

Caring

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Carers UK
members'
magazine

NEWS • CAMPAIGNS • SUPPORT • EXPERIENCES

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Tough decisions

Talking about the
dilemmas involved
in caring

Plus...

A Carer's Guide
The 'Guilt Monster'

Help & advice
Power of Attorney

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We connect carers so no one has to care alone 

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In this edition we're exploring the tough decisions we have to make when we're caring.

There are the quick-fire, instinctive decisions we need to make to keep our loved ones healthy or fulfilled. Is the doctor getting a true impression of their condition? Can they manage a trip to the park? What activity or conversation will help lift their mood?

Then there are the times we're confronted with a particularly emotional or difficult decision. Perhaps a decision which has been lurking in the back of our minds until we can ignore it no longer – and the impact of our choice feels momentous. Caryl, Don and Anne share their experiences of these dilemmas and tips for others going through a similar situation (p4-9).

Difficult decisions are often accompanied by that all-too familiar feeling of guilt. It's a word that comes up all the time on the Carers UK online forum, with some members referring to it as the 'Guilt

Monster'.

They share their thoughts on how you can keep it under control, or kick it away altogether (p10-11).

I was moved by Richard's account of rediscovering a sense of purpose and belonging through volunteering with Carers UK after losing the wife he'd looked after for 28 years (p17). It's moments like this when being part of our supportive community can be most powerful.

The magazine also shows some of the fantastic things we have achieved together (p18-19), to inspire us for the opportunities that lie ahead. With Carers Rights Day coming up on 25 November (p24), events taking place across the UK (p15) and our UK-wide AGM and Members Conference on 10 November (p16), we hope you'll be able to join us.

Thank you once again for all your support.

David Grayson – Chairman

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Tough decisions



We can all recognise key points in our caring journey when we have been faced with a particularly emotional or difficult decision – or seen them looming on the horizon.

Sometimes it's a decision we have planned for, or at least held at the back of our minds. Other times it's something unexpected that leaves us feeling out of control, altering our plans in ways we didn't anticipate.

Either way, these decisions shape us. Caryl, Don and Anne open up about a tough decision they have faced, and share their experience for others who are grappling with a similar dilemma.

Caryl:

“It was a promise I couldn’t keep”

When Tom was diagnosed with Alzheimer’s and vascular dementia, Caryl promised herself that she would never consider a care home. As his condition progressed, it became a promise she couldn’t keep.

“Tom never discussed his diagnosis or what might happen – that was just his way.”

“Tom and I met whilst working in Oxford – him as a physics teacher, me a pharmacist. Next year will be our 50th wedding anniversary. Our home was always full of music, singing and cricket. We went on some wonderful holidays and raised five children.

Once the children were much older, we moved to Nottingham for my work. Tom retired early and that was our life for about 10 to 15 years. It’s hard to pinpoint exactly when Tom became unwell but it slowly became clear that something was wrong. He would get lost whilst driving as his spatial awareness suffered. A nurse asked me if he had managed to find his car – I had no idea he had lost it.

Tom was eventually diagnosed with Alzheimer’s and vascular dementia. He never discussed his diagnosis or what might happen – that was just his way.

He was then diagnosed with Apraxia and sometimes

needs help to stand. I was struggling to support him in such a physical way, but it was still a shock when a consultant said he should go into a temporary nursing home in Nottingham. I had never thought about care homes.

I still had hope that Tom would recover enough to be able to live with me. I moved and made adaptations to a new flat in Cardiff, closer to our family, but he was never well enough. I had to put his welfare first and accept what I could and couldn’t manage. I now have a lot of pain in my arms from trying to lift him.

Nottingham Social Services said they would continue to partly fund Tom’s care in Cardiff, in a care home they approved. It was down to my daughter and I to find somewhere. We searched online, rang around and visited our four preferred homes – one of which was within walking distance. But Social Services would only deal with one of them so in the end there wasn’t much

of a choice. Luckily, we were happy with it.

Driving Tom from Nottingham to Cardiff wasn’t easy. When we got there it was even worse and it took seven people to get him out of the car and settled into his new home.

It broke me two days later when I was told Tom couldn’t stay there as they couldn’t manage him. We were devastated as we’d spent so much time and



Tough decisions

energy finding a suitable place. I asked them to reconsider and give Tom a bit more time to adjust. They agreed but I realised that at any point we could be asked to find somewhere else.

“Now he’s settled, I know Tom is happy.”

Now he’s settled, I know Tom is happy. He still enjoys listening to music and watching cricket. He often asks me who I am, but I know something in him recognises me. The other day he asked me who I was and I told him I was his wife and he said, “Oh, I don’t need one of those!”

I still care for Tom, only now I do so from his nursing home. I realised that I can care for him better whilst he’s there. I try to visit him at least once a day. I support him even though he no longer knows who I am; I hold his hand, I organise medical appointments with the dentist or chiropodist and I feed him at meal times. They’re very good at the nursing home but it is tough sometimes knowing I’m not in total control. There are some things I would do differently.

