

Carers speak out

The voices and experiences of unpaid carers of all ages across Cambridgeshire, Peterborough and Norfolk



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My child is too disabled for help

“My son has a unique medical need he is the only child to have survived. This is something to be celebrated. In practice means he is not allowed to attend school, we cannot have respite (even though he has been assessed as requiring this) we have to rely on charities to help and support us because his needs are too unique for any statutory service. It feels like falling down a well and no one can help us get out. I understand that no one expected him to live but he deserves to be supported.”

Michelle, parent carer



Foreword

I am Steve Acklam, voluntary chair of the Caring Together carer council.

Although my wife became disabled in 1985 and suffered a double bleed on the brain in 1989, I continued working at a senior level until 2012. At this time my wife's Alzheimer's became more pronounced and her care had to be my priority.



Being a carer is hard. Whatever circumstances lead to our becoming a carer, we are not prepared for or qualified to deal with the challenges this involves. Almost certainly we do not appreciate the emotional, physical, and financial questions that will be asked of us in our caring role. We have no reference point for how a serious and debilitating condition will affect our loved one. Everyone is different; everyone deteriorates at a different rate; everyone's illness manifests itself differently. Inevitably we put those we care for first and take an enormous risk with our own health.

If we are lucky, we have family who are sympathetic and supportive, but they have their own issues to deal with, and it can be very difficult for all concerned to be made aware of how serious and unpleasant things have become. And, if as time passes and we realise and accept we cannot manage on

our own any longer, identifying the local and national networks that can provide elements of the support and assistance we need becomes an essential but additional pressure. **Being a carer is hard.**

Unless you have been in this situation it is impossible to understand exactly how many difficulties carers face. Every day more and more of us are becoming carers, or someone being cared for. This affects or will affect us all. Those who could make a difference are willing to listen and in my experience are very empathetic of our situation. Sadly, and especially at this time of political turmoil, care never feels to receive the priority it deserves. Carers do not have the luxury of being able to wait for this to change. Carers and those they care for need help now. They need help that is appropriate, easy to access, enshrined in law, and is given freely. **Being a carer is hard.**

From Miriam Martin, our chief executive

While 2022 has been an unprecedented year in many ways, one thing has not changed, and that is just how urgently in need of support unpaid carers continue to be.

Since launching the Carers Speak Out platform, we have heard from carers of all ages wanting to have their voices heard.

From carers with their own health challenges, to parent carers desperate for help for them and their child, to young carers bearing the brunt of the cost-of-living crisis, there has never been a greater need to improve the recognition and support for carers.

Reading each personal message, what struck me was that while each experience was unique, we could very quickly see four key messages that were coming through loud and clear from carers:

1. Caring continues to have a huge impact on the health, wellbeing and lives of unpaid carers of all ages.
2. Carers feel that they are not recognised, nor is the vital role that they play in supporting the person/people they care for.
3. Carers need there to be better communication from and with professionals supporting the person they care for.
4. Carers and the people they care for are not getting the support that they desperately need.



The coming months are likely to present even more challenges – from the pressures on health and social care budgets, to the continued cost of living pressures being faced by families.

This is why carers need to be at the front of all of our minds and there is a real need for both a local and national response if carers are to get the support that they need and deserve.

As a local charity, Caring Together will continue to do all that we can to support as many carers as possible, but this is not something we can do on our own – we need your help.

Finally, I would like to say thank you to all of the carers who took the time to speak out – I know the demands on your time are huge, but your messages are so powerful.

It will continue to be my goal and that of Caring Together to ensure your voices are heard, and that they bring about change.


Introduction

Forgotten. Ignored. Struggling. Unsupported.

These are just some of the many words used by carers to describe how they are feeling right now.

Every day we hear from carers who are struggling. Through our carer helpline, at our carer hubs, and through our young carers forums. And so often they say they don't feel heard by those making the decisions – we are determined to change this.

In Carers Week 2022, we launched **Carers Speak Out** - an open platform for carers to have their say, when they want to. There were no set topics or mandatory questions – simply a space for carers to tell us all what they want us to know, and what needs to change for them and their families.



