



Carers Speak Out

Slipping through the net

May 2026

Contents

Welcome	3
National picture on carer identification	4
About Caring Together Charity	5
Introduction to carers' voices	6
What is Carers Speak Out?	7
Carers Speak Out - How your feedback makes a difference	8
Lack of recognition, inclusion and co-ordinated support	10
Focus on young carers	14
Lack of practical support and respite	18
How you can support someone you know	22
Where to get help as an unpaid carer	23

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 2026.

Front cover image: Tracey who had been caring for her adult son since he was a toddler. She then had a stroke.

Welcome

'Slipping through the net' is the theme of this year's Carers Speak Out report, highlighting the often challenging and deeply personal experiences of unpaid carers across Cambridgeshire, Peterborough and Norfolk.

We frequently read words such as 'ignored' and 'invisible' used by carers sharing their stories on the Carers Speak Out platform, and for many carers there are likely to have been multiple missed opportunities to help them.

As an unpaid carer myself, I know how challenging it can be to find yourself plunged into a caring role you never planned or prepared for. It can be incredibly difficult to find yourself alone, expected to cope, and struggling to get support, especially as demands grow.

Despite how common caring for a family member or friend is, and how challenging it can be, not to mention the enormous cost savings to health and social care services, as a society we still don't recognise unpaid carers.

For this reason, I volunteer to chair the Carer Council at Caring Together Charity, hoping to contribute to our mission of ensuring no unpaid carer is left in crisis, isolated or struggling alone. However, this starts with GPs, nurses, paramedics, social workers, paid carers, teachers, neighbours and friends knowing who an unpaid carer is, and telling the carers they meet there is help available.

The voices heard in this report remind us that carers urgently need support. I encourage those with the power to influence to listen and give the help carers deserve.

With thanks,



Steve Acklam
Chair of the Carer Council



National picture on carer identification

Most people who give up hours of their day to support a family member with health problems do not recognise themselves as an unpaid carer.

Most see themselves primarily as a family member or friend just 'doing the right thing', 'doing their duty', helping someone they love, or making sure their family member can stay in their home as they wish to. Some feel they have no choice and this is expected of them.

Many unpaid carers self-exclude from the definition, thinking that if they aren't living with the person they care for, or aren't providing personal care with bathing and toileting, they 'don't qualify'.

Some don't like the 'label' of unpaid carer, realising that the person they support would not like to think they need 'care', or that the family member is a 'carer' rather than simply a son, daughter, spouse or partner.

Whatever the reason, thousands of people across our region have one thing in common – they are **slipping through the net**.

As a society, and as people working in health, social care, education, politics and many other sectors, it is our responsibility to notice unpaid carers, tell those in caring roles there is help available, and help them access it.

Nationally, 73% of people who are providing, or have provided, unpaid care in their lifetime have not identified themselves as a carer.¹

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.²

Nearly half of those who took longer to identify themselves as a carer (46%) said they missed out on financial support, such as Carers' Allowance, because of not knowing they were a carer.³

Meanwhile, 35% missed out on practical support, including carers' breaks, support at work, and advice and information from their local carer organisation, such as Caring Together Charity, that could make a huge difference to their day-to-day lives.⁴

¹⁻⁴ I care: Carers Week report on unpaid carer identification - June 2023

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.

Across our region there are at least 150,000 unpaid carers.¹

An unpaid carer can be any age. You don't have to live with the person you look after, or care for a certain number of hours a week, to be an unpaid carer or use our services.

Services we offer 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.

Our vision is that no unpaid carer should be in crisis, isolated or struggling alone. Please join us in working to make this vision a reality.



¹ Census 2021

Introduction to carers' voices

Unpaid caring is an experience that will touch almost every one of us at some point in our lives, whether we provide care ourselves, rely on it, or support someone close who does.

But caring often remains unrecognised and misunderstood. The majority of individuals who provide vital, unpaid support to family members or friends do not realise they are unpaid carers and have not been identified as such.

This creates a significant barrier to accessing the information, services and support available to unpaid carers, thus '**slipping through the net**'. The lack of recognition can leave carers feeling isolated, undervalued and overlooked.

The 2026 Carers Speak Out report brings together the experiences of carers of all ages and situations across Cambridgeshire, Peterborough and Norfolk. Behind every statistic, there is a personal story shaped by responsibility, resilience and, often, hardship.

Over the past 12 months, unpaid carers have had their say about what affects them through our Carers Speak Out platform. We have also heard their stories via our advice services and local hubs and forums. Children and young people we support who are in a caring role (young carers) have had their say too, loud and clear!

Many unpaid carers describe daily life as a struggle, marked by limited support, financial pressures and challenges navigating systems such as benefits and Blue Badge applications.

Their experiences highlight why Building Carer Friendly Communities – the theme of Carers Week 2026 - matters.

Carers need greater recognition, joined-up support and co-ordinated action from organisations, services and the wider community.

This report calls on organisations, decision makers, and us all as family, friends and colleagues, to play a stronger role in supporting carers.

What is Carers Speak Out?

Launched during Carers Week in 2022, Carers Speak Out is Caring Together Charity's online platform where any unpaid carer can express their views in a public forum.¹

Since this time, dozens and dozens of carers have aired their opinions and shared their experiences of the vital role they play and the problems they face in looking after a family member or friend.

There are no set topics or mandatory responses, simply space for carers to have their say about what needs to change to help them and the ones they care for.

Visit the website for yourself and take a look at the entries (the most recent are at the top, scroll down to view more).

See caringtogether.org/carers-speak-out

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.

If you are an unpaid carer and want to make your voice heard, make sure you add your message to Carers Speak Out at caringtogether.org/carers-speak-out

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.

Carers Speak Out - How your feedback makes a difference

We identified the Blue Badge application process could be an issue for unpaid carers after a member of our Carer Council shared the difficulties he faced when reapplying for his wife's Blue Badge. Despite his wife having a degenerative condition, he was required to start the Blue Badge application process from scratch. This involved completing lengthy forms and repeatedly explaining her circumstances.

When we invited carers to share their experiences of applying or reapplying for a Blue Badge, we were overwhelmed by the response.

The complexity and length of the application process was a recurring issue. Carers describe it as "absolutely exhausting", involving extensive forms, repeated requests for evidence, and numerous follow-ups.

Inconsistent decision-making further undermines trust in the system. Some applicants were initially refused but later approved after appeals or even a single phone call, indicating that decisions are not always based on a full or accurate understanding of need. Others reported repeated cycles of refusal and appeal, particularly for individuals with non-visible disabilities, such as autism or dementia.

The assessment experience can also be distressing, with one carer describing being treated as though they were attempting to 'scam' the system, highlighting a culture of suspicion that can discourage legitimate applicants.

There is also a lack of flexibility in the system. Current rules exclude people with short-term but serious conditions, such as recent stroke patients, who may urgently need accessible parking during recovery.

As a result of this wave of feedback, our Carer Council Chair Steve Acklam wrote to Blue Badge teams across Cambridgeshire, Peterborough and Norfolk, as well as carer leads within local authorities. Responses have been mixed. As a result, the Carer Council asked Caring Together Charity Chief Executive Miriam Martin to contact Carers Trust to see if this is a common theme that they are hearing from other carers so we can see whether we need to respond locally or on a national basis.

Given the inconsistencies in the process, there is a concern that applying for a Blue Badge can feel like a postcode lottery. Although this is a work in progress, it remains an important item on the Carer Council's agenda, and highlights that in expressing your experiences as a carer, you can make a difference.



"My son had a badge for 30 years, but it was refused when he fell into the new 'hidden disability' category. There was a total lack of understanding that there are many risks for someone who is mobile but with autism and severe associated behaviours."

"My husband couldn't walk very far when he applied. We went for his assessment and was made to feel like we were trying to scam a badge and what right did we have even applying."



"Lack of a short-term Blue Badges is a major oversight by The Department for Transport. People face short-term but serious conditions that limit their mobility. What about people who may temporarily need to use a wheelchair or cannot walk far?"

Lack of recognition, inclusion and co-ordinated support

We have heard many experiences from unpaid carers who feel ignored, excluded, or undervalued by the institutions that are supposed to support them.

'Years without any recognition', 'Just do the best you can', 'Total neglect of unpaid carers', 'Keep going till we drop'.

This is just a small sample of the headlines from submissions we have received from angry, tired, burned-out, frustrated carers on our Carers Speak Out platform.

These statements also echo Carers UK's recent findings that 53% of carers feel exactly that way on a national level, often due to a lack of support from stretched health and social care services.¹

Key issues emerging from their testimonies include:

- Not being involved in major decisions affecting the person they care for, such as hospital discharge planning or other care arrangements.
- Lack of recognition by government and statutory services.
- Poor co-ordination between different services and authorities.
- Feeling invisible despite providing essential care that effectively saves the taxpayer £184 billion per year nationally.²

Carers simply want **greater recognition of their role, meaningful involvement in decisions about the person they care for and not feel the effects of slipping through the net.**

¹⁻² Carers UK, State of Caring 2025 – October 2025



"People think caring for my wife, six years into her dementia journey is difficult, but it isn't, not really. The difficult bit is constantly having to battle a broken system, to get the help, support and education I need to do my job."

"I struggled to care for my mother with dementia while holding down a job in a different part of the UK. I finally went to ask for help, to be told I wasn't a 'proper carer' and to 'get on with it as best you can'. Being refused by the very people who claim to be on your side is a slap in the face and so demoralising."



"I am a single mum to a learning-disabled daughter. We have no relatives and few friends who understand. I felt ignored and expected to continue until I dropped."



"Proper training is essential to understand the many and varied circumstances of carer life in the UK right now."

"I have cared for my son for all his 23 years of life. Support was at a minimum from day one once he reached 18. I'm in debt to my neck and constantly shooting in the dark while doing a doctor's job, it's disgraceful."



Page 9



"Hospital discharge teams seem completely unaware of their responsibility to involve carers in discussions in relation to sending patients home. It is assumed that carers are prepared to continue with the caring duties, even if these duties are greater than before."

What needs to change

To ensure carers are proactively identified and supported, we recommend:

1. **Local health and social care decision-makers should invest in unpaid carer identification training** across their teams. Although health and social care services are financially stretched, this wise investment would pay dividends in ensuring unpaid carers are supported to continue caring, saving statutory services vast sums of money. It would also pay dividends in the quality of life, health and wellbeing of unpaid carers who often find themselves exhausted and desperate without support. GP surgeries can apply for our Carer Friendly Tick Award free of charge which includes free awareness training.
2. **GP surgery staff should proactively look for unpaid carers using their services**, often through transporting patients to appointments, accompanying them in the consulting room, collecting their prescriptions and making appointments for them or with them. Every spouse, partner or other family member undertaking these tasks should be advised that they are an unpaid carer and there are specialist services to help them. Every person should be given a Caring Together Charity leaflet or contact details.
3. **Staff working in hospital wards and departments should be alert to the many unpaid carers visiting inpatients and supporting outpatients with transport and during appointments.** As above, they should be provided with Caring Together Charity leaflets and information. Staff should ensure unpaid carers are proactively involved in the discharge planning process and in agreement with the plan. Where the cared-for person has additional needs following discharge, the carer should be supported to manage these at home if they are in agreement with a discharge home.
4. **All professionals meeting unpaid carers should advise them to request our Carers' Card**, which is a useful way of being identified as an unpaid carer in a number of settings, or in Norfolk a Carers Identity Passport is available for use in health and social care settings.
5. **In Cambridgeshire, unpaid carers can also register for a What If? Plan**, which can be activated to support the 'cared-for' person in an emergency if anything happens to the usual unpaid carer.

Focus on young carers

Almost 54,000 children and young people are recorded as unpaid carers in this country, but this is thought to be a significant underestimate.¹

With 72% of schools reporting they have no young carers, many more young people are slipping through the net for the support they need, with Carers Trust estimating around 193,000 as a more reliable figure.²

We spoke to young carers who we support at Caring Together Charity to get their views and experiences on the important role they play that can sometimes be overlooked.

They often do not consciously 'become' carers. Instead, the role is assigned to them as part of their everyday lives looking after a parent, sibling or other family member with disability or long-term illness.

Many describe a moment where "someone told me", giving a label to what had always felt normal. For some, awareness develops gradually, such as when a parent's illness worsens or when professionals introduce them to support groups.

Others only recognise their role later, sometimes after being referred by schools or youth services. In some cases, identification appears unclear from the young person's perspective, with external adults or organisations defining their situation rather than the carers themselves.

Schools can play their part in identifying child carers by getting involved in awareness training. For example, an infant school in Norwich reported having **seven** young carers prior to receiving awareness training, rising to **30** once they had received this and were better equipped to identify young carers.

Young carers highlight a constant worry about the wellbeing of the person they care for, or pressure from other family members. A recurring theme is the loss of childhood, with some feeling like a "second parent" and lacking personal time.

Breaks from caring are therefore highly valued. These moments provide relief from continuous responsibility and an opportunity to relax and socialise. Many young carers enjoy meeting others in similar situations as they form friendships where they feel understood. Activities outside the home allow them to have fun, try new things, and briefly step away from their caring role.

These breaks help improve confidence, physical and mental health and wellbeing, and social skills, not just on the day, but for the long term too.

¹⁻² Carers Trust, Young Carers and the School Census - Spring 2024



What's the hardest part about caring?

"It's just finding other people who are also young carers who you can talk to about it because I don't really have anyone else I can speak to."

What's the hardest part about caring?

"As I've got older, it's worrying about when my mum goes out by herself and where she's going."



What's the hardest part about caring?

"The lack of understanding because a lot of people just don't know what caring is, so they don't know how to help you."





What do you enjoy most about having a break?

"It relieves the stress of caring for someone 24/7 and gives me a chance to meet friends and make new ones."

What do you enjoy most about having a break?

"I enjoy not having to be 'second parent' and not be the responsible one or the one taking care of everything."



What do you enjoy most about having a break?

"It's good to get a break as nobody you're with needs help with anything."

What needs to change

To help young carers feel recognised, supported and less isolated in their roles, we recommend:

1. Every school should nominate a **Young Carer Champion** to spread awareness about young carers across the school and ensure colleagues are able to identify young carers through observing common signs such as children who are frequently late or missing school, children who struggle to complete homework on time, or children who are tired in school. The Young Carer Champion should advocate for a culture of professional curiosity to identify young carers early on.
2. **Increased access to emotional support and safe spaces, such as young carers' groups and support networks.** Many young carers value the chance to meet others in similar situations, as they often feel they have no one else to talk to, so this would help address feelings of loneliness and stress.
3. **Provision of regular and reliable respite opportunities.** Breaks allow young carers to relax, socialise and experience a sense of normality, as well as providing the long-term benefits of boosted mental health and the building of social skills.
4. Schools and colleges recognise the demands placed on these students and offer **understanding, adjustments and pastoral support**, where needed.
5. **Guidance and support for wider families** of young carers that could help create a more balanced distribution of care and take some of the weight from their shoulders.
6. **Schools give exemptions to young carers over mobile phone use in specific cases.** Young carers often need a phone because of their caring role and the need to be in touch with the person they care for.

Lack of practical support and respite

A consistent theme among the responses we have received from unpaid carers is the absence of reliable support services.

Carers remarked that they were left to manage complex needs alone, due to a lack of respite and social care support.

Some felt they had no choice but to continue struggling on with their caring role because alternative support was unavailable, inadequate, or unaffordable.

As a result, carers expressed how they often felt at the end of their tether highlighting the detrimental impact on their mental health.

Feelings of loneliness and isolation and being overwhelmed by their situation are commonplace, mirroring Carers UK's recent findings that 73% of carers had felt anxious or stressed and 68% felt they needed more help to look after their own health and wellbeing.¹

Their recent report also notes that 52% of carers are spending more hours each week looking after their loved one over the last 12 months, and 76% are finding it harder to spend time with family and friends.²

All in all, carers frequently feel they are **left to cope with difficult and demanding situations alone**.

¹⁻² Carers UK, State of Caring 2025 – October 2025



"My mum has late-stage dementia and looking after her, my mum's disabled sister and work became unmanageable. There is a serious lack of help for carers, you feel like you never leave the house and have time for yourself. In turn this makes you feel guilt and shame for wanting this."

"We are at breaking point with having no free time for just the two of us. We are running on empty with no sign of anything ever changing."



"I feel like jumping off a cliff! I can't afford to get to my mum's, I've been going without food to achieve this, no more I feel ill!! My mum has cognitive decline and begged me not to go home until 9pm and I had to walk 3.5 miles with my arthritic knee and chronic sciatica along a lonely country road."



"I feel like a slave, my old life has been taken away from me. I no longer have my hobbies, my group activities or social life. I have lost my freedom."

"There is no option to stop caring, no financial or housing support, and no real help. I've lost my job prospects, health, friendships and freedom. I feel trapped, unseen and exhausted. I don't want to do this anymore but there's no pathway out, just guilt, fear, and watching the people I love fade, while I disappear with them."



"While caring for my mother with dementia is a choice - one for which I have given up not just career but any chance of paid employment - it is a choice I have made because the alternative was either unaffordable or inadequate for her needs. I am grateful to many organisations for the support I receive."

What needs to change

To improve access to respite and practical support, we recommend local authorities:

1. **Expand respite care and short-break provision** to help carers maintain their health and wellbeing and to make caring more sustainable..
2. **Ensure flexible respite options for carers**, whether in the home, through day services, or residential stays. This could include creating partnerships with care providers to offer reliable respite placements and emergency respite options for carers in crisis.
3. **Fund and facilitate local carer support groups and networking opportunities**, whether online or in-person, such as the popular carers' hubs we operate in Cambridgeshire, supported by Cambridgeshire County Council.

One carer outlined how vital such sessions are for them: **"The carers' hubs and meetings we were encouraged to go to once we had settled in this area were very helpful. You also meet up with people in similar circumstances and believe it or not, we all in our own way helped each other by talking about how we could deal with certain things."**

4. **Support community volunteer schemes** to provide companionship and practical help, such as our Norfolk Befriending Service.
5. **Invest in counselling services for carers** to support their mental health and wellbeing, and help them sustain their caring role.

We also recommend:

1. Healthcare services **introduce carer wellbeing clinics and priority access to mental health support to carers.**
2. **Employers proactively promote flexible hours for working carers and Carer's Leave** to prevent carer burnout and help them be able to continue caring safely. Although it is only compulsory for employers to offer unpaid leave of up to five days per 12-month period, we recommend that paid leave is offered to better support unpaid carers.

How you can support someone you know

Building Carer Friendly Communities is the theme of Carers Week 2026 and we can all do our bit to help a carer who we know may be struggling.

Research shows the most common way in which people realise they are a carer is through the help of a family member or friend. That's people like us!

Almost a third (29%) of unpaid carers were identified in such a way.¹

As such, we all have a part to play in helping family members, friends and colleagues understand and recognise the role they play as an unpaid carer and access the support available to them.

If you think someone you know is an unpaid carer we encourage you to:

- **Start a conversation with them.** If you are a unpaid carer, it may help to consider how you felt when you first discovered you were a carer.

How would you have liked people to approach you? Did you feel you had to prove you could carry on without help?

You could prompt a chat about how they are feeling. If you are concerned about someone's wellbeing, let them know, as they may not have stopped to think about the impact of caring on their own health.

Remember, they may feel they are coping well now and don't need any help. But by having this chat you can help them get support later on or when they need it.

- **Tell them about Caring Together Charity.** Explain how we can support them in many ways, including offering advice, breaks, counselling, paid-for homecare and more, and help spread awareness that they are not on their own. Visit our website at caringtogether.org
- **Tell them to sign up for our free magazine and newsletter.** Our Caring magazine (available in digital and paper format three times a year) and Inside News (monthly by email) provide lots of useful advice for unpaid carers. Sign up at caringtogether.org/keepintouch
- **Tell them about our downloadable leaflets and fact sheets.** With lots more information on topics ranging from carers' rights to carers' hubs, our leaflets and fact sheets offer handy guides on the support available. Download at caringtogether.org/download-resources

¹ I care: Carers Week report on unpaid carer identification - June 2023

Where to get help as an unpaid carer

Caring Together Charity provides expert support for unpaid carers across Cambridgeshire, Peterborough and Norfolk.

By speaking to one of Carer Advisors, we can work with you to identify what support will be most beneficial to you and your family.

You can get in touch in the following ways to let us know about your situation.

- Call 0345 241 0954 Monday to Thursday 9am-5pm, and Friday 9am-4.30pm
- Email hello@caringtogether.org
- Visit caringtogether.org/ask-for-support for more details

Adult carers in Norfolk can contact our team who provide the Carers Matter Norfolk Advice Line on 0800 083 1148, email info@carersmatternorfolk.org.uk or visit carersmatternorfolk.org.uk

If you are an adult carer living in Peterborough, contact Making Space on 01480 211006 or by email at peterboroughcws@makingspace.co.uk

All unpaid carers in Cambridgeshire, Peterborough and Norfolk are entitled to receive our FREE Caring magazine (available in digital and paper format three times a year) and Inside News (monthly by email), providing lots of useful advice for unpaid carers.

Sign up at caringtogether.org/keepintouch

Caring magazine and Inside News are also available free of charge to anyone supporting unpaid carers in healthcare, social care, education or employment settings.

If you are an organisation that supports unpaid carers, please get in touch as we can send you free leaflets, postcards or posters to help you make more unpaid carers aware of the support that is available to them in Cambridgeshire, Peterborough and Norfolk. See caringtogether.org/resources



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