I believe I’ve done the right thing by Tom but I can’t just ask him what he prefers. That’s the hardest thing, his often blank face. I do feel

guilt sometimes, especially if there is a day I’m not able to visit. I’m concerned about going away for a week, even though I know I need a break.

I do have a bit more time for me now and I’ve got back into singing, which I enjoyed before. It feels strange to be able to go out to the shops without thinking. I still organise my days around caring for Tom, which hasn’t changed.

Tom and I are not living the life we imagined. During retirement I hoped we’d live together, share memories and have time to travel. I’ve also got to be much more careful about money, to pay part of Tom’s care and because I’m retired myself.

At times I do feel lonely. You never get used to going home to an empty flat, after having a big family. At night I still reach over even though Tom’s no longer there. At very sad moments

“I still have to organise my days around caring for Tom, which hasn’t changed”

I feel like a widow. My husband is there but he’s lost to me - he doesn’t laugh with me anymore.

What’s really kept me going is support from my family, especially my children and sisters. Organisations like Carers UK have also been so valuable - the online forum has allowed me to get in touch with other carers and share tips and support.

If I could start this journey again, I would have tried to find out more and much earlier. I would have considered that Tom might have other problems as he got older, just like anyone else, and not just dementia. Perhaps this would have made me better prepared for the decision I had to make about Tom’s care. ”



Don:

“We had to think about the future”

Carers UK Vice President, Don Brereton, and his wife Mary cared for their son Sam, who has Down's syndrome, at home his whole life.

It's not easy to let Sam go because we feel like nobody can look after him like we can. But it got to the point where we had to think about supporting him to have more independence and trusting others to care for him.

Sam has a fun, good natured and generous character. We always knew that he could never live alone. He has learning difficulties and struggles with his motor skills, which means he can't cook his own food, bathe himself or cope in an emergency like a fire.

We've been caring for him his whole life and although it's been tough, as a family we've coped. He's never happier than when he is at home with my wife, Mary, and I. That's why I never really considered any type of supported living arrangements. It was only when Sam was in his early 30s that I began to think differently.

It was hard not to consider the future. What might happen when we all grew a decade older? If one or both of us passed away, got ill, or had an accident? It would be a disaster for Sam who needed us for everything. It wasn't an easy thing to think about. We worried he wouldn't get the same love or support somewhere else. We wanted him to be in a place that feels like home.

“We knew we would miss him and it would be hard but we had to keep thinking long term.”



We knew we would miss him and it would be hard but we had to keep thinking long term. It would be better for Sam to get used to being away and get settled now instead of being forced to later due to circumstance.

When we began looking into supported living, there was very little information or availability. There was no grand list of places he could go or tips for what to look out for. I also had no idea how Sam would react. We attended 'independent living days' to find out more but these just upset Sam. Without a tangible place for him to go he didn't really understand and it made him worried about losing his family. In the end, it took us five years to find a supported bungalow, where Sam settled in well. It made it all the more traumatic when it didn't work out and he moved back with us for a year.

For the last few months Sam's been living in a new supported housing development during the week and with us at the weekend. They have many activities which suits Sam because he's so sociable and finds it hard to occupy himself. We're still a bit anxious because of what happened before but it does feel like he is happy and cared for.

Although we miss Sam, we know the independence he's gained will help him in the future. After decades, it's also been very liberating during the week to be able to go out without a detailed plan or visit places Sam wouldn't enjoy. We've all got a new life that we didn't have before.

Anne:

“The hardest decision I ever had to make”

After years of being stretched to the limit juggling work with caring for her mum, Anne knew that the situation could not continue as her mum’s dementia progressed.



Mum was born in 1927 and was a true Cockney. She had me late in life and always said I was her greatest achievement. As an only child, I spent a great deal of time with her and we were extremely close. Whatever I did or wherever I was, she was in my corner. I never thought of myself as a carer, it sort of crept up on me. At the start, mum’s care needs were mainly physical but then she was diagnosed with dementia too. The saddest aspect for me was that it robbed her of her personality. Never again will I experience that unconditional love.

Once I’d begun to really struggle, I started looking into care homes. Mum kept saying she didn’t want to go and no matter how unwell she got, she still had that strong-minded streak.

I had a 40 to 50 hour working week on top of caring, which became more intense as mum’s dementia progressed. Paid care workers visited mum during the day but only spent 20 minutes at a time and often called me at work. All my weekends and holidays were spent with mum. I moved closer so I could dash over in the night. I was living in a strange parallel universe, with work conference calls in hospital car parks and food shopping online, on my commute. I never felt part of the normal world.

“I was living in a strange parallel universe... I never felt part of the normal world”

For a year and a half I was stretched to my limit. I lived from phone call to phone call and still jump now when I hear the phone ring.

When social services would come, mum would insist she was fine. I made sure I was there, often at short notice, to tell them what was really going on. It got to the point where she couldn’t answer the phone – she thought the ringing was coming from her TV remote.