It was only as I became hopelessly exposed to the emotional, financial and physical challenges of looking after my wife that I accepted I was a carer. I needed support in every respect, yet the process for achieving any financial support, for example, is at least as draining as caring itself."

Steve, adult carer

Carers Speak Out

Carers were able to use Carers Speak Out to say whatever was on their mind and whatever they wanted people to hear about life for carers.

Posts covered topics from finances, to experiences of local services, to what life is like being a carer, but there were four common themes which emerged:

1. **Caring continues to have a huge impact on the health, wellbeing and lives of unpaid carers of all ages.**
2. **Carers feel that they are not recognised, nor is the vital role that they play in supporting the person/people they care for.**
3. **Carers need there to be better communication from and with professionals supporting the person they care for.**
4. **Carers and the people they care for are not getting the support that they desperately need.**

I am a full-time 24/7 carer of my mum. £69.70 Carer's Allowance is so difficult to make ends meet. I get so upset when people say 'You have it easy not working sitting at home all day'. If only they understood how hard work it is being a carer all day, all night having everything to do for the person you care for. Lack of sleep on the go all day never being able to relax. It would be nice if we were appreciated once and a while."

Debbie, adult carer

Recommendations

Local recommendations

The need to identify and support carers should be included in the new Integrated Care Strategies with clear actions; carers and carer support organisations should be viewed as a key part of integrated care partnerships.

Carers need to be included as a priority group within any local schemes to help with the cost of living or combat 'winter pressures'.

Ensure that the needs of support for parent carers are included within the refreshed carers' strategies and that work on the pathways for accessing support for parent carers are prioritised.

All health and social care professionals should receive carer awareness training.

Integrated Care Systems should sign up to the Carer Friendly Tick Award - Health and Carer Friendly Tick Award - Employer, and strongly encourage other healthcare organisations to ensure they are carer-friendly and include a requirement for carer-friendly practices into commissioning.

All hospitals to ensure that hospital discharge processes proactively seek to identify and involve carers, and ensure carers (including young carers) know about support available. Funding from the national £500 million Discharge and Workforce Fund should be used to provide additional support to carers after hospital discharge over the winter months.

All schools to sign up to the Young Carers Challenge to ensure every young carer in Cambridgeshire, Peterborough and Norfolk knows they have someone to talk to when they are in need of support and knows what support is available.

National recommendations

The Government needs to commit to a cross-Government Carers Strategy covering the needs of carers of all ages including young carers and parent carers.

Provide a top-up payment for unpaid carers with an entitlement to Carer's Allowance to support them through the winter and recognise the additional costs they are facing amid the unprecedented cost of living crisis.

Department of Health and Social Care and Department for Education should undertake a joint review of how the Care Act 2014 and Children and Families Act 2014 are working in practice for carers.

Review all carers' benefits, including Carer's Allowance, to ensure that these work well at supporting all types of unpaid carers and preventing them from falling into financial difficulties as a result of their caring role.

The Government needs to continue to support the Carer's Leave Bill, to increase rights for carers in the workplace.

Caring continues to have a huge impact on the health, wellbeing and lives of unpaid carers of all ages

Through Carers Speak Out, local carers have reinforced the findings of recent national surveys which highlighted the huge pressures that can be placed on carers, whether they are caring full-time or trying to balance caring with working or studying

50% of carers' messages highlighted the significant impact that caring has on them. From finances, to mental health, to carers' own physical health, carers of all ages are reporting that caring is having a huge impact on their health, wellbeing and lives.

"My only income is carer's allowance of £69.70 per week and for everything else I sponge off my family. It's so undignified. I care full-time. In social situations other people class me as 'not working' or a kept woman. It's shameful."

Adult carers, parent carers and young carers all highlighted the pressures on finances. There were carers who were struggling with working full-time as well as caring, some for multiple people. Many carers raised concerns around the benefits system – both the complexity of it, and how it leaves them not being able to afford a reasonable quality of life.

One young carer also reported how they were getting in trouble at school because of the impact of the cost of living crisis.

"I've been getting detentions at school because I haven't got the equipment I need. I'd rather get in trouble than ask mum or dad for money I know they don't have."

