Caring

Issue 75 | Winter 2025

“We managed this as a team.”

carersUK

Image © Skye Kilgannon

Welcome

Welcome to the final edition of *Caring* for 2025. As we come to the close of our 60th anniversary year, I'd like to take this opportunity to look back at how our theme of 'Equality: today and tomorrow' has carried through in everything we've achieved.

We've pushed on multiple fronts to ensure carers are seen and heard, demanding that policy and practice catch up with the reality of caring. Earlier in the year, we challenged the Government's welfare reform proposals, highlighting the urgent risks for carers – including possible loss of entitlement to benefits such as Carer's Allowance and Personal Independence Payment.

We've held a wide range of events, taking place up and down the UK. From marathons and fundraising challenges to our art, photography and poetry competitions, carers have made their voices heard through their activism and creativity, and our Members' Conference in April gave members the chance to share their experiences and connect with other carers.

> "Looking ahead to 2026, we will take forward the lessons we've learned and keep the momentum going."

Our Mary Webster lecture series has provided a platform for debate about the future of caring, and I am especially proud of two landmark events: the inaugural Carers UK Awards, which celebrated the individuals and organisations working to make life better for unpaid carers, and our first Carers UK Carol Service.

But there's no time to rest on our laurels. Our research this year has revealed stark truths: unpaid care in the UK now has an estimated annual value of £184 billion, yet nearly half of carers say they've had to cut back on essentials like food, heating or transport due to the cost of care. We know that more than half of carers are providing more hours of care than a year ago, that many are struggling with their own health and that work-life balance is a myth for too many.

Looking ahead to 2026, we will take forward the lessons we've learned and keep the momentum going.

Finally, as the festive season approaches, I want to conclude the year with a heartfelt 'thank you'. Thank you for your commitment, for the hours spent caring that have gone unseen, for speaking out and for showing up. You are at the heart of everything Carers UK exists to achieve.

Wishing you a peaceful end to the year and hope for the future.

Helen Walker, Chief Executive

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News

State of Caring 2025

Over 10,500 carers and former carers took part in this year's State of Caring survey. Thank you to everyone who shared their experiences – you've helped show what life is really like for carers, throughout the UK, today.

We're releasing a series of reports based on your insights, providing powerful evidence to help us push for a better life for carers.

Our report, *State of Caring 2025: The Cost of Caring* – the impact across carers' lives, highlights just how much carers are doing – and the toll it can take on finances, health and wellbeing, work, and future security:

- More than half (52%) of carers are providing more hours of care than a year ago
- Nearly half (49%) have cut back on essentials like food, heating and transport
- Over a third (35%) of carers in paid employment have reduced their hours
- Almost three quarters (74%) feel stressed or anxious.

No one should have to face these challenges without the right support. That's why we're calling for a fairer settlement for carers and urging the UK Government to deliver a new National Carers Strategy, long-term investment in social care, improved financial support, and statutory paid Carer's Leave.

Our findings have already made headlines on Good Morning Britain, BBC local radio, and LBC News – helping to make sure carers' voices are heard loud and clear.

Later in this issue of Caring you'll find an article about our new *Thinking ahead* report, which is based on findings from the State of Caring 2025 survey.

You can also explore our recent State of Caring reports at go.carersuk.org/state_of_caring

carersUK

State of Caring 2025

The cost of caring – the impact of caring across carers' lives

October 2025

Save the Date: Carers UK Members' Conference 2026

Tuesday 28 April 2026 | 9.30am-4pm | London and online

We're pleased to share that the Carers UK Members Conference will be returning in a hybrid format for 2026. Join us at Woburn House, London or from home via Zoom Events.

No matter how you attend, you'll enjoy the same uplifting, informative and supportive experience. You're welcome to be with us for the whole day or to drop in online whenever it suits your caring responsibilities.

We'd love you to join us: register at carersuk.org/about-us/agm-members-conference

Understand the law on social care with AccessAva

Do you need support or have questions in relation to the law and social care in England?

Carers UK has teamed up with the charity Access Social Care to provide an online tool called AccessAva. This free online tool is designed to help you understand the law on social care in England. It can help you find out about the rights you have and the rights of anyone you're caring for, and provides things like template letters developed by expert lawyers.

To find out more, visit: carersuk.accesscharity.org.uk

Carers Parliament 2025

The Carers Parliament 2025 was held at the Apex Hotel in Edinburgh on Thursday 30 October.

It is the biggest annual event for unpaid carers in Scotland, giving them the opportunity to address their concerns and questions on caring directly to national and local Government decision-makers.

This year's event was chaired by Becky Duff from Carers Trust, and saw 125 carers from across Scotland attending in-person, plus 100 more online. With an election in Scotland coming up next year, the focus of the event was on 2026 and beyond to address the main priorities for unpaid carers and how their lives can be improved.

Thank you to everyone who joined us and took part in the discussion, both in-person and online. Your input is so valuable in steering our work to improve the lives of carers in Scotland.

Being Heard guides

Our refreshed new guides have been updated to provide even more tips and guidance on how to self-advocate as a carer.

There's a version available for each nation, to give you the tools and confidence needed to help secure the formal support you and loved ones need.

To download your free copy, visit: go.carersuk.org/Being_Heard

Secret Art Exhibition

As part of the 60th anniversary celebrations, Carers Wales held a Secret Art Exhibition at the Queen Street Gallery in Neath.

Artists from across Wales, the UK and even internationally donated pieces of their work to be displayed and auctioned off anonymously to raise funds for Carers Wales.

We're delighted to say that the auction successfully raised £18,500 for Carers Wales, money that will be put to use to make carers' lives in Wales better, through a range of activities.

One of our longest-serving volunteers and member of the Carers Wales committee, Jocelyn Prosser, had the original idea and was the driving force behind this event. With the support of her friend and South Wales artist, Therese James, they contacted artists and encouraged them to donate their work, while Jocelyn also liaised with galleries across South Wales to find the perfect venue.

Jocelyn also helped bring extra sparkle to the launch by inviting Welsh weather presenter Sian Lloyd and other well-known Welsh artists and personalities. The exhibition and auction would not have happened without her and Therese's enthusiasm and expertise: we want to thank them both for their support.

Scotland's National Carer Organisations launch election manifesto

The National Carer Organisations, including Carers Scotland, have launched our manifesto for carers for the upcoming 2026 Scottish Parliament election.

The manifesto focuses on improvements in areas that carers tell us are of greatest concern: access to support, looking after their health and wellbeing, and having financial security.

The manifesto is calling for bold action by the next Scottish Parliament to fully deliver the support that carers need.

There are 10 key actions for the Scottish Parliament, which can be read in full here: go.carersuk.org/NCO-manifesto

Celebrating 60 years of Carers UK

60th anniversary scrapbook

Throughout our 60th anniversary year, we have hosted special events across all four nations.

