survey said they had bad or very bad mental health³.

The feedback we receive from carers backs this up. There is little support to ease the immense pressures that many carers experience, including financial pressures associated with the high cost of living, high energy costs and low incomes, often resulting from having to reduce working hours to care.

Although public services are universally under-resourced, we would argue that supporting unpaid carers should be a very high priority, and is a sound investment. The value of unpaid care to the economy was calculated at £162 billion in 2021⁴. In comparison the budget for NHS health service spending in England in 2021/22 was £156 billion. Without the dedication, sacrifice and incredibly hard work of unpaid carers the NHS simply could not cope. Unpaid carers are saving taxpayers literally £billions every year.

Despite the immense savings unpaid carers are delivering to the public purse, the support they need and deserve is desperately hard to come by. It is the carers themselves who are paying the cost, and this is not sustainable.

³ Carers UK (2025) State of Caring' (www.carersuk.org/media/rjknz2jt/state-of-caring-mental-health-and-social-care-feb-2025.pdf).

⁴ Carers UK (2021) Valuing Carers (www.carersuk.org/media/2d51e03c/valuing-carers-report.pdf).

⁵ We attempted to make contact with this carer within 24 hours of this message being posted to offer practical support services.



My caring means 24/7/365 and not 35 hours a week, but nothing in the benefits system changes. The UC (Universal Credit) lady at my local Job Centre Plus, offered a food bank voucher. Council social worker, through a carer's assessment, laughed me out the door and every charity, including this one, signposts me to the next, too scared to speak on my behalf. The NHS person charged with looking after carers disappeared. Two years on - Debt Relief Order, severe depression, health deteriorating but I'm still caring⁵.

There's a lack of healthcare support in particular

I'm a carer for my 33-year-old son who has autism, anxiety and a severe stammer. He gets on well with his GP, but you can't get an appointment to see her! Recently he told me he had blood discharging from his bowel. The receptionists would not give me even an advance appointment, they also told me to ring at 8.30am on the Thursday. When I rang them, they told me they'd given the appointment to someone else... the impossibility of getting a face-to-face appointment is DREADFUL and receptionists let you down.

"My mum cares for her long-term elderly partner. At 87, in the last 10 years or so he's had cancer, a haemorrhagic stroke, a heart attack and now he's been diagnosed with dementia, possibly at a medium to advanced stage. The GP stopped him driving, he lives a fair walking distance from the GP with no buses. The GP and hospital services offer telephone or online appointments despite knowing he can't hear."



What needs to change

1. Identify and prioritise unpaid carers in GP surgeries

Surgeries should proactively ask patients, and those accompanying someone to a medical appointment, if they are an unpaid carer. The form of words of this question is important as many people looking after a family member would not think of themselves as their 'carer'. GP surgeries should code patients who are carers on their Carer Register. This is then flagged on patient records and enables any person engaging with that carer to recognise that they have a caring role.

GP surgeries should introduce measures to support unpaid carers. We recommend:

- a) That each surgery has a Carer Lead to oversee the support for carers and ensuring this is embedded across the surgery. This person does not need to be a medical professional.
- b) Unpaid carers are provided with alternative means to arrange appointments, either for themselves or the person they care for. This may mean they can email as well as phone, are given flexibility in the time of day when they can contact the surgery, or are given a priority phone number for appointments.
- c) Longer appointments are offered to unpaid carers to enable them to obtain health support for the person they care for and themselves in a single appointment.
- d) Face to face appointments are offered to unpaid carers as a matter of course, alongside phone or online appointments. This flexibility allows the carer to arrange an appointment type that is most suitable.
- e) All unpaid carers are told about, or referred to, local support services for carers.

2. GP surgeries work towards achieving the Carer Friendly Tick Award

Healthcare services including GP surgeries and hospital departments should work towards achieving our Carer Friendly Tick Award for health organisations. The process for achieving the Carer Friendly Tick Award includes awareness training and adopting or adhering to key standards to support unpaid carers.

3. Tell carers who are patients about our What If? Plan in Cambridgeshire and Peterborough, and make it available in Norfolk

If a carer falls ill, needs hospital admission, or is otherwise unexpectedly unable to care, the What If? Plan enables us to step in and cover that care for up to three days. Unfortunately, this service is not available in all areas at present. We would recommend that statutory service providers in Norfolk fund this vital service which relieves pressure on the NHS and Adult Social Care.