“I felt incredibly guilty but also very desperate”

Frequently, ambulances had to be called out in an emergency to take mum to hospital. On one occasion, she introduced the doctor as her nephew. But they still decided she could make her own decisions regarding care. I felt incredibly guilty but also very desperate. I said I was withdrawing all support from mum and would hold the hospital responsible if anything should happen. I wouldn’t have gone through with it but it caused them to reassess and agree she needed nursing care. I’d already researched homes near me, visited many of them and knew which one I wanted mum to be in. I’d even hang around care home car parks at different times of day, getting honest reviews from visiting family and friends.

From hospital mum went straight to the nursing home. It was the worst day of my life. There was no harder decision I’ve had to make and I still wasn’t sure if I had made the right choice. The worst thing was that I’d done

it behind her back and against her wishes. The first week was the hardest. I left in tears every time.

After a while Mum did settle down even better than I'd hoped. It put my mind at rest knowing she was getting her meals and medication, and being cared for by people who got proper time away. I still visited her every day and managed her care with the nursing home.

It's been over a year since mum passed away but I think of her every day. Even towards the very end, that love remained. Once I asked her "Do you know who I am?" and she replied "No, but I know you love me".

I still feel guilty. I don't know what mum would have told me to do if she really knew. Reaching out to people on the Carers UK forum who had been through a similar situation made me feel less isolated. It was my link to the outside world, and a place where I could be honest and open. It helped me accept that guilt always comes with love. As a piece of practical advice, it's better to be prepared and to do some research about different options, even if you're not sure what route you'll go down. Then, if circumstances change at least you'll have that information. I couldn't have selected the right care home whilst mum was in hospital, in the middle of that stressful time.

Are you facing this decision?

If the person you look after is no longer able to look after themselves and you are unable to provide the care they need, for whatever reason, residential or nursing care is a sensible and realistic option.

Here are some tips and pointers to help you approach this decision:

1) Ask for an assessment or re-assessment There may be more help you can get at home, such as increased support from social services, equipment in the home, adaptations to the house or more frequent short term stays in residential care for the person you look after.

2) Talk about it Researching care options will feel easier if you've already talked with the person you look after about what is best for both of you. If they are unwilling or unable to discuss the situation, it may help to talk it over with someone else.

3) Give it time It can take ages to find out about all the options, let alone explore them. Researching care homes before your loved one actually needs or wants one might feel awkward and upsetting, but it's useful to have an idea of what's out there and what your options are.

4) Consult the regulators and the reviews

Read the inspection reports on the Care Quality Commission (England) or the regulator for your nation. Visit carersuk.org/cqc for information. There are also new care review websites such as *Find Me Good Care* and the *Good Care Guide* where you can find personal reviews.

5) Ask questions *Which? Elderly Care* has prepared a 'Visiting A Care Home' checklist containing 45 useful questions to ask about everything from fees and food to guest accommodation and residents committees. Print it out, take it with you and tick them off!

which.co.uk/elderly-care/care-homes-checklist

6) Ask more questions Before committing to a home, follow Anne's approach and pay a surprise visit or talk to people in the car park – anything to give you more insight into how the home functions, what families think about it and how staff interact with residents and families on a day-to-day basis.



A Carer's Guide to: the 'guilt monster'

Guilt. It's a word that rears its head all the time on the Carers UK Forum, where it's often referred to as the Guilt Monster. Here, a member explains how being part of that community can really help to tame the beast.



“ The signs are easy enough to spot. Sometimes people come right out and say it: ‘I feel so guilty’. Other times, it's more hidden, but it's there, between the lines: ‘I can't stop thinking about it’, ‘Did I do the right thing?’, ‘I should have done more’. As carers, we face heart-wrenching decisions on a regular basis. We have to live with the knowledge that we can't always make

things better, that we can't go back to how things were.

We own our feelings and carry them around with us every day. By turning these feelings into the 'guilt monster', we're taking a small action to turn the guilt into something external to us. Something we can interact with – something we can redefine, kick away, break down.

My top tips for tackling the guilt monster...

Sit with it

At times there are only tough choices and whatever we do, we feel guilty. If we take a break, we feel bad for leaving the person we're caring for. If we stay, we won't be able to do our best because we're exhausted. It can help just to accept that guilt is normal and that we only feel it because we care.

Redefine it

Guilt can eat away at us, filling us with doubt and making us feel that we've done something wrong. But consider why we're in this situation: because of love and care and sad circumstances out of our control. Sometimes reframing guilt as sadness can make it that bit easier to cope with.

Kick it

Healthy guilt can come from different places – from making a painful choice to a mistake in our caring routine. Healthy guilt can help us keep doing our best. But sometimes it arises because we set standards we can't possibly meet. Or because other people impose judgements on us. In both those cases, we need to kick that guilt monster away!

Break it down

Just being open and honest about the guilt monster and the impact it's having on us can help. Being able to talk to people who understand what we are going through and how it's making us feel can help us break down the guilt bit by bit, and feel less isolated with it.



For me, it was being part of the Carers UK forum that helped me. When I joined this March, I was at my lowest ebb.

This was my first message:

“Hello. My husband is 71 years old and has had strokes which have speeded up vascular dementia. His complex needs mean he has to go into a nursing home. He has been in hospitals since November. Although we have a wonderful and supportive family, the situation consumes me and coping with the loneliness at times is difficult. I understand that others are worse off etc. and I try to acknowledge this. I also know that hubby is grieving in his own way. It’s good to share these feelings.”

Within hours people had heard my cry and were there with the words I needed to hear. Bits of advice that made me think ‘I will do that’, and made me start to get back some control. Moments of laughter that took the edge off the most difficult situation I’ve ever been in. Above all, comfort when I needed to know that I wasn’t the only one.

I was soon in touch with someone who seemed to understand exactly how I felt. She was the one who said to me ‘*This guilt monster... we need to redefine it, or we’ll collapse*’.

She wasn’t wrong. After the diagnosis, I was consumed with the thought that I could have done more. Why didn’t I recognise the signs?

“I was soon in touch with someone who seemed to understand exactly how I felt. She was the one who said to me ‘This guilt monster... we need to redefine it, or we’ll collapse.’”

Why didn’t I push harder for a diagnosis? I now see that the outcome would have been the same. What has happened isn’t anyone’s fault, and it’s heartbreaking for us both.

It’s a strong monster and never gives up entirely. Before I found it, my family were my only outlet. But it was difficult for them too – they had their own guilt and sadness to deal with, and taking on mine as well could get overwhelming. But thanks to the lovely people on the forum, I now have a place where I can let off steam and share what I am going through with people who absolutely understand what it is like, but who aren’t directly involved in my specific situation. I honestly don’t know how I would cope without it.

I know that if he could, my husband would have said all the things that other people are saying to me. ‘Why feel guilty? You can’t do any more’. I try to keep reminding myself of that, and cherish the moments we still share – the warm welcomes and the moments where the man I married shines through. ”

Ask the expert

Putting plans in place to manage someone's affairs can be complicated – especially when a condition such as dementia is involved. Jen from the Carers UK Adviceline sheds light on the key things you need to know, and the different options that are available.



How do I manage mum's affairs as her dementia progresses?

Q

“ My 84-year-old mum was diagnosed with vascular dementia one year ago. At the moment I am trying to care for her in her own home, and want to put things in

place to help her manage her affairs as the dementia progresses. I'm finding it difficult to know what to do – what sort of things should I be thinking about? ”

A

Jen from the Adviceline says...

“ It's really important to think carefully and realistically about what the future may bring and how someone's condition may progress, so it's great to hear you're thinking about this already.

There are different ways of helping your mum to manage her affairs depending on whether she is able to make her own decisions at the moment or not. This is often referred to as having or lacking mental capacity.

If it is just benefits that your mum wants a bit of help with then you could apply to be her appointee, and you can do this regardless as to whether she is able to make her own decisions or not. To do this, contact the relevant benefit department.

However, if it is more than just benefits your mum wants help with it does get slightly more complex.

The next thing to consider is if your mum can make her own decisions and is likely to continue to be able to do so. If so and she just wants a bit of help with her financial affairs – such as you being able to access her bank accounts – then she could look into making a third party mandate with her bank or granting you ordinary power of attorney. To make a third party mandate your mum would need to speak to her bank. To grant you ordinary power of attorney it would be a good idea for your mum to get some advice from a local advice agency or a solicitor.

However, both of these can only be used while your mum can still make her own decisions. So if your mum can make her own decisions now but wants to make arrangements so that you can manage her affairs if she was unable to make her own decisions in the future, then she could grant you lasting power of attorney. This would mean you would have the authority to make certain decisions on her behalf. When making decisions on your mum's behalf the decisions have to be in her 'best interests'.

There are two different types of lasting power of attorney and your mum could just grant one or both types:

- Power of attorney for property and financial affairs, which covers things such as bank accounts, paying bills, collecting benefits or pensions and selling a home. This can be used while your mum can still make her own decisions, if she so wishes, and can then continue to be used when your mum is unable to make her own decisions.
- Power of attorney for health and welfare, which covers things such as medical care and social care. This can only be used when your mum is unable to make her own decisions.

To grant you lasting power of attorney there are forms your mum would need to fill out which can be accessed at: gov.uk/lasting-power-of-attorney

If your mum is unable to make her own decisions now, and there is no lasting power of attorney in place, then this would no longer be an option. Instead, you could apply to be your mum's court appointed deputy.

If your application was successful it would mean you would have the authority to make certain decisions on her behalf. Again, decisions have to be in your mum's 'best interests'.

There are two different types of court appointed deputy and you could apply to be just one or both types:

- Court appointed deputy for property and financial affairs, which covers things such as bank accounts, paying bills, collecting benefits and pensions and selling a home.
- Court appointed deputy for personal welfare, which covers things such as medical care and social care.

To apply to be a court appointed deputy there are forms you would need to fill out which can be accessed at: gov.uk/become-deputy/apply-deputy

Your experiences

The Carers UK Forum is here 24/7 if you need to talk to other carers who understand – just visit carersuk.org/forum to get started.

Today has been an interesting day because I now finally have both power of attorneys for my mum. It is a big weight off my shoulders and is one less thing to worry about. Hopefully it will make things so much easier when I'm trying to talk to people on mum's behalf.

Thank you everybody on the forum who encouraged me and guided me through.

Well done! I'm so pleased it's one weight off your mind. It all can be very scary, especially when feelings are raw with emotions.

We all have to deal with the financial side of our caring situation as we see fit and in the way that's best for our family and ourselves.

You may be able to get a local advice agency to help you through these processes, or pay for a solicitor to help.

Good luck with everything, and remember that if you need to talk this through you can contact the Carers UK Adviceline on **0808 808 7777** (Mon-Fri, 10am – 4pm) or email us at advice@carersuk.org

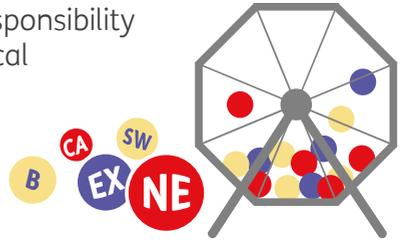
To find out more on mental capacity and managing someone's affairs, visit carersuk.org/managing-someones-affairs



Help us protect Attendance Allowance

Government is considering transferring responsibility for Attendance Allowance to individual local authorities in England.

We think this is a bad idea that could lead to a postcode lottery of support for older people and their carers in the future.



Government has said these proposed changes won't affect you if you're already claiming Attendance Allowance, or you care for someone who is. However, you can help us protect this vital benefit so older people and carers don't lose out in the future.

Why is Attendance Allowance so important?

Attendance Allowance is a benefit for people aged 65 years and over. It helps with the extra costs of long-term illness or disability.

It is also a vital 'gateway' benefit, allowing a person who looks after them to claim Carer's Allowance.

What changes are being considered?

Government is considering devolving responsibility for Attendance Allowance in England from the Department for Work and Pensions, to local authorities.

What does Carers UK think?

We strongly disagree with the proposals.

Under the current system, Attendance Allowance is a national entitlement with demand for the benefit reflected in the funding. The new proposals could mean that local authorities have a fixed budget to fund demand in their local area. Local social care budgets are already stretched, with demand growing as our population ages.

Local authorities could be given the freedom to set their own eligibility criteria for Attendance Allowance, while others may choose not to provide a similar payment to Attendance Allowance at all, using the money for our underfunded care system.

We think this could lead to a postcode lottery for older people and those caring for them.

What has Carers UK done?

We've set out the arguments and evidence against the proposal in our response to the consultation, highlighting our strong opposition. We have raised our concerns in a meeting with the Secretary of State for Work and Pensions, with officials at the Department of Health, Department for Work and Pensions and with local government representatives. We've also briefed MPs both in person and in writing.

What can I do to help?

We need as many people as possible to write to their MP to let them know why it is important for carers that Attendance Allowance stays as it is.

You can help by downloading our letter template and sending it to your MP, along with your own message about why Attendance Allowance matters to you.

To find out more and download the letter, visit carersuk.org/protect and if you require a printed copy of the letter, contact our Policy team at policy@carersuk.org.

Make your voice heard



Carers speak up on the issues that matter most at events across the UK.



With welfare reform taking place across Northern Ireland, the Carers NI Summit on 10 October will see carers join together in the Guildhall, Derry/Londonderry, to get the latest information and speak out about the issues that matter to them.

The fifth Scottish Carers Parliament is taking place on 2 November in Edinburgh, and will see two carers from each of the 73 Scottish Parliamentary constituencies representing carers in their area. Later in the month the Carers Scotland Summit will take place on 29 November in Edinburgh City Chambers with the Minister for Public Health & Sport, Aileen Campbell MSP, attending to listen to what carers in Scotland have to say – book your [place at carersuk.org/scotland/summit](http://carersuk.org/scotland/summit)

The second All Wales Carers Assembly is taking place on 18 November in Cardiff, with carers from across Wales representing each of the 60 Assembly Member's constituency and regional seats. The new rights for carers brought in with the Social Services and Well-being (Wales) Act 2014 last April is sure to be a key topic of discussion. Carers Wales want carers to help them 'Track the Act' and speak up on if these new rights are making a difference to you – visit carersuk.org/tracktheact to share your experiences.

See page 18 to find out about our UK-wide AGM and Members Conference in London.

Creative writing competition



It's been another inspiring year for our creative writing competition, with 700+ poems and short stories submitted.

Award-winning poet Cheryl Moskowitz has selected the winning entries and we'll be launching our creative writing anthology volume three in the run-up to Christmas. A selection of the winning poems and short stories will be featured in the next issue of Caring magazine and on the Carers UK website from January 2017.