Many carers also made reference to how tiring caring is, and how it can often feel never-ending. Carers reiterated the importance of being able to access a meaningful break from their caring role and the challenges they are facing in accessing respite



The difficult part of being a carer is the relentlessness of it. If I'm having a bad day or feel unwell, nobody else makes the dinner or does the cleaning, and I can't have a 'night off' or even an early night (unless my husband wants one too) as you can guarantee it will be a toileting or otherwise medically complicated night just when I could really do with a rest! Other couples share everyday chores and responsibilities; for me it's just me, all the time."

Jen, adult carer

Carers feel that they are not recognised

"Forgotten army"

"Banging my head on the brick wall"

Carers of all ages feel forgotten. Throughout the COVID-19 pandemic and beyond, carers have continued to save the Government over £130 billion each year¹ and provide support that is vital.

Carers highlighted the sacrifices many of them have had to make, from giving up work, to the financial and the psychological cost:

"My partner struggles on a daily basis with Borderline Personality Disorder, without me she simply would not be alive." **Paul**

"The government seem to have forgotten about carers, especially those whom give up their career to care for their severely disabled child or adult and are on their own, so have to rely on universal credit and carers allowance - the carers allowance is counted as income and taken off the little you get in universal credit. The government always talk about getting people back to work and think those claiming benefits do so as they don't want to work, but never do they mention those people whom give up a job they loved and made sacrifices to care." **Sally**

Many carers and young carers also said how they feel their expertise and the vital role they play is often ignored by the professionals involved in the care for the person they look after. They feel they are not listened to, and their experience and knowledge about the person they care for, is not taken into account.

"I'm angry at being dismissed as unimportant while I'm saving the country about £2,000 per week in care home fees."

"We are being asked to work as a member of a team alongside professionals, nurses, doctors and paid carers. PLEASE, if this is the case, ensure that professionals respect the information carers offer. When things go wrong we must learn how to complain. I am not always good at this. We need to record issues and ask staff to record them too. I often feel there is a barrier between me and the professionals. They do not see me as a member of a team at all. It becomes very frustrating." **Joy**



When mum was in hospital, no-one was listening to me... 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. I now worry about if she has to go in again."

James, young adult carer

Carers need there to be better communication from and with professionals supporting the person they care for

If a person with care needs isn't in hospital or residential care, it is the carer who is there providing the ongoing support that they need

The carer knows the most about the person they care for and can often spot when their condition is changing. When someone is discharged from hospital, without the carer, many patients would find themselves back into hospital within days or even hours of leaving, particularly given the current pressures on social care. Yet carers have reported that they are often not being involved in discharge-planning conversations and are not being given key information.

Carers are also really keen for health professionals to routinely make sure that carers are linked into the available support for them.

"Carers need to be regularly asked if they are coping with their situation. It should never be the case that professionals assume that carers can and will deal with all the aspects of caring required. When discharges take place the first question asked could be 'and how will you as a carer cope with this new situation'. Are you aware you have rights? It is not a crime to reach a point where caring for a loved one is no longer feasible." **Joy**

"Carers need to be regularly asked if they are coping with their situation."

With the increased pressures on the adult social care system, carers also reported how things which were supposed to be put in place as part of hospital discharge either weren't happening in practice, or were subject to significant delays.

"I have lost faith in much of the NHS. In particular, that there are enough staff and resources to deal with all the issues of health care that people need. I feel that waiting times and treatments are so delayed now, that people are really suffering. In some areas like mental health and dentistry the NHS seems almost non-existent. I also feel that hospital staff are glad to get rid of patients as quickly as they can. Social services seem unable to cope with the fall out."



When discharge takes place the Discharge Team should be able to check that everything they have put into place is actually happening. If there is little or no contact post discharge, carers can be left in the lurch with no one to talk to. Yes, we may complain, but dealing with poor plans, poor communication can be disastrous for carers to cope with."

Joyce, carer

Carers and the people they care for are not getting the support that they desperately need

The need for more information and support was a common issue for carers, with 49% of carers highlighting the importance of there being more support available.

Carers said they are in need of financial support, respite, peer support and more information about what they are entitled to.