Here is a look back at a small selection of the special occasions we have shared throughout 2025.

January

Bank of England 60th anniversary launch event

April

Paws for Carers

Kiltwalk

Members' Conference

May

Mary Webster Lecture Scotland

Most Valuable Portrait display on the South Bank

June

BBC Radio 4 Appeal

October

Carers UK Awards

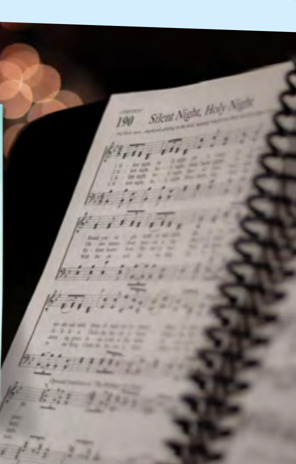
Carers Wales Postcard Exhibition

60th anniversary Belfast & Derry Mayor receptions for carers

November

Mary Webster Lecture London

December

Carers UK Carol Service

CARERS UK
Awards
2025
CARERS UK

Shining a light on unpaid carers

A remarkable night at the first Carers UK Awards

An inspiring new national event celebrating unpaid carers and the people and organisations making life better for them.

The first-ever Carers UK Awards brought together carers, supporters, charities, employers and community organisations for a truly uplifting evening dedicated to recognising the enormous contribution of unpaid carers across the UK. Held at Plaisterers' Hall in London, the event, which wouldn't have been possible without the generous support of, Phoenix Group, was created to honour not only those providing care day in, day out, but also the individuals and groups who are working tirelessly to improve carers' lives.

From the moment guests arrived, the atmosphere was charged with excitement and anticipation. The Awards provided something long overdue: a national platform that celebrates carers' achievements, acknowledges their challenges, and recognises the vital importance of the support they provide to families, communities and society.

The Awards dinner, hosted by actor and comedian, Stephen Mangan, saw 11 winners walk away with coveted Carers UK Awards trophies spanning community and workplace Awards as well as the Johnnie Walker Lifetime Achievement Award, which was presented to Baroness Jill Pitkeathley OBE.

Speaking after being announced as Carer of the Year, Amy Elizabeth said, “These Awards are just unbelievably important. More than any Oscars, any BAFTAs, any big awards ceremony. I mean, celebrating caring for other people, literally the clue is in the title, is the most important thing for humanity.”

Through each category – from Carer of the Year to Exceptional Carers Network – the Awards shone a light on extraordinary people whose dedication often goes unseen. There were moments of laughter, pride and emotion, and the room frequently erupted into applause as finalists stepped forward to be celebrated.

But this wasn't just an occasion to highlight individual achievements. It was also an opportunity to acknowledge the organisations, employers, local services and volunteers who are driving meaningful change for carers. Their work – whether improving workplace policies, providing innovative local support, or raising awareness in their communities – is essential to helping carers feel valued and supported.

For Carers UK, the Awards marked an important milestone. After 60 years at the forefront of the carers' movement, hosting this event reinforced our commitment to building a society that recognises and supports the millions of people who provide unpaid care. The Awards were a powerful reminder of why our mission matters, and why we will continue to push for better rights, better services and better understanding for carers everywhere.

Above all, the evening was a celebration of you – the carers who show up, care deeply and give so much of yourselves every day. Your strength, love and perseverance inspire everything we do. The Carers UK Awards were created to honour that spirit, and we look forward to continuing to celebrate your contributions in the years to come.

> "Celebrating caring for other people...is the most important thing for humanity."

You can find a full list of the winners and finalists at carersuk.org/awards and take a look back at the awards dinner at bit.ly/4p4tKv2

Thinking ahead

A recent Carers UK report has highlighted that many carers are missing out on much-needed financial support. We offer some guidance on how to take control of your finances.

On Carers Rights Day, we launched our new report *Thinking ahead: supporting carers to manage their finances*, sponsored by HSBC. Based on carers' insights and experiences shared in the State of Caring 2025 survey, this research highlights that many people are missing out on support – despite the intense financial pressures that caring can bring.

63%

of financially struggling carers have accessed no financial guidance or resources in the past year

Concerningly, carers told us they often do not know where to turn for guidance, struggle to navigate a complex social security system, and can lack confidence to plan for the long term. This can put both their financial security and wellbeing at risk.

Carers UK is calling on the UK Government to take action to alleviate these financial pressures. This includes calling for a fairer benefits system, improved support for those who wish to remain in paid work, and a new National Carers Strategy – with clear commitments on financial wellbeing.

Alongside campaigning for change, we are raising awareness of the financial guidance and support that already exists. This is vitally important, as the State of Caring survey found that:

- almost two-thirds (63%) of financially struggling carers have accessed no financial guidance or resources in the past year
- 41% of carers do not know what social security benefits they are entitled to, rising to nearly half (45%) among those struggling to make ends meet.
- over a third (37%) of struggling carers need support to manage stress and anxiety linked to money worries.

Read our report to find out more
go.carersuk.org/thinking_ahead

Five steps towards taking control

We've outlined five steps you can take to help take control of your finances

Do you ever feel anxious or stressed when thinking about your financial situation? You're not alone. Our recent research shows that 60% of carers feel this way.

It can be tough to make ends meet, especially if you've had to give up a job or reduce your working hours to care. You may worry about how you will manage unexpected costs or plan for the future.

If you're looking for ways to feel more in control and address such concerns, we have put together five simple first steps you can take:

Step one: See if you're entitled to any financial support

You can contact an adviser by emailing advice@carersuk.org and ask for a benefits check. This is free and many people find it helpful as an opportunity to review their situation. They will let you know what details would be helpful to provide. Some people also find that using a benefits calculator helps as a starting point: go.carersuk.org/Benefits_Calculator

Step two: Plan ahead

Many carers worry that they won't have had the opportunity to gain enough National Insurance Credits through employment, as needed, to build up a pension. If you're not eligible for Carer's Allowance, which would provide you with credits, one option is to look at whether you would qualify for Carer's Credit. You can find out more on our pension planning page: go.carersuk.org/planning-ahead-pensions

Managing the finances of someone else in the future may also seem daunting but our guidance can help offer some reassurance and options: carersuk.org/help-and-advice/practical-support/different-ways-of-managing-someones-affairs

Step three: See what financial resources are available for carers

There is a plethora of information available – see our website or our printed guide *Looking after someone* for suggestions of ways to top up your income or reduce your outgoings: go.carersuk.org/Financial_Support

You can also find out what support your bank or building society can offer – they should have a specialist team who can help if you're worried. If you're considering giving up work to care, it is important to seek advice before making any big decisions: go.carersuk.org/thinking-of-leaving-work

Step four: Are there any grants you could apply for?