Welfare change in Northern Ireland

The Northern Ireland (Welfare Reform) Act 2015 is currently being rolled out across Northern Ireland, and means a range of changes that could affect carers.

In June, Personal Independence Payment was introduced, replacing Disability Living Allowance for all new claimants aged 16–64 years old.

If you live in Northern Ireland and want to know more about how these changes may affect you, visit

carersuk.org/ni/welfarechange, or contact your local office for advice and information on 028 9043 9843 or at advice@carersni.org



“My advice would be to seek advice and support as early as possible. Too often I am dealing with calls from carers who have reached crisis point before seeking help.”

Making a difference

Every autumn we report back to our members on what we've achieved together during the last financial year.

Our annual report and accounts give the full picture and will be presented at our AGM and published on our website soon afterwards. In the meantime, here's a snapshot of 2015-16:

We help

21,399 enquiries handled by Adviceline

1,613 calls answered by trained Listening Support volunteers

280 Upfront guide completions each month



“

What a valuable 24 hours this has been for me thanks to your staff and volunteers!

Your volunteer made me feel properly heard and validated. I felt very different at the end of our conversation to the way I had felt at the beginning. Your Adviser has really taken in the problem and offered advice that was very pertinent and helpful. This too was a deeply valuable conversation and from both I've had exactly what I needed!

”

“

Reading your Caring magazine reminds me how valuable my role is. Well done Carers UK for raising our profile. Glad to be a member of your movement.

”

1,011,947
people accessed specialist information online





We connect

6,700 hours volunteered

365 volunteers recruited

700 entries in creative writing competition

15,000 carers reached by Carers Week 2015 activities



8,202 new members joined Carers UK



Now I use the forum to let off steam when something's bothering me and I get such good information and encouragement from people who've been through it all before that I really feel like I'm sharing the load. Instead of sitting there with my head in my hands I go away with a practical solution and I feel there's lots of people on my side now. Before, I felt no one was on my side.



We campaign

£132bn Value of carers' contribution

5,035 Articles in the media

31 Research reports, responses and policy briefings published

4,572 carers and former carers responded to our 2015 State of Caring survey



We innovate

3,049 people downloaded Jointly



thank you

As a member of Carers UK the achievements in this report are your achievements.

With your support, we will help, connect, campaign and innovate even more in 2017. There are lots of ways you can help make life better for carers.

To find out more visit: carersuk.org/how-you-can-help

>>> Join us for our AGM and Members Conference! Turn over for more details >>>

Coming together to achieve change

AGM & Members Conference

10 November 2016, London

As a member of Carers UK, you are part of our growing movement of carers. Join us at our AGM & Members Conference to:

- Find out about our five year strategy, and how you can get involved
- Connect with other members, for ideas, support and understanding
- Share ideas about how we can work together to give support and influence change
- Find answers to your questions about caring, about Carers UK or about your experience as a member.

"I'm looking forward to meeting other carers at the Members Conference so we can learn from each other, share ideas and help Carers UK spread the message to more people looking after a loved one."

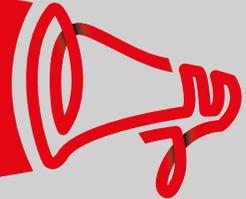
Palwinder, Carers UK member



"Being a Carers UK member is all about being part of a community that understands caring."

Book your place online at carersuk.org/membersconference

carers
RIGHTS DAY
Friday 25 November 2016



There are loads of ways you can get involved – from attending an event at your local carers' service to helping us get vital information about caring to the people who need it.

Find out more at carersuk.org/carersrightsday

Volunteering is the perfect tribute to my lovely wife



Richard Cross lost his wife Sheila after being her carer for 28 years. Here he tells us how volunteering has helped him rebuild a sense of purpose and belonging.

“My wife Sheila had multiple long-term conditions and I became her full-time carer in 1991. I loved my wife and wanted her to have as good a quality of life as she could. But life was very hard and at the beginning we had no support whatsoever. There was no one on our side.

I didn't realise how difficult being a carer was going to be and I would end up looking after Sheila for the rest of her life. My back-up was good, so I was able to take breaks every now and again to volunteer with Carers UK, acting as an expert by experience to help shape the development of the volunteering programme.

It's important to tell people our stories and why we need support. My volunteering has involved doing presentations and carer awareness sessions with hospital staff and MPs, running information stands and even meeting David Cameron. It was fantastic to go through the famous black door of 10 Downing Street!

I've enjoyed every minute of it. Volunteering always gave me a lift, and hopefully helped to make life better for other carers too.

When I lost my lovely Sheila in April 2016, it was the worst experience I've ever had. For a quarter of a century we were together night and day. Even though she was poorly and spent lots of time asleep, the fact Sheila was here meant I had somebody in my life. Now our home is just a house. I rattle around in it. But there's no life or atmosphere there. Gardening has always been my hobby and our garden used to be full of flowers every

summer. Now it's just overgrown. I've not had the motivation to do anything about it. Until last week I didn't know what to do, apart from feel sorry for myself. Then I decided to volunteer at the Guy's Hospital's Cancer Survivors' Day and I suddenly came alive again. The day helped me realise that volunteering and meeting people who are on the caring journey that I'm so familiar with makes me feel at home.