"It would be very good to have an expert talk to us about benefits of all kinds. Someone who knows the ins and outs of claiming and who could answer our questions. I am older now and find forms more difficult than I used to and just a little information and encouragement would help me to know if I am claiming what I can."

Parent carers in particular highlighted the lack of support that is available for them, despite the pressures they face being similar as other groups of carers.

For some carers, it wasn't themselves who needed more support – it was the person they care for.

"I care for my disabled mother who has unfairly fallen through the net of support and care services."

We heard from carers who experienced problems with accessing things they were entitled to such as the COVID-19 booster vaccinations. The current financial pressures has also resulted in some carers no longer being deemed eligible for support which they had received over a number of years.

"I have had a blue badge parking permit for 3 years, which has proved invaluable in enabling me to take my husband to 'help' with my weekly shop and also to visit National Trust properties, garden centres and country parks etc. I have just had to reapply after 3 years and Cambridgeshire County Council have just turned down the application."

Carers also wanted to show the positive impact that getting support can make to their health and wellbeing.


"Social Services gave me two weeks respite, sending Pauline to Rheola Care Home. I'm very thankful for that break it did me the world of good. We've been married 60 years last October and both just 80. Thank you Social Services."




Sadly, I have to work full time (no other option), I have one child diagnosed ASD, the other is currently being assessed for ASD and has been diagnosed with a personality disorder. This child is currently under CAMHS for her mental health as she is suicidal and has attempted suicide and been hospitalised in the past. I feel completely unsupported."

Nicky, parent carer


Carers said...




There is nothing good to say! Here's a few words to describe the situation! Depressing, worrying, resentful, tired, frustration, alone, restricting, hate, spite, guilt, upset, fed-up, dread, impending doom! As you can see there is nothing good about being in a carers situation. Sorry about this, i could put more but i don't have the time or enthusiasm!"




No public toilets offer wall-attached toilets at a height that doesn't involve much pushing up and causing my 84-year-old disabled wife pain. We feel that we are confined to barracks, and only ever manage to get out once a fortnight to do the shopping, and even then, we make sure we don't stay out long. My wife needs to go to the toilet at least once every hour, which makes long excursions almost impossible for us to undertake. It makes being disabled a punishment."



Mum isn't able to work, and I know mum and dad are worrying about money at the moment. I've been getting detentions at school because I haven't got the equipment I need. I'd rather get in trouble than ask mum or dad for money I know they don't have."



I've been the sole carer for my wife since 2011 and like all of us there have been good times and bad times. There doesn't seem to be many good times anymore now. I've always tried to earn a living but that's more difficult now and am still waiting for carers allowance - I applied in January."



I love looking after my mum. And I have been caring for her from the age of 3 years old. I find at times it gets difficult as I'd like to have my own time."

Full recommendations - local

If carers are going to be properly recognised, listened to and supported, then there is an urgent need for action on a local and national level.

The need to identify and support carers should be included in the new Integrated Care Strategies with clear actions and carer support organisations should be viewed as a key part of integrated care partnerships

Integrated Care Systems have got a key role to play in improving health outcomes for everyone, but particularly those who face additional challenges to their health and wellbeing. Given the impact that caring has on the physical and mental health of carers of all ages, Integrated Care Systems need to ensure that the needs of carers are central to their new Integrated Care Strategies

Integrated Care Systems should sign up to the Carer Friendly Tick Award - Health and Carer Friendly Tick Award - Employer, and strongly encourage other organisations to sign up and include a requirement for carer-friendly practices into commissioning.

Carers need to be included as a priority group within any local schemes to help with the cost of living or combat 'winter pressures'

In both Cambridgeshire and Norfolk, many carers have been able to be assisted through the Household Support Scheme which has been of great benefit.

Over the coming months, it is vital that carers continue to be prioritised for any subsequent schemes as well as any 'winter pressures' projects designed to reduce the challenge that the winter months place on the health and social care system.

Ensure that the needs of support for parent carers are included within the refreshed carers' strategies and that work on the pathways for accessing support for parent carers are prioritised

Parent carers have highlighted the lack of support available for them and that assessments/reviews are not happening as they should. Work needs to continue in Cambridgeshire, Peterborough and Norfolk to ensure that parent carers can access meaningful assessments, and that there is support available to meet identified needs.