There are many organisations that want to offer support. You can find guidance on our website on where to start researching what grants and support could be available to you: go.carersuk.org/Grants_and_Schemes

Step five: Do forms and paperwork make your head spin?

Many people are put off applying for the support they're entitled to because of the perceived effort and time it takes. We have some handy hacks to help you navigate this process: go.carersuk.org/filling-in-forms

Remember to take your time and never feel rushed into making any kind of decisions when it comes to your finances. If an offer or scheme seems too good to be true, then it probably is. Many people are being caught out by scams, so see our scams guidance too: go.carersuk.org/safe-from-scams

For further support and tips see our guidance on ways to save money at home: go.carersuk.org/save-at-home

You can also access our ways to save money factsheet: go.carersuk.org/ways-to-save-factsheet

You'll find all the steps above — plus more tips and links — in our new online Financial Toolkit available here: go.carersuk.org/financial-toolkit

Accessing support if you are not online

If you are based in England, Scotland or Wales you can access advice on benefits, debt and money by speaking to the Citizens Advice Bureau. Contact your local council to find out how to get in touch with your local branch of the Citizen Advice Bureau. In Northern Ireland, you can request a free benefits check by calling 0800 232 1271.

Making Carers Rights Day a success

On Thursday 20 November, our members put carers' rights in the spotlight.

Whether you attended our events in Belfast and Cardiff, joined us online, shared your experiences, emailed your MP, got involved in your local community, or raised awareness on social media, you helped to connect more carers to essential support and information – we'd like to thank you!

The theme for this year's Carers Rights Day was 'Know your rights, use your rights' as it's important that all carers understand their rights and feel empowered to use them.

If you didn't catch it on the day, we wanted to give you a flavour of our 'Know your rights, use your rights' campaign by sharing our member Geoff's story below.

It's a great example of the difference putting your rights into action can make.

> "It's important for carers to be able to talk about their own situation."

Geoff's story

Geoff has been a full-time carer for many years for his wife Jean, who has multiple sclerosis, uses a wheelchair and is paraplegic. Geoff's care has meant that Jean has been able to live at home, and they continue to lead a full life together.

We spoke to Geoff about his experience of using his rights, and why he feels this helps carers, like him, to navigate the system.

Geoff has a carer's assessment each year, as he values the opportunity to open-up about his caring situation and to talk to someone who understands. In his area carer's assessments are offered by the local carers' centre on behalf of the local authority. He's always found that the staff conducting the assessments are understanding, listen to his concerns and try to help. For instance, by liaising with the council to find out information and answers.

Geoff said he would 'definitely' encourage fellow carers to consider having an assessment as, "it's important for carers to be able to talk about their own situation." He highlighted the utmost importance of ensuring carers are looked after, as without them, "what would happen to the people they care for?"

You can also find out more about your rights by reading our updated *Being Heard* guides. The guides are designed to help you get your voice heard.

Check out the *Being Heard* guide here: go.carersuk.org/Being_Heard.

Carers in conversation: Nuala and Natalie

“Caring is a natural extension of our relationship”

Natalie cares for her wife Nuala, who was recently diagnosed with uterine cancer. Here, they discuss what their caring journey has taught them about themselves – and each other.

Natalie: “I’m American and I work in legal tech. Nuala and I have been together for over 30 years – and we got married as soon as we could. We live in London.

Nuala: “I’m Scottish and a film festival director. I had breast cancer more than 10 years ago and then, last year, I was diagnosed with uterine cancer. We – and I do mean ‘we’ – have gone through the whole journey of surgery, chemotherapy and radiotherapy for a second time. Now the treatments are behind us and we’re beginning to get our life back again, while taking time to reflect on what we’ve been through and what may lie ahead.

Nuala: What was the hardest part about stepping into a caring role?

Natalie: Being your carer this second time around meant I knew some of the pain and uncertainty that lay ahead for you; and I had a slight dread of the exhaustion I might experience again. I knew how hard the journey could be.

Image: © Skye Kilgannon, who posts on Instagram as @alonglines

"Now the treatments are behind us and we're beginning to get our life back again, while taking time to reflect on what we've been through and what may lie ahead."

– Nuala (pictured on the left with Natalie)

> *"Caring can involve flashes of anger, real exhaustion, hopelessness: it is hard on your mental health. And I didn't really consider my own mental health at the time."*
>
> – Natalie

Natalie: What was it like for you, seeing me take on a caring role?

Nuala: When I got a diagnosis or was being prepared for surgery and treatment, you were there listening, really listening, taking notes. So if I had trouble taking anything in, you were able to tell me afterwards. I knew you were a good listener in our everyday lives but feeling the effects of you listening during this experience with cancer was quite incredible.

Nuala: Has caring changed the way you see our relationship?

Natalie: I think caring is a natural extension of our relationship. It's kind of what relationships are for! One thing I love about our marriage is how balanced our roles are (for the most part!) When one of us is sick, the other one takes on a caring role, so we have some experience as short-term carers. But in terms of keeping the household running over months and months, it is hard when only one of you has energy to do all the roles.

Nuala: Is there anything you've learned about yourself that you wouldn't have, had life not taken us down this road?

Natalie: I learned something about considering my own mental health in tough situations. Cancer had a long tail for me the first time around. It took more than a year, I'd say, to process what I'd been going through as a carer and to name and acknowledge my own feelings. At the time I was proud of being hopeful – but keeping it real – during your treatment. And while I still think a positive attitude towards the patient helps, I don't think I sought enough outlets for my own negative feelings. Caring can involve flashes of anger, real exhaustion, hopelessness: it is hard on your mental health. And I didn't really consider my own mental health at the time. My energy was too outward-looking.

Nuala: I learned or re-learned how important your faith and your church are to you. At the time of my first cancer diagnosis and treatments, you weren't a practising Christian. But the second time around, you were. I saw and appreciated the practical help, care packages, prepared meals, prayers and spiritual support your church community gave you – and to both of us. I'm not a believer, but I learned that religious belief can be a source of great nourishment in tough times.

"I want to see a future for carers where...

Natalie: "Carers are recognised and supported by the government, by society, by everyone for the work they do – often over and above their day job and their other responsibilities."

Nuala: Is there a moment where you've felt proud of us as a team?

Natalie: When we created a care rota for your daily radiotherapy appointments. Family and friends stepped in and took you to the hospital for some of the weeks. I felt proud of how we managed this as a team, that we got everyone involved and that it worked well and took some pressure off both of us. I also thought our friends were amazing!

Nuala: I loved that this team work not only gave you a much-needed break from caring, but it gave me the chance to catch up with people and keep my extravert self happy.

Nuala: What do you wish other people understood about the reality of being a carer?