On the day I ran a Carers UK information stand, handing out information and talking to people who are caring for family or friends about our shared experiences and some of the support available. I also spoke to people about the challenges and the frustrations they were facing.

I know there are still far too many carers out there without the support they need. And now I have travelled the end of life path with Sheila, I want to use my experiences to help other carers who are also facing this part of their caring journey. If I can help them, or influence those who have the power to make changes in any way, then that will be my tribute to my lovely Sheila's memory and gratitude to all those I know at Carers UK who have helped and supported me throughout these last few weeks. ”

Get involved

If you've been inspired by Richard's story and would like to volunteer with Carers UK, visit carersuk.org/volunteer or give us a call on 020 7378 4997.

**POP THE
KETTLE
ON!**



Hold a tea party
and dish out in-
formation about
caring this Carers
Rights Day

Pop the Kettle On *for Carers UK*

Carers Rights Day is coming up on Friday 25 November and is all about helping carers get the right information and advice at the right time.

One way you can get involved is by holding a Pop the Kettle On. It just involves serving up plenty of refreshments and dishing out information about caring while collecting donations for Carers UK.

When you Pop The Kettle On you will be helping us to raise awareness of caring, celebrate the role of carers, raise much needed funds and point those who need us to where they can get help, support and advice.

How you do it is up to you. We'll make sure you've got everything you need to get your friends, family or colleagues clued up about caring and inspired to donate towards our cause.

All you need to do is Pop the Kettle On and get baking!

Proudly supported by Nutricia



"I'll pop the kettle on."



To download your free pack and sign up, visit carersuk.org/popthekettleon

Want to find out more about getting involved in Carers Rights Day? Turn to the back cover!

Thank you



Ride London

On a sunny Sunday in July we made our way to Kingston to cheer on the eight cyclists who took part in the Prudential Ride London-Surrey in support of Carers UK. This 100 mile cycle starts at the Queen Elizabeth Olympic Park, and finishes on The Mall – but not before the cyclists take on the leg trembling Leith Hill and Box Hill in Surrey. The cyclists also had some extra support of the four legged variety!

All in all the team have raised well over £6,000 – a huge thank you to all of them for their amazing support!

Paul Rowland and Richard Jones

We'd also like to say a huge thank you to cycling chums Paul and Richard, who raised over £700 in support of Carers UK. They set out from Cardiff at 4am, cycled 115 miles to Aberystwyth, then retraced their steps (or wheels!) to head back towards the Welsh capital, as part of their joint fundraiser for Carers UK and the Brain Tumour Charity.

Richard had personal reasons for choosing to support Carers UK, as a friend of his became a full-time carer to his brother after he was seriously injured during an assault on a night out a few years ago.

Thank you to both Richard and Paul for their amazing achievements – we're so grateful for their support.

If you'd like more information about joining our Ride London team for 2017, or on how to arrange your own sponsored cycle, then email fundraising@carersuk.org or call 020 7378 4952.



“The support out on the road was superb. A brilliant day”



“Despite her advanced age, for me she looked charming!”

We are delighted to have received funding from the Marie-Louise von Motesiczky Charitable Trust to help us reach more carers with tailored advice and information about taking a break

Marie-Louise von Motesiczky (1906-1996) was an influential artist whose principle subject was the ageing mother she cared for, trying to capture the charm which remained as her condition deteriorated.



I Care: Ruth

Ruth is a chemistry graduate, IT specialist, entrepreneur, body painter, Druid and self-proclaimed eccentric. She also cares for her wife, Sonia, who has a condition called Sacral Agenesis which causes mobility and other health issues.



“I grew up on the Wirral in England, where, as a child, I was often bullied a lot for being “different” – I was intellectually bright and quite eccentric.

When I started university, I remember feeling very lonely and wishing that I’d meet ‘someone’. I was studying chemistry at Oxford and wrote a short piece called ‘The Chemistry of Love’, all about a lonely complex ion searching the universe for their ideal electron.

One evening I had a revelation that I would probably be a lot happier in a relationship if I was able to express myself as a woman. A few months later, I wore a dress while performing in an opera. A couple of people noticed how happy and relaxed I was, and we sat outside under the stars and had a very deep conversation about it.

It was a key moment in my life – the first time people understood how I felt and were positive and

accepting of me. It began a period where I lived as a woman as much as I could, without fully deciding how far I wanted to go with my gender.

I was painted yellow when I first met Sonia, on the way back from a body painting event in 2003. We hit it off instantly, and quickly discovered we have a lot of mutual interests, including a love of food, music and animals.

We got married in 2005, where we had two ceremonies on the same day – a wedding where we married legally as husband and wife, and a handfasting ceremony in our back garden, where we effectively married as wives.

“Sonia’s disability is a big part of what makes her her.”