Find out more

The Carer Friendly Tick Award

Visit caringtogether.org/carers-friendly-tick

Email carerfriendlytick@caringtogether.org

The 'What if?' Plan

Visit caringtogether.org/whatifplan

Email hello@caringtogether.org

Why is change needed?

Unpaid carers are looking after a person with challenging health problems. When that person is not able to get the help and healthcare they need, the carer bears the brunt.

"Caring can... be emotionally and mentally tiring, particularly when carers do not get enough advice and guidance about how to support the person they care for. Many carers feel they are left alone to deal with clinical tasks, while others find it hard to manage the changing needs of the person they care for." (Carers UK - State of Caring, 2025)

We regularly hear from carers that it has become extremely difficult since the COVID pandemic to get a face-to-face appointment with a GP or other healthcare professional. However, online and phone appointments can be difficult to manage, especially when you are a carer supporting a family member or friend through their appointment.

The requirement to phone a doctor's surgery early in the morning to secure an appointment can also be very challenging as a carer. The person you look after may need your undivided attention first thing in the morning and you are simply not able to make phone calls at that time.

One carer, who looks after her husband, made the point that if she or her children were unwell, then they should be seen by a doctor quickly, so that she can continue her caring role. If a carer is unwell, it is not only them who is impacted. It may be that they are not well enough to care, or their recovery is slowed because they are continuing to care while sick. In a similar way, if a carer is a parent with children who fall ill, they may be taken up with caring for a sick child and be unable to fulfil their usual caring role.

Primary healthcare services should be flexible enough to prioritise and support unpaid carers. This would be a sound investment as through providing flexible care to cared-for and carer, carers will be more able to continue their caring roles, thus reducing the burden on other NHS services (including hospital in-patient care when a carer cannot look after a family member for a period).

The difference supporting carers can make

The Burwell Surgery near Cambridge has been awarded our Carer Friendly Tick Award - Health.

Here's what a few of the carers using their services told us:



"Burwell has fantastic support for carers via the GP service or via local knowledge and posters. We have a drop in twice a month for carers and the person they care for, plus a monthly coffee morning for carers to have a chat and discuss problems. Every village should have a facility for carers like Burwell."

"At Burwell Surgery part of the role of one of the receptionists is carer support. She can ensure that carer awareness is kept on the agenda in the surgery, maintain the carers register and liaise with us in the local carers group. This makes for more streamlined support of carers. The local carers group can then offer social, practical and emotional support."

"Initial contact regarding concerns about your partner's decline in cognition and memory is very scary. Our GP surgery made the whole process easy and accessible. Once we had an interim diagnosis we were sign-posted to a lot of local services. Some of those services contacted me directly. For example - carer's coffee morning, drop in, and from there Caring Together and help with financial avenues. These services in Burwell have been my saviour."

Through proactively supporting carers, The Burwell Surgery is ensuring that carers are equipped and helped to support their cared-for person. This will prevent them becoming overwhelmed, exhausted and ill themselves, which in turn reduces pressure on The Burwell Surgery services.



The lovely 101-year old gentleman I help look after was discharged from 2 months in hospital on Saturday. In distress he rang his lifeline and they called me. I found him in his home sitting on the sofa surrounded by his bags. No one had made him a cup of tea, sorted his belongings or made sure he was ok. They just dumped him there. And now we find he wasn't sent home with enough catheter bags. I've had to chase up with the GP. There's little basic compassion and care in the NHS now.

Financial support for carers is desperately inadequate

I gave up work 8 years ago to care full-time for my husband who had been diagnosed with Non-Hodgkin lymphoma. He had a poor prognosis, but somehow pulled through (and again 3 years later). My husband received PIP (Personal Independence Payment) and I received Carer's Allowance, until last year when I reached state pension age. As you're not able to claim State Pension and Carer's Allowance, I lost the latter. I have health issues too now and paying for help is costly. Now we've lost Winter Fuel Payments too! It feels unfair.

"The Winter Fuel Payment (changes) have caused us a lot of problems. I am caring for my wife who is very poorly and wheelchair bound and in constant pain. We can't afford to run the heat like we did as we are both pensioners and I am disabled too. This is a necessity not a luxury and should not be means tested. I am an unpaid carer and again this should not be means tested. Seems all wrong."