Natalie: That it involves the whole person – it's physical, emotional and mental. It's often a full-time job, and can be required on top of the other full-time job you might have.

Natalie: What do you wish people understood about the reality of needing care?

Nuala: That I'm more than just a person living with cancer. Cancer doesn't define me. I'm still the same person I was before I got ill.

Nuala: What advice would you give to other couples in a similar situation to us?

Natalie: If you're able to, try to name the feelings when you're feeling them or as soon as you can afterwards. Saying out loud 'I feel scared when I imagine life without Nuala' or 'I feel angry because it's unfair she's been diagnosed with cancer for a second time' helped me. Naming my emotions meant that the post-treatment cancer tail was shorter the second time around. I also gave myself more opportunities to process with friends than the first time around.

> *"Naming my emotions meant that the post-treatment cancer tail was shorter the second time around."*
>
> – Natalie

Natalie: What advice would you give?

Nuala: Your love can blossom and you can get to know each other in a very deep way during a difficult time like this. But also, try to have time away from each other too – even if just in a different room if you can't get out of the house – so that you still retain your own individuality.

"I want to see a future for carers where...

Nuala: "People who do the parenting, nursing, teaching, cleaning, caring are celebrated and appreciated. During the Covid lockdowns we all understood and appreciated what our 'essential workers' were doing. I'd like to see carers being paid a living, decent wage for the work they do and the care and love they give."

Finding support this festive season

We know that the festive season can be challenging for many, especially if you feel exhausted from caring or are missing a loved one. Please read on for different ways of staying in touch over the festive period.

December Care for a Cuppa

We will be running a Care for a Cuppa online get together on Thursday 18 December at 7.30pm-8.30pm, where you can join to chat with other carers over Zoom. We'd love to see you there!

You can sign up at go.carersuk.org/online-meetup

You can also connect with other carers on our online forum 'Carers Connect'. Our forum is made up of a community of carers and former carers. Many enjoy meeting others and exchanging tips and advice, reaching out to fellow carers and offering invaluable support.

The forum can be found here: carersuk.org/forum

Carers UK telephone helpline

Our telephone helpline will continue to be available throughout the festive period, and will be open Monday to Friday, 9am–6pm (including Christmas Day, Boxing Day and New Year's Day.)

The number is 0808 808 7777 and is free to call from landlines and mobiles.

Our email helpline service will be offering a reduced service from Wednesday 17 to Friday 19 of December 2025.

The service will be closed for the Christmas period and will reopen on Monday 5 January 2026. Please be aware that that responses might take longer than usual during this period.

You can find further sources of support on the Carers UK website if you are struggling: go.carersuk.org/emergency

If you need somebody to talk to or a listening ear, the Samaritans are available 24/7 and can be reached by telephone on 116 123 or by email at jo@samaritans.org

Tips to help you cope over the festive season

We know that the festive season can be challenging for many, especially if you feel exhausted from caring or are missing a loved one. It can be easy to become burnt out with everything you're juggling. Here are some tips on how you can look after your physical and mental wellbeing.

1. Try to take a break when possible

Even if you can only snatch moments in between your caring tasks, you'll have a much better frame of mind if you take some time out by going for a quick walk, reading a few pages of a good book or having a short nap.

2. Build your circle of support

The 'to do' list at this time of year may be even more overwhelming than normal and it can feel isolating and stressful tackling it alone. Keep in touch with other carers by joining online events or in-person get-togethers in the local community if you can. Your local council or Health and Social Care Trust will be able to suggest local organisations that can help.

3.Stay nourished

Try baking some homemade seasonal treats if you can find time, such as mince pies or gingerbread. These could be healthier, tastier (hopefully) and cheaper than shop-bought ones. Baking is also known to be a good form of relaxation.

4. Keep warm and well

Cold weather and icy conditions can make it hard to get out and about so you may feel very restricted. If you need to stay in, try to make a regular habit of speaking to friends or family – and ensure you keep warm and cosy. If you're worried about heating bills, you could look to focus heating the rooms you spend most time in.

For our tips on saving on energy costs, see: go.carersuk.org/help-with-energy-costs

5. Stock up on vitamin D

In winter, many of us get tired because we're lacking the vitamin D we would normally naturally gain from the sun. The Department of Health and Social Care recommends that all adults consider taking a daily vitamin D supplement from October to March.

6. Protect yourself against flu

If you are a primary carer receiving Carer's Allowance, or if you are the main carer for an elderly or disabled person who may be put at risk if you became ill, you will be entitled to a free flu jab.

You can find out more on our information page or enquire about this with your GP practice: go.carersuk.org/flu-jabs

7. Dementia support

If you care for someone with dementia, this time of the year can be particularly hard.

The Alzheimer's Society has developed some tips on how to reframe the season to help you and those with dementia enjoy it, in spite of the challenges: alzheimers.org.uk/blog/how-support-dementia-christmas

You can find more help and advice on looking after yourself over the festive period on our website:

go.carersuk.org/your-health-and-wellbeing

Further support

If you need somebody to talk to or a listening ear, the Samaritans are available 24/7 for everybody. **They be reached free by telephone on 116 123 or by email at jo@samaritans.org**

The Shout service is also available 24/7. Shout is a text-based service for times when people feel they need immediate support if they are feeling low, anxious worried or lonely. **They can be contacted for free by texting SHOUT to 85258.**

If you're worried about the immediate safety of yourself or another person, call 999.

Christine’s story

Practising self-care

Christine, who cares for her daughter Evie, shares her caring story – and how she boosts her own wellbeing when things get tough.

“I became a carer for my daughter Evie just before her second birthday. Evie had a huge epileptic seizure which the doctors couldn’t stop, so they had to intubate her.

“Evie spent a week and a half in intensive care and when the doctors bought her round she had regressed hugely. She could no longer sit or stand up, she’d lost all head control and could no longer eat, talk or walk.

“We spent just over five months in hospital and Evie had numerous tests to try to determine what caused these devastating changes. Evie had two MRI scans whilst in hospital, which showed significant brain atrophy, and sadly we were told this atrophy would likely continue even though we still didn’t have a diagnosis.

> “Evie is now 11. She is defying the doctors everyday...
>
> we cherish every day we have with her.”

“We got the devastating news that the doctors didn’t think Evie would live for very long and likely wouldn’t make her third birthday. Plans and equipment were put in place for us to leave hospital, and in the doctor’s words, ‘make memories’.

“Evie is now 11. She is defying the doctors every day but we are very much aware that her prognosis is still a short life expectancy, so we cherish every day we have with her. Evie got a diagnosis of MEF2C Halpoinsufficiency Syndrome in 2018 and her particular variant is very rare. Because of this, we don’t have a lot of information on her condition, which is really hard.