Sonia’s disability is a big part of what makes her her. It’s given her opportunities she wouldn’t otherwise have had, including a passion for disability dance

and powerlifting. However, her mobility is getting progressively worse. She now uses an electric wheelchair and a hoist to get in and out of bed – which is a hospital bed in the lounge. She can often be in a lot of pain, and does get frustrated about not being able to take part in all the activities she would like to.

My job means long hours during the week. I’ll prepare breakfast for Sonia then leave at 7am to travel two hours to Birmingham, and don’t return until 8pm. Sonia has two to three hours of care each day from a team of care workers, with regular visits from district nurses due to the severity of her illness and the associated kidney and bowel issues.

The rest of the time, I’m fetching things, making sure Sonia’s got enough medication, keeping an eye on her health. As well as making tea, cooking, tidying up – just ordinary things that come with chilling out together. At the weekend, I often take Sonia out in

our wheelchair accessible minibus – whether heading into town or longer trips further afield to visit relatives and friends or go to the seaside. I’m always checking that she’s OK and that she’s happy; I’m usually one of the first people to notice if she isn’t quite right health-wise.

Being a geek, I’m always thinking of ways to use technology to make life easier for Sonia. In our lounge, we have lights Sonia can control from a remote control or from her phone. I’m waiting on some kit from the States to make them voice-activated. I’m also working on a system to control our central heating and then my next project is to make an entryphone with a magnetic door catch.



We have had our fair share of emergency hospital visits, and I’ve had to take a lot of leave from work at short notice, once missing a ceremony

“I tend to think of myself more as Sonia’s wife first and foremost ...we both care for each other in our own way, and I care for her because I love her”

where I was going to receive an award in acknowledgment of my work. Luckily I have understanding employers. One of the people I report to has a disabled son, so knows what it is like.

I tend to think of myself more as Sonia’s wife first and foremost, in that we both care for each other in our own way, and I care for her because I love her.

Professionals can make inaccurate or inappropriate judgments about our relationship. Sometimes hospital staff assume that I am Sonia’s care worker, and not her wife, so I have to make it clear.

I have a hectic life and cram as much as I can into each day. I often use social media when I’m travelling home from work. For me, online support through Twitter, Facebook and forums has been a lifesaver. That’s how I found Carers UK.



There are quite a lot of people who are LGBT and either carers or being cared for. I would love to be able to network with more people in a similar situation – especially within the LGBT community – and also help out with my technology and computing knowledge.

A movement for change

From campaigning to volunteering, there are all kinds of ways to get involved and make a difference.

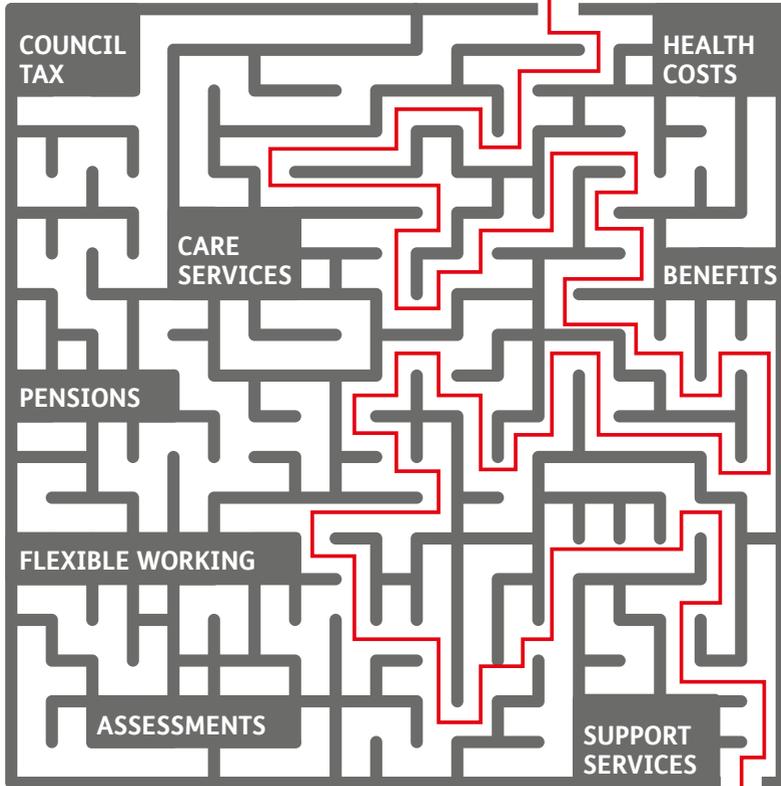
carersuk.org/how-you-can-help

Need help and advice?

0808 808 7777

advice@carersuk.org
carersuk.org/help

Carers' rights can feel like a maze...



We're here to guide you

Every year millions of pounds of carers' benefits go unclaimed because carers are unaware of their rights. As well as campaigning for reform of these benefits, we're here to make sure carers know exactly what help and support is available.

We've just launched a new *Looking after someone* guide to bring this information bang up to date. Order yours today.

carersuk.org/carersrights