All health and social care professionals should receive carer awareness training

Carers raised a wide variety of issues relating to their experiences with health and social care – from poor communication, to systems not working as they should, to a failure to ask carers something as simple as "How are you doing?". Mandatory carer awareness training for health and social care practitioners, as well as those who are training, would increase the early identification of carers and increase the likelihood of a better experience for carers and the person they care for.

All hospitals should ensure that hospital discharge processes proactively seek to identify and involve carers, and ensure carers (including young carers) know about support available

Carers of all ages have fed back about negative experiences when the person they care for is in hospital, with some worried about them going back in. The Health and Care Act 2022 gives specific rights to carers and young carers to be consulted ahead of discharge of an adult. This presents a real opportunity to ensure hospital processes are supporting staff to identify carers and young carers and ensure they are linked into support. Given the current pressures on adult social care, local authorities and Integrated Care Boards should look to use an element of the Discharge and Workforce fund to provide additional support to carers at hospital discharge, to reduce the chance of carer breakdown and the person being cared for being readmitted to hospital.

All schools should to sign up to the Young Carers Challenge (caringtogether.org/youngcarerschallenge)

With young carers being added to the school census in January 2023, every school should sign up to the Young Carers Challenge to ensure every young carer in Cambridgeshire, Peterborough and Norfolk has someone to talk to when they are in need of support and knows what support is available.

Full recommendations - national

The Government needs to commit to a cross-government Carers Strategy covering the needs of carers of all ages including young carers and parent carers

The last national plan for carers finished in 2020. The issues raised by carers through Carers Speak Out cut across numerous government departments, such as Health and Social Care, Education and the Department for Work and Pensions. In order to address these issues, there is an urgent need for a cross-Government Carers Strategy, complete with clear actions, accountability and resources for implementation.

Provide a top up payment for unpaid carers with an entitlement to Carer's Allowance to support them through the winter and recognise the additional costs they are facing amid the unprecedented cost of living crisis

Given the current financial pressures on carers, there should be an additional payment to help carers eligible for Carer's Allowance through the winter. Funding should also be available to support carers facing financial hardship.

Department of Health and Social Care and Department for Education should undertake a joint review of how the Care Act 2014 and Children and Families Act 2014 are working in practice for carers

2023 will see us approaching the ten-year mark for the passing of legal rights for carers, young carers and parent carers. But there hasn't been a national review of how this is working in practice for carers. There should be a joint review examining how the Care Act and Children and Families Act rights are working for carers.


Review all carers' benefits, including Carer's Allowance, to ensure that these work well at supporting all types of unpaid carers and preventing them from falling into financial difficulties as a result of their caring role

While short-term financial support for carers would be welcome, current carers' benefits are forcing carers into a life of poverty. There needs to be a wholesale review of carers' benefits such as Carer's Allowance to ensure carers can look after their own needs as well as those of the person they care for.

The Government needs to continue to support the Carer's Leave Bill, so as to increase rights for carers in the workplace

It is welcomed that the Government is supporting the Carer's Leave Bill. As a minimum, the Government should commit to ensuring the Bill becomes law and is properly implemented. It should also seek to expand on the Bill so that carer's leave is paid leave, so as to avoid effectively penalising carers for needing to take time off of work to care.

Times have changed and so has unpaid care!

We're not in the 1950's any more! Many people juggle caring with work, we don't live 'round the corner' from our loved ones, caring is hard physically and mentally, not just popping in for a cuppa and a chat. We get isolated, depressed, ill, out of touch with friends and family, stressed from arguing with authorities who don't understand and have no resources. We lose our quality of life as much as the person we care for. We become carers in an instant, it doesn't end until our loved one dies."

Gil

All day every day

“Unpaid carers work 24/7/365. There's no sick pay, union, workers rights, clocking off or holiday days for us. Our loved ones rely on us to be there for them and more often than not during the pandemic we've been asked to step up and take on even more caring. Many of us have given up our careers to care full time and gone from earning good money to being paid a weekly pittance known as Carer's Allowance. How many MPs would take on the levels of responsibility we have for such a small amount of money?”



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