What needs to change

Changes proposed by the government in March 2025 to disability benefits, could be disastrous for unpaid carers. We are very concerned about the proposed changes affecting Universal Credit and especially the tightening of eligibility criteria to claim Personal Independence Payment (PIP).

- a) PIP is a 'passport' benefit for claiming Carer's Allowance, so some carers are going to lose eligibility for their Carer's Allowance. We know that around half of all Carer's Allowance claimants care for someone receiving PIP.
- b) 150,000 carers claim both PIP and Carer's Allowance. With the tightening of eligibility for PIP, many carers may face losing their PIP. We also know that 28% of carers are disabled so may be receiving PIP without claiming Carer's Allowance.

The government's own Impact Assessment shows that there will be £1.1 billion less spent on direct carer financial support over the course of the parliament.

As a Network Partner of Carers Trust, together we will advocate for carers during the consultation process, urging the DWP to mitigate the impact on carers losing access to carer benefits.

1. Local MPs should advocate for their constituents who are carers

MPs of the local constituencies, where the carers we support are living, should advocate for them when issues are being discussed which may affect unpaid carers. This will include the proposed changes to disability benefits, and regulation of energy providers especially in terms of price caps and costs for vulnerable customers.

2. Employers should seek to be carer-friendly

By taking steps to be carer-aware, employers across Cambridgeshire, Peterborough and Norfolk will be better able to retain skilled and valued staff who are carers. Businesses benefit, as do their employees, who are then better able to stay in work. Our Carer Friendly Tick Award - Employers will equip them to achieve this.

All employers should be identifying staff in their workforce who are carers and proactively informing them of their right to Carer's Leave to help them in their caring role.

Why is change needed?

We have heard from many carers who are struggling to manage financially. Carers can find themselves in a 'perfect storm' of increased costs due to the needs of the person they care for and high energy bills, compounded by high costs of living, and reduced incomes. Carers often have additional household costs because of the needs of the person they look after. This can include expensive specialist diets, high heating costs, additional laundry due to incontinence, transport costs to frequent medical appointments, or running specialist equipment powered by electricity.

Working carers are frequently forced to reduce their working hours to care, or give up paid employment altogether. On average, 600 people per day give up work because of a lack of support to juggle work and care⁶. On top of this Carer's Allowance, at £83.30 per week in 2025/2026, is one of the lowest benefits of its kind and not available to all carers. In winter 2024, the previously non-means-tested Winter Fuel Payment paid to those of state pension age changed. It is now only paid to pensioners receiving Pension Credit or other means-tested benefits.

Carers often feel that considering all they give and sacrifice to care, the benefits system and lack of financial support is enormously unfair.

⁶ www.carersuk.org/policy-and-research/our-areas-of-policy-work/juggling-work-and-unpaid-care

"I stopped working full time to care for my husband so lost the affordability to contribute to my pension on retirement, and this will be affected when I retire. As income was greatly reduced, I cashed in a pension, drawing a small amount each month and I work part-time. I am able to claim Carer's Allowance but because I draw on my pension the Carer's Allowance takes me over the tax bracket, so I pay tax on it. I am losing all round, and when I retire my pension will be much less than it could have been."





I am an unpaid carer caring for my mum with dementia and living with my husband who is a pensioner. We have lost our Winter Fuel Payment as we are just above the income to receive Pension Credit. I am unable to work due to my caring role and unable to claim Carer's Allowance as this would affect my mum's money. I feel there should be a way to monitor and include families who are doing their role in caring to be able to receive the Winter Fuel Payment.

The bigger picture – Caring Together Charity working with local authorities

The Care Act 2014 placed a statutory duty on local councils to support unpaid carers. Councils must provide a carer's assessment for unpaid carers to assess the impact of their caring role upon them. To be eligible for this, unpaid carers do not have to be caring for a minimum number of hours per week, as eligibility for an assessment is based solely on them having the 'appearance of need' for care and support.

Unfortunately, we hear frequently that carer's assessments are not helpful to carers. Carers will only benefit from an assessment of their needs if it leads to practical support measures for that person.

Caring Together Charity works closely in partnership with Cambridgeshire County Council and Peterborough City Council to provide services to carers which they fund. However, not all Caring Together Charity Services are funded, although we know these are highly valued by carers.

Although local authorities across Cambridgeshire, Peterborough and Norfolk do commission young carer services (provided by other organisations), the types of breaks we know are needed are not funded. We provide children and young people with opportunities to have time off, have fun, make friends and grow in confidence. Our trips include days at the seaside, winter light trails, trips to zoos and park farms, and opportunities to try water sports.

We are extremely grateful to our donors and supporters who make our full range of services available. Without donations and other fundraising support we could not provide services such as our Norfolk Befriending Service, young carer services, and some of our hubs across Cambridgeshire.



Caring Together has given me time away from the family to recharge. I'm able to be with others that are like me and have time talking and laughing with them. Just being able to act like children and do what we do best, laughing and chatting away about stuff that makes us happy!

A young carer

Your rights as an unpaid carer

1. Help at local hospitals

As a carer, you are entitled to support if the person you look after is in hospital. If they are an inpatient at a hospital in Cambridgeshire, Peterborough or Norfolk you are entitled to a carer's passport. Find out more:

- Carer's passport: Addenbrooke's Hospital and The Rosie (Cambridge University Hospitals NHS Foundation Trust)
cuh.nhs.uk/about-us/quality-assurance-and-performance/how-we-look-after-you/information-carers
- Carer's passport: Peterborough City Hospital, Hinchingsbrooke Hospital and Stamford and Rutland Hospital (North West Anglia NHS Foundation Trust)
nwangliaft.nhs.uk/information-for-carers
- Carer's Identity Passport: Norfolk
carersmatternorfolk.org.uk/information-and-advice/carers-identity-passport

Each hospital offers unpaid carers different things such as concessionary parking and overnight beds. Be sure to find out what is available to you.

2. Support when someone is coming home from hospital

The Health and Care Act 2022 places a duty on NHS Hospital Trusts to make sure that you, as a carer, are involved in planning for the person you care for to leave hospital.

The hospital teams involved should ask whether you are willing and able to carry on with some level of caring once the person you look after goes home.

If the person you care for cannot go home safely with the level of support you can provide, other plans need to be agreed. As their carer, you should be part of those discussions and decisions.

Find out more at caringtogether.org/discharge-planning

3. Your rights as an unpaid carer at work

As an employed unpaid carer, under the Carers Leave Act 2023, you are entitled to up to one week of unpaid Carer's Leave each year.

You also have:

- The right to request flexible working.
- The right to time off for emergencies (usually unpaid).
- The right to parental leave if you care for a child (under 18) and have continuous employment with your employer for one year (usually unpaid).
- The right to protection from discrimination because of your caring role.

4. Your right to a carer's assessment

A carer's assessment is not an assessment of how you are performing as a carer. On the contrary, it is an assessment of your needs with a view to you being supported in your caring role. Under the Care Act 2014, all unpaid carers are entitled to one. This applies regardless of how much care you provide, what sort of care it is and the stage of your carer journey. To request a carer's assessment if you live in Cambridgeshire or Peterborough, we can refer you to the relevant organisation. Alternatively:

- If you live in Cambridgeshire contact Cambridgeshire County Council
Tel: 0345 045 5202
Website enquiry form: cambridgeshire.gov.uk/residents/adults/looking-after-someone/carers-assessments
- If you live in Peterborough contact Peterborough City Council
Tel: 01733 747474 Email: adultsocialcare@peterborough.gov.uk
- If you live in Norfolk contact Carers Matter Norfolk
Tel: 0800 083 1148 Email: info@carersmatternorfolk.org.uk
Website including live chat: carersmatternorfolk.org.uk

5. Your entitlement to emergency planning help

Sometimes the unexpected happens and you may be unable to perform your usual caring role due to illness, travel problems, needing emergency hospital treatment or something else.

- If you live in Cambridgeshire or Peterborough you are entitled to register a 'What if?' Plan with us in advance. This can then be actioned if needed, giving you peace of mind that the person you look after would be supported free of charge by our team.
Call: 0345 241 0954 Visit: caringtogether.org/whatifplan
- If you live in Norfolk, Carers Matter Norfolk can help you write an emergency plan and you can get an emergency card from Norfolk County Council.
Call: 0800 083 1148
Visit <https://carersmatternorfolk.org.uk/information-and-advice/making-an-emergency-plan>



Caring Together Charity

No unpaid carer in crisis



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