"A typical day for myself starts at 6.30am with Evie's first medications of the day (it can be earlier than this, as Evie's sleep patterns can vary greatly). Evie relies on myself fully for all her care needs, including medications, feeds (she has a feeding tube), respiratory management (cough assist, chest physio, suction) washing and dressing, physio stretches (she has dislocating hips and elbows and scoliosis) hoisting and transferring to her wheelchair. If Evie goes to school, she's there between 9am and 3.30pm and then the care routine continues when she gets home until her last medications at 11pm.

"I usually spend the time Evie is at school catching up on admin (medicine ordering, sorting appointments, emailing professionals) and also trying to get some rest if Evie's had a bad night. I'm also volunteering for a local community interest company that supports people with their mental wellbeing as this is a huge area of passion for me.

"If Evie is on school holidays, we love to go on days out to the park, sensory spaces, meeting up with friends and family. Although we are now reliant on only going to places that have proper changing places facilities, which can be limiting.

"Evie relies on myself fully for all her care needs, including medications, feeds, respiratory management, washing and dressing, physio stretches, hoisting and transferring to her wheelchair."

"One of the biggest challenges I've faced is fighting every year to meet the criteria for NHS respite care. Every year, we have to have an assessment to establish Evie's care needs and despite these not getting better – and in some areas, they have got worse – we've had to battle to keep our current respite package. This has sometimes involved getting Evie's consultant involved to back up the need for it. It's a really draining and upsetting process.

"We also had to leave Evie's last respite provision due to poor management and mistakes being made in her care. Thankfully, despite myself and Evie's dad not being together, we still work well together for Evie and he is a great dad. He loves spending time with Evie and looks after her to allow me to have a break. This has been especially beneficial whilst we look for a new place to offer respite.

"I'm only able to cope with the above by having some me time and practising the self-care routines that I know improve my ability to cope."

"Another challenge is the seemingly lack of care and empathy from professionals. I constantly have to chase people who don't reply to emails and I feel like I am the one who has to sort everything out, which is draining; I'm often the middleman between professionals.

"We have been in numerous hospital appointments where consultants ignore Evie and show a real lack of empathy in the way they deliver difficult information about her condition. It just very much feels like professionals don't really care sometimes and we are just left to it, even when we say we're struggling.

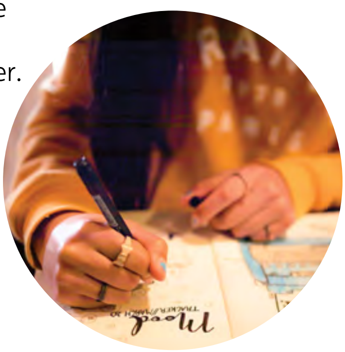
"I'm only able to cope with the above by having some me time and practising the self-care routines that I know improve my ability to cope.

"I've learnt over the years the importance of looking after myself. I like to go for a run or a walk as being outside in the fresh air really helps me clear my head, and also feel better physically.

"Yoga has been a life-saver for my back problems, and I find it a really calming experience. Journalling has also been huge for me and I find it really helps to empty my head onto paper.

"I also work for a mental wellbeing company, which has helped me realise a passion of mine and helped me greatly with my own mental health.

"Journalling has also been huge for me and I find it really helps to empty my head on paper."



"I would definitely recommend local support groups if people are struggling."

"From my work experience, I have learnt that we are in a mental health crisis in this country; there are so many people struggling and getting to crisis point. If more support was available at an early stage, we could prevent so much of this.

"I would definitely recommend local support groups if people are struggling. We have the wonderful Reuben's Retreat, which supports families with children with complex needs to be around other families that get it. It is crucial and such a valuable support system.

"My Couch to 5k group has been an incredible source of me time support from my fellow carers. It's allowed us to meet up do some exercise and have a lovely catch up and cup of tea after. Personal development workshops also help to give practical tools and techniques for helping with mental wellbeing."

"I want to see a future for carers where...

We feel heard and seen and not the forgotten people of society.

I want our role to be valued by the Government and society more, and financially be recognised for this.

I want respite packages to be awarded without the battle, to allow us all to have that much needed vital break and time for us. I want us to be respected by professionals and for them to know that we know the person we care about the best. I want there to be a support package to provide for us if our loved one passes away."

Carers UK online meetups

Carers UK online meetups offer a wide range of sessions where you can meet other carers who understand what you're going through.

You can find out the full schedule and register here: go.carersuk.org/online-meetup

Ben's story

Caring for a partner

Earlier this year, film-maker Ben released a short documentary about his mother's story of caring for his father, who was diagnosed with Type 2 Degenerative Multiple Sclerosis. Here, he shares the impact caring has had on him and his family, and what they learned through the making of the film.

“I've been supporting my mum with my dad's care for several years, doing my best to support them both physically and emotionally through constantly worsening circumstances. But I felt like what I could do for them was becoming increasingly limited.

“As the physical demands of caring began to increase, the grief they felt became harder for them to communicate, which compounded a crippling feeling of isolation from the rest of the world. There are very few accurate and honest representations of the carer's journey in mainstream media.

“Making the film was a way of being able to restart the conversation with them both, to reflect their struggles and loss, but also remind them of their incredible endurance and commitment to each other so that they could see themselves like I see them.

“My parents decided that they wanted to be honest so that their experience was accurately represented. But speaking from such an intimate place was incredibly sensitive, so to make my mum and dad feel as comfortable as possible, I shot the film by myself so that they would only have to talk to me.

“As the physical demands of caring began to increase, the grief they felt became harder for them to communicate, which compounded a crippling feeling of isolation from the rest of the world.”

“Managing all of the technical tasks and conducting the interviews at the same time was tough, and asking my parents very personal questions and hearing their responses was overwhelming at times. I had to put my personal discomfort to one side, like my mum and dad were, and remind myself that we were making something that had the potential to bring us closer together.

“Our family dynamics have changed significantly. Through many stressful situations and difficult decisions that have to be made, we’ve had to let go of some of our expectations about traditional family roles and learn to be much more emotionally available to each other.

“While this has been liberating for my relationship with my mum and dad, their relationship as a couple has changed from being equal partners to becoming caregiver and dependent. It puts an enormous strain on them both to keep their connection as their vision of a future together has been reshaped.

“My mum was shocked when she saw the finished film – she couldn’t believe how clearly and rationally she had expressed her journey. I never doubted her, but she just needed to be reminded of her own strength.

> “It puts an enormous strain on them both to keep their connection as their vision of a future together has been reshaped.”

“I wanted to know how other carers would react to the film, so I connected with Carers Isle of Wight – a fantastic charity that provides vital guidance and support for unpaid carers – and we arranged to screen the film at their annual carers conference.

“The response was overwhelming – nearly 100 people attended and despite all facing different challenges, they saw their own experiences reflected in the film. I learned that their journeys all had common touchstones with my parents’ – fears for the future, adapting to change, feelings of isolation but also a constant discovery of their own strengths and capabilities.

“The reaction to the film has been varied. Carers and people who are cared for have said that the film reflected the realities of caring which made them feel seen and heard, which is truly humbling.

“Our local MP has also expressed a deep admiration for the courage my parents display in the film. But some film organisations, charities and press outlets have commented that the film is depressing and not a positive depiction of disability. These reactions have shown me that the realities of unpaid caring are still somewhat invisible to the general public, which is not surprising considering that many media depictions prioritise inclusivity and uplifting narratives.

“While I fully understand that focussing on the negatives can be reductive, to ignore the reality of caring sidelines the feelings of isolation and exclusion that many carers and their loved ones experience.

“I hope that our film reminds carers of their resilience, encourages them to recognise their dedication and emboldens them to talk openly about their experiences without fear of judgement. And I hope the film inspires empathy and a greater appreciation of unpaid carers from the general public.

“Unpaid carers provide a vital service, not only to the people they care for but to the country itself. Your commitment, your compassion and your empathy are what make Britain great. Despite the difficulties you face, remember that diamonds are formed under pressure. ”

> *“I hope that our film reminds carers of their resilience, encourages them to recognise their dedication and emboldens them to talk openly about their experiences without fear of judgement.”*

You can watch Ben’s documentary here: bit.ly/4ioTMqb

For further information and support about caring for someone with a specific condition, you can visit our conditions advice page: go.carersuk.org/conditions_hub

Winter is coming. Are you prepared for the possibility of a power cut?

Don't wait for the weather to turn. If you or a loved one has a disability, are hard of hearing or may find a power cut worrying or difficult, you can register for our free Priority Services for yourself or on their behalf.

From text updates to our free BSL video relay service, we ensure communication is never a barrier. We can help create a power cut plan tailored to your individual needs so you can have peace of mind all winter.

If you know bad weather is coming, you could prepare by packing an emergency kit and ensuring your mobile phone is charged. This kit could include a wind-up torch (or check you have spare batteries for a battery-powered one) some food, warm clothing or a blanket and any medications you might need. You could also fill a flask with hot water and write down any emergency contact phone numbers you may need.

For more information and eligibility on SSEN's Priority Services Register, visit ssen.co.uk/priorityservices, call for free on 0800 294 3259 or textphone 0800 316 5457.

If you don't live in SSEN's distribution areas in the north of Scotland and central southern England, please visit thepsr.co.uk. There you can enter your postcode to see who your Distribution Network Operator (DNO) is and how you can visit their Priority Services Register site.

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Martin and Lorraine's story

"Love carried us": how carer Lorraine helped her husband Martin regain his strength

Martin won our 2025 Carers UK Poetry Competition, with a poem inspired by his wife and carer, Lorraine. They shared their journey with us, and how their love and support of one another has carried them through.

Martin has lived with myalgic encephalomyelitis (ME) and post-traumatic stress disorder (PTSD) for most of his life. His wife Lorraine, despite her own disabilities, is his full-time carer, and according to Martin, best friend and anchor. Along with their children, Leanne and Martin, they have faced a number of challenges over the last few years.

In 2021, they moved into what should have been an accessible council home, but essential adaptations never took place. For three years, Martin had to sleep, eat, and use the toilet whilst sat in a reclining chair. With no nurses, no agency carers, and no community support, Lorraine and their children kept him alive through their love and care.

However, things continued to deteriorate and Martin's body began to fail.

"My body was filling with carbon dioxide – almost 13.5%," Martin says. "My organs were shutting down. My brain slipped into a kind of standby mode. I lost sensation in my legs. A brain injury erased years of my life."

One February morning, he collapsed and woke in hospital, trapped inside his body but able to hear nurses whisper that he was dying.

> "With no nurses, no agency carers, and no community support, Lorraine and their children kept him alive through their love and care."

“My heart began to slow and then I had a full-blown, leaving-this-life, near-death experience.

“I found myself somewhere desolate – a vast desert beneath overcast, storm-heavy skies. Behind me, a distant dark mountain range loomed, and before me stretched an endless wasteland.

“Yet in the distance stood a man I instantly recognised as Jesus. He smiled, and I knew I must walk behind him, out of that dead place where nothing lived. I stepped into sunlight and warm sand. When I looked back, his arms were still stretched wide – he hadn’t moved – and I realised that from the front he was welcoming me, and from the rear he was now protecting me.”

“When I opened my eyes again, I was back in that hospital bed, and the love in the room was beyond words. The pain was still there – but so was the immeasurable peace that hasn’t left me.”

Doctors told Martin that he would never get out of bed, go home, or walk again, but supported by Lorraine and his children, he did. Lorraine never left his side through it all.

“She’s my rock, my conscience, my lighthouse,” Martin says. “When I couldn’t carry myself, she carried me.”

Martin says that that Lorraine’s love became the inspiration for his poetry, especially his winning poem I Carried Him.

“I wrote it for Lorraine,” he explains. “It’s a love letter to her and to every carer who quietly keeps someone alive while the world looks away.”

When he gave Lorraine the poem, she smiled and burst into tears.

“To see our life written down like that, all the pain and love, it was overwhelming,” Lorraine says. “For once, I felt seen.”

When Martin performed the poem for the first time, he said he was terrified. Fighting agoraphobia, he wanted people to see Lorraine.

“When I finished, the room went silent,” he remembers. “Then everyone stood up. A standing ovation. I was embarrassed but moved – because they hadn’t just heard me. They’d heard her.”

“God saved me. Writing keeps me sane,” he says. “When I can’t speak, I write. When I feel like I’m drowning, it gives me air. Writing turns pain into purpose.”

“To see our life written down like that, all the pain and love, it was overwhelming...For once, I felt seen.”

Martin says his advice to carers is, “Don’t give up. The darkest hour really is before the dawn. Keep going. Keep believing. Shout for help if no one’s listening. There is always hope always light – even in the hardest nights.”

Through their experience, Martin and Lorraine say they have learned that love and faith can keep a family alive, but that shouldn’t be what survival depends on.

They would like to see a system that listens – one where GPs, hospitals, and the DWP treat carers with compassion, not suspicion. A world where caring isn’t an act of survival, but one of dignity and respect.

“We may not be powerful alone but united, we matter. It’s time the world heard our voices.”

I Carried Him

by Martin Seare

I watched the lion stumble.
Not in some slow fall from grace—
but a vicious tearing down.
His body, once god-like in strength,
betrayed him in silence, in swelling, in
stillness.
His breath thick with carbon, skin
screaming with sores,
and still—
he was *my king*.

Doctors whispered him dead with eyes
that never saw me.
Nurses fussed and fumbled,
measuring his days in drips and charts,
while I stood vigil
on the cliff between this world and the
next.

He slipped,
and I caught him.

Not with hands of marble—
no.
I caught him with shaking palms and
blistered knees.
With prayers screamed in the dark
and sheets wrung from sweat and sobbing.

I bathed the wounds.
I kissed the fever.
I spoke to the man inside the ruin,
told him:
You do not leave me.
I will drag you from the edge
with nails, with love, with rage.
Because without you, I am airless.
I am spine without bone.
I am not alive if you are not.

They told him he'd never walk.
But he walked.
Because I stood behind him,
spirit braced like stone—
my belief louder than death,
louder than the pitiful prophecies
of white coats and cold machines.

I saw him reborn,
not in a cradle of ease,
but with blood in his mouth and fire in
his eyes.
He stood because I willed the sun to rise
for him.
Because my love
was the breath in his broken lungs.

You see—
I did not marry a man.

I married *war*.
I married *resurrection*.
And I am not just wife.
I am battleground.
I am temple.
I am nurse, priestess, lover, Mother and
shield.

So let them marvel.
Let them whisper of miracles.
But know this—
He walks because *I carried him*.
And I will carry him
again
and again
until the stars forget to shine.

If you'd like to hear more of his work, Martin shares his poetry on TikTok as HoboDad. Martin's poem, as well as the other finalists in this year's poetry competition, can be found on our website: go.carersuk.org/poetry-competition-2025

We run a wide range of online sessions that can help inspire you to get creative and try your hand and writing – you can see a full list of our online sessions here: go.carersuk.org/online-meetup

Landlines in the UK are going digital.

Are you ready?

The UK's landlines are getting an upgrade and soon most phone calls will be made over a broadband line. Don't worry, your landline is here to stay. Your phone number won't change, and over 99% of handsets work with the new system.

For most customers, the move to Digital Voice - BT's new home phone service - is as simple as plugging your phone into a router rather than the phone socket on the wall.

If you don't have broadband

Don't worry, BT will be offering a dedicated landline service, allowing customers to use their landline in the same way they do today.

Supporting customers every step of the way

If you identify as vulnerable or need additional support, please contact your phone company. BT customers can call **0330 1234 150.**

If you use a healthcare alarm or medical pendant which allows you to press for help in an emergency, or a burglar alarm, inform your phone company and check with your equipment provider about any needed upgrades before the switch.

For more information about Digital Voice, visit: **bt.com/digitalvoice**

Whether you're looking for some inspiration to help bring more physical activity into your life, or want to find out where to get started, you can visit the Carers Active Hub

Carers
Active

Carers Active returns

We're excited to announce the return of our Carers Active programme, made possible thanks to funding from Sport England.

As an unpaid carer, it can be difficult to find the time to look after your own health and wellbeing. Carers Active offers information and resources to help empower you with the knowledge, confidence, and opportunities to be active in a way that works for you.

Whether you're looking for some inspiration to help bring more physical activity into your life, or want to find out where to get started, you can visit the Carers Active Hub.

You'll find a wide range of carers' stories, practical exercise videos, activity ideas and tips to help you overcome common obstacles and support your physical and mental wellbeing.

Find out more here: go.carersuk.org/Carers-Active-Hub

“I need energy for caring”

Susan shares her experience of how she keeps active while having arthritis and caring for her mum.

“Rheumatoid arthritis has affected my life in many ways. I was diagnosed 15 years ago, though I believe the symptoms started earlier. Physically, I can no longer do some of the activities I loved. I used to climb Scottish Munros and spend hours hill walking, but now I’ve had to adapt. These days, I stick to gentler walks and ride my horse when I can.

“Like many people with arthritis, I live with constant pain – always there, like background noise. On top of that, I have other conditions, including Fibromyalgia. My treatment involves tablets and two injectable medications. What’s harder for others to understand is the brain fog, extreme tiredness, and frustration. You want to do things, but your body slows you down, and everything takes longer.

“I’m excited to showcase Chi Me for Carers UK because it supports both physical and mental health.”

Caring for mum

“My mum is 92, blind, and living with Alzheimer’s. She’s fiercely independent, but carers visit twice a day to help with medication. I manage everything else – her banking, shopping, changing the bed, and even setting up the TV. For peace of mind, I monitor her front door via a camera.

“Sometimes she needs me late in the day, which can be tough when I’m exhausted or in pain – but I go because there’s no one else. I keep a detailed diary for appointments, prescriptions, and utilities. It’s a lifesaver when brain fog hits.

Staying active and volunteering

“I walk to mum’s most days – just seven minutes, but it counts as exercise. On bad days, I drive. After a hospital stay, I joined a local walking group for fresh air and mental health. The walks are short, but they keep me moving.

“Sundays are for riding. Spending time with my horse and friends lifts my spirits, even if I ache afterward. Living alone and caring for mum means conversations can feel repetitive, so outside interests are essential. Short, regular exercise works better for me than the gym – I need energy for caring.

“Looking for support, I discovered Arthritis UK’s self-management course. It taught me pacing and the importance of staying active to reduce pain and maintain independence. Later, I joined their online support group – and now I run it! I’ve also trained in Chi Me, a Tai Chi-based program designed to help people with arthritis.

“I’m excited to showcase Chi Me for Carers UK because it supports both physical and mental health.

My advice to other carers

“Find outside interests, even in small doses. It makes a huge difference to wellbeing. Next on my list? Yoga and Pilates – manageable sessions that fit around caring duties.

“Above all, look after yourself and don’t lose who you are.”

Why is sleep so important?

Dr Nerina Ramlakhan shares her tips for getting a good night's sleep, and why sleep is so important to wellbeing.

I have spent almost three decades helping people to sleep more deeply and restoratively. I passionately and firmly believe that sleep matters. My lived experience, as someone who suffered from insomnia from childhood and into my 30s until I learnt how to sleep well, also lies at the core of my passion. I believe that sleep is healing medicine, and my lived and professional experience bears this out.

How can a good sleeping routine improve physical and mental wellbeing for carers?

Good routines matter, but this is more than just about what you do in the hour before you get into bed. We are preparing ourselves for how we are going to sleep from the moment we wake up. Do you reach for your phone and dive into the day first thing? Do you start your day with anxious and fearful thoughts or thoughts of must dos, have to dos, should dos? Do you skip breakfast and load up on caffeine to get you started? Do you take mindful breaks during the day – even just for a few minutes or so to check your breathing? Are you getting enough movement and natural daylight? Do you have nourishing and nurturing relationships? What do you do in the two hours before you go to bed? Do you eat late? Binge on boxsets? Fall asleep in front of the television? Do you watch the news obsessively?

Our daily choices profoundly impact our nervous system, creating either balance or imbalance. When we are balanced, we feel safe, calm, peaceful – even in challenging situations. When we make poor choices, our nervous system is dysregulated, we feel unsafe and jittery, and we can't sleep or sleep is fitful and non-restorative.

> "When we are balanced, we feel safe, calm, peaceful – even in challenging situations."

How can carers improve their sleeping habits around busy schedules and potential sleep disruptions caused by caring responsibilities?

I believe it is more helpful to focus on lifestyle habits rather than 'sleeping habits', as such. If we take small steps during the day to energise and resource ourselves (see above), being woken during the night will have less of an impact. 'Micro' choices, 'micro' moments, 'micro' rest – managing all of this during our waking hours is key so less emphasis and pressure is placed on nighttime sleep.

Focusing on 'resting' if you are woken during the night is key and this can be facilitated by focusing on breathing, using calming, peace-inducing affirmations, visualisations or prayer, not checking the time obsessively – all of this can help to calm the nervous system so that rest becomes possible even if sleep is elusive.

What top, easy-to-follow techniques and routines would you recommend for carers?

A good place to start is with my five non-negotiables – five habits that will reset the nervous system and give you more access to inner safety and rest:

1. Eat a nutrient-rich breakfast every day within 30-45 minutes of rising

When you have breakfast, your body shifts into the rest and digest parasympathetic nervous system gear. In simple terms, this stops the body from running on adrenaline and cortisol – the stress hormones. Include a source of protein in the breakfast, eg nuts, eggs or full-fat yoghurt. If you don't usually eat breakfast or tend to do so much later, this might feel challenging at first. Start small with a banana and a few walnuts, almonds or brazil nuts, and then have another more substantial snack later. Over time, you will notice that it becomes easier to eat breakfast, and you may even wake up feeling less tired.

2. Stay well hydrated by drinking one to three litres of water per day

We all know that keeping hydrated is invaluable for your overall health. When your body is in a state of hydration, the brain can function at its optimal rate and produce the hormones and neuro-peptides that are essential for good sleep. You can make up this quota with diluted fruit juice or squash but avoid tea and coffee as these are diuretics that will cause you to lose more fluid than you retain.

Aim to hydrate throughout the day rather than drinking in the evenings as doing so will increase the frequency of needing to go to the toilet during the night.

3. Reduce or abolish caffeine completely

It takes five hours for caffeine to completely leave your system and can stop you from getting into a deep sleep as it is a stimulant with similar effects to adrenaline. Wherever possible, don't drink caffeine after 2pm, don't substitute meals for caffeinated drinks, and ideally, drink no more than two cups of tea or coffee per day.

> "The blue light can suppress your ability to produce the sleep hormone, melatonin, making it harder to get to sleep and stay asleep"

4. Start the electronic sundown an hour before getting into bed

This might seem a hard thing to do if you are used to being on your phone or tablet while in bed, but the blue light can suppress your ability to produce the sleep hormone, melatonin, making it harder to get to sleep and stay asleep.

If you really do need to have your phone in your bedroom, try to avoid looking at it just before you go to sleep and when you wake up during the night. I recommend that you get an old-fashioned alarm clock if you need to have an alarm and avoid looking at the time when you wake during the night (which is normal) – checking the time will make it harder for you to get back to sleep.

5. Aim to get an early night

This means being in bed by 10pm. This doesn't mean that you have to be asleep at this time, but it's best practice to turn off electronics by this time. It's recommended instead that you swap your phone for reading, journaling or meditation.

According to research, going to bed earlier has been linked to significant health benefits. Traditional Chinese medicine and Ayurveda suggest sleep before midnight has deeply healing and restorative effects.

Avoid falling asleep in front of the TV as this will then stop you from falling asleep easily when you get into bed. Ideally, watch TV in another room, sitting upright to keep you alert, and if you notice that you're getting tired, then that's the time to head to bed.

By following these five easy steps, after seven to ten days, you should begin to notice the difference to your energy levels, quality of your sleep and overall health.

Optimising the sleep environment is also important – particularly for those with sensitive nervous systems, which can include those on the neurodivergent spectrum, women in perimenopause, menopause, and post-menopause. Paying attention to sights, sounds, smells, and creating a safe space and sanctuary in the bedroom are all key.

This is the first stage of my unique sleep methodology that has been tried and tested on thousands of people. This reset then opens the door to doing deeper work that includes breathwork, meditation, cognitive behavioural techniques, trauma work, journalling and more.

Questions to the forum

Question one

"I am a carer for my husband, who is suffering from anxiety and depression. I have had feelings of guilt about how I feel about it and wanted to talk about it, but didn't feel there was anywhere – so I'm glad I found you all."

Response from the forum...

"Welcome to the forum! I hear you. Feel free to share as much or as little as you like. Guilt is a VERY common feeling for lots of different reasons. FYI, I made 'should' a swear word and as soon as I did, I realised how it set up so many unrealistic expectations, or how it felt like 'others' criticising... when actually we're the ones walking in our shoes everyday. Big hug. You're not alone."

Question two

"I am a nurse who has cared for my 90-year-old mother in her own home setting. She was diagnosed in 2008 with MND (Motor Neurone Disease) and her health has slowly declined. Last five years, she has been hoisted and chair-bound. In 2024 she was diagnosed with Alzheimer's.

"I have had carers four times a day and the family input has consisted of myself, sister and brief visit from my niece. She has lived on her own but recently overnight, she has rolled onto the floor, requiring hospital admission which has led on to nursing home placement. I initially thought that I would feel relieved that she was receiving 24-hour care, but it is making me feel unwell that this decision has been made. My question is, will I ever feel better regarding this outcome?"

Response from the forum...

"You absolutely have made the right decision – albeit a tough one. You will find time to recharge and realise that your life is as important as your mum's. My mum went into care in February, as I had given all I had to give. She is classed as medically non-compliant, so everything I put in place for her to stay at home was soundly rejected and we lurched from crisis to crisis. In the end, she was told to go in to a care home by a very helpful GP, who could see I was becoming ill myself by trying and failing to make her happy."

Talk 24/7 to carers who understand at: carersuk.org/forum

If you need information or support, our Helpline is available on 0808 808 7777 from Monday to Friday, 9am – 6pm or you can email advice@carersuk.org

Together, we can turn recognition into real change

Christmas for many is a time of festive gatherings, and a sense of celebration marking a special day, but for millions of unpaid carers it is just another day of looking after someone else. Their care is constant – but all too often, their contribution is overlooked.

A donation can change that. By supporting Carers UK, you'll help provide expert advice through our Helpline, connect carers together through our online community, and help deliver a stronger voice in our campaign for carers' rights.

Through your generosity, we can ensure carers feel recognised, valued and supported, because no matter how caring affects you, Carers UK is here at Christmas and every day.

If you are able to, please donate now to help: go.carersuk.org/christmas

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