Caring through a lens

Celebrating our 2017 creative writing and photography competition winners

Plus...

A carer’s guide
Staying positive

I care
Emily’s story
EATING WELL

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This issue of Caring is all about sharing our stories and experiences, to support each other and call for lasting change.

I’ve been stunned yet again by the power of the stories told as part of our 2017 Creative Writing and Photography Competition. These profoundly moving words and images take us through the whole range of human emotions, and sometimes to its extremes. In our lead feature (pg 4–7) Carers UK members and poetry prize-winners Elizabeth Dunford and Margaret Wilmot tell a story of life not going to plan – of caring carrying them away from the trajectory they thought their life would take. Writing or talking about these moments can help us make sense of them.

It was wonderful to share stories with many of you in person at the Member Conference in October, and at our recent Member Roadshow events. Along with our Nation Summits, these events give us a chance to tell our own story as an organisation, reporting back to you about our progress together over the last year (pg 20–21) and setting our priorities for the year ahead.

For Carers Rights Day on 24 November, we will be focusing more than ever on the power of sharing stories and information. This year’s theme is Make Connections, Get Support, and with that in mind, we’re asking members to say loud and clear that ‘We Care’ – sharing our stories throughout our networks and connecting carers together to build support in our local communities.

Together we can improve understanding of caring and make sure none of us has to care alone.

David Grayson – Chairman

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Greta Ross

The soap that lives in my drawer
is your old conglomerate,
its once Ivory core invaded
by odds and ends from baths and sinks:
Camay pinks and Simple blues
bearing the imprint of your thumb.
Its smell recalls how you clung to self
dissolving like the soap you saved
as if salvaging scraps of memory
by smoothing out cracks, tears,
flakes in the tectonic plates of this ball
that once was Lux, Lifebuoy and Pears.
I find again your fingerprints
in the fist-shaped mass, and feel
in this strange way we can still
hold hands.
Sooner or later most of us will find ourselves caring for someone. But a life of caring for loved ones is rarely the plan we had for our future. Poetry competition entrants Margaret and Elizabeth talk about changing plans, the challenges this can bring and positive new paths that open up.

Margaret
Highly commended poem, Patient

“banishing myself from my home, my husband had cancer. I couldn’t believe it. He looked like he needed all the support in the world, my mother had just died and it was the last thing I felt like giving. We were about to travel, do all these things together – we were free. It felt like a loss, but I also felt selfish for thinking it.

Robert was diagnosed with prostate cancer in 2010 and I suppose I wasn’t really caring for him straight away. He had chemo and it seemed to be contained. He didn’t have the same energy, but we continued our normal lives. Things returned to normal to such an extent that he accepted an offer to play the organ for six months on an island in Norway. It’s a rocky, unpopulated place that he loved. It was interesting and lovely, until his cancer came back. We were in this strange place and I had to get him to hospital by boat. We came home and after that he was in and out of hospital for a year and a half before he died. He got to a point where we had to move the bed downstairs and he had care workers. We live in the countryside in East Sussex and I started doing his jobs, bringing in the coal and wood. I hated to do it – it implied that he couldn’t do it any more.

I’m not a natural carer at all. I was being pushed beyond what I felt comfortable giving. But for better or worse you give them everything and I don’t think I’m very good at giving anything. The emotional support was the hardest, and now I can’t help feeling I could have done more.

Poetry has been a way of channeling my feelings or getting rid of exasperations. It’s my outlet. I wrote Patient (pg7) while I was caring for Robert.

I never showed it to him, I would hate for him to think he was being watched, but it helped me deal with the emotions of caring.

I like travelling now. I used to live abroad so I’ve visited old friends and I’ve been to New York recently. Life is not empty.

“T’s not a natural carer... Poetry has been a way of channeling my feelings or getting rid of exasperations”

Many of us may have felt the disappointment of watching our plans for the future whither away with a diagnosis. Sometimes our life experiences change us in unexpected ways and the new opportunities in front of us, while not what we originally planned, might turn out to have an upside.

Read more poems and stories: carersuk.org/creative
My son is thirty, he has a beard and is much taller than me, but it has occurred to me we have the kind of relationship that someone of my age might be having with their grandchild. That’s when I think, ‘This wasn’t the plan.’

Christopher is on the autistic spectrum. He lives in a residential home, but he comes home every weekend and he lived with us until he was 18. I have three children and he’s the eldest.

It’s hard when you first find out. Obviously, you don’t know right away, he was a beautiful baby, but there were niggly little things at age two and three that didn’t seem right. I had fears that he wasn’t developing as other children were, but he was my first child so I had nothing to compare it to.

It can have a huge pressure on a marriage. That was hard, it’s ok now but I know a lot of marriages can’t cope with the added pressure. Fighting to get the right education for him was also hard. He went to the local primary school and that was just about ok with the help of a one-to-one assistant. He couldn’t have coped with the local secondary school so he went to a special school, we had to fight for that.

It was hard juggling looking after him, my other two children and trying to work as an English teacher. Christopher took up a lot of time and energy. The affect on our other children has been profound. They got neglected quite a bit. Family outings could be horrendous and they worried about bringing friends to the house. But I also think it’s made them more caring and empathic people.

I still look after Christopher as though he were much younger. I tell him to look both ways before he crosses the road, every single time. He’s often in a dream world. There are nice things about that as well, he’s got a lovely sort of innocence – he doesn’t know how to lie.

One of the things we like to do together is walking. The poem is about walking one Sunday afternoon near where we live. Christopher often talks about things from a world of books and films. He’s got an incredible memory and will reproduce stories word for word. While we walk, I try to engage him with things around us using Beatrix Potter characters.

My husband, David, and I are both quite high achievers, he went to Cambridge and I got a good degree. I suppose when Christopher was first born I imagined that he would end up having a professional life. I would have just assumed it, but you revise your ideas a lot as you go along and it’s not the most important thing at all anymore. I really just want my children to be happy. I think overall Christopher is reasonably happy.

I’ve recently started doing a part-time masters in creative writing for therapeutic purposes. I don’t think I would have done that if it hadn’t been for my experience with Christopher. After not writing for years, I’ve been reading poetry and writing a lot too. It’s been a real lifesaver. That wasn’t in my original plan, but it’s a good thing.

Most of the time I’m just getting on with things, but now that I’ve stopped working, I actually have time to think. I do think Christopher’s autism has changed all our lives. It’s different from what I might have imagined, but it’s not all bad.
Elizabeth and Margaret’s poems in full...

This was not in the plan...

Elizabeth Dunford

Sunday afternoon.
A walk along the towpath
to wear you out a little.
I point out bare black winter branches or
beech buds about to burst into leaf or
green foliage turning gold
as appropriate.

You don’t reply,
Your face impassive
or illuminated, smiling
at your own thoughts.

Look, I say, those purple flowers –
foxgloves, like in The Tale of Mr Tod.
And see those water-lily pads?
Just like the picture in
The Tale of Mr Jeremy Fisher.
And those hazelnuts – I think
Squirrel Nutkin gathered ones like that.

Time to go home.
You charge ahead
or lag behind
or suddenly halt for reasons of your own.

We make hot chocolate.
You scrutinise the mug for specks or smears.
Curled up at my feet
you rest your head on my knee,
the Beatrix Potter box set arranged in
symmetrical piles
alphabetically or in order of publication.
Shall we have The Tale of Samuel Whiskers
today? I offer,
observing the way your hair has begun to
recede at the temples
and that your beard could do with a trim.

Highly commended

Patient

Margaret Wilmot

My husband pushes his bike
out of the gate leaning on it heavily
he has forgotten his cap
suffers from cold
I don’t shout out the window
who wants to feel watched
he looks older than my grandfather
it’s strange to see your husband
turn into the grandfather who
took his cap and stoop and a way
of moving with a wheelbarrow
out of your life so early
these are the thoughts
which balloon in the mind
how unsteady he seems
around the house too
is he going to fall
should I leap up
do it for him
remind him
what normal no longer is
the daily life
he took for granted
his accommodating body
energy
these are the poems
one can’t write but
write themselves as I check
the Rayburn before he wakes
toss the last coal into the firebox
refill the hod bring in logs kindling
it’s May but we’re still
making an evening fire
take away the ashes
take away.
This is caring

Opening up about loneliness

The Jo Cox Commission on Loneliness shone a spotlight on feelings of isolation among carers. We awarded the Jo Cox Poetry Prize and encouraged carers to share their feelings of loneliness by writing anonymous letters.

Among the letters carers shared with us, we heard stories of treasured friendships, helpful health workers and complete strangers that made a difference when it mattered most. Here, we’ve picked our favourite.

“Dear _______________

It was close to Christmas, I was working full time and caring for my mother. You had very kindly covered for me on the numerous occasions I’d had to dash home because she had fallen. None of the managers knew about my little excursions which were becoming more and more frequent.

You did baking in your spare time and often brought cakes into work. Each Christmas you took orders for mince pies and Christmas cakes. I loved your mince pies and ordered some every year, but that year I forgot.

One day I came into work. I was late and I snapped at the first person who spoke to me. I ended up crying in the toilets because I thought everyone must hate me. I never smiled anymore and I couldn’t remember the last time I laughed.

Then you came in laden with boxes of mince pies for everyone. I wished I’d ordered some and the way I was feeling at the time, it felt like something else I’d failed at.

When everyone had taken their orders, you handed me a box containing 12 mince pies. I was puzzled – I hadn’t ordered any, and you always reminded people that unless they put their name down you couldn’t make them. You explained that you knew I had a lot on my plate and thought you’d make me some anyway.

I was so overwhelmed I gave you a hug. I reached for my purse but you whispered to me: “No, these are for you. When you go home, have a cup of tea and eat all 12 of them if you like.”

Well, I cried for the second time that day: that was the first thing anyone had done for me that entire year.

That day, I went home and emailed my siblings and informed them I was going on holiday over Christmas and one or all of them would have to arrange cover. This was not a popular decision and I was even called selfish by one of them. But I’d stopped caring by then.

Your simple gesture inspired me to do something for myself.

Thank you for giving me that little spark I needed – for reminding me that the little things in life are the most important. I will never forget what you did and I try to do little things for other people now.

Laura”

For more anonymous letters please visit: carersuk.org/letters
Catherine Graham won our Jo Cox Poetry Prize for her poem, *The Washing Machine*. Here she tells us how sometimes it’s not only the carer that can experience feelings of loneliness.

In her day my mam, Doris, was the life and soul of any get together. We were inseparable and I adored her. She was 90 when she passed away last November. I was mum’s carer for ten years, eventually she became housebound and I did everything for her. It was a privilege to care for her – you only get one mum.

Seeing mum struggling to be her loving, gentle self was hard. The love was still there but she was getting so weary. She would get cross with me and it would break her heart. Sometimes I would cry buckets, but I didn’t cry in front of her.

At times my full-of-joy mam was still there. I would put her favourite music on and we would sing or dance a slow waltz.

The thing that irritated mum the most was the washing machine. The poem is my daily experience of caring for her. She’d say, ‘I don’t care if the washing gets piled high, I just want your company Catherine, I’m lonely.’

You don’t have to be alone to feel lonely. Looking on the Carers UK website was comforting. Knowing other people were feeling the same was a kind of companionship in itself. Mum has inspired many of my poems. Whenever I read her a new poem she would say, ‘Aye, if you like it Catherine, but it doesn’t rhyme.’

It’s almost a year since my mam passed away and I can imagine what she would say, ‘You won, I hope this one rhymes.’

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**The washing machine**

**Catherine Graham**

She dislikes the sound of the washing machine so I sing as it starts to spin, willing it to stop before she calls for me from the bathroom.

She used to love hanging the washing out, proud to peg ‘the whitest sheets in the street’ and watch them as they billowed on the line.

Sometimes, they’d be bone dry but she’d leave them out, on show to Mrs. Ridley. I remember how Mrs. Ridley and my mother would stand, arms folded, like bookends in headscarves and slippers exchanging the latest chinwag. I remember the pleasure Mam took in folding the bedclothes with me, how she’d do that little dance towards me until our fingers met; her fingers gentle and plump.

‘Where are you?’ she shouts from the bathroom, ‘I’ve sat here two hours!’ It’s been two minutes. I hurry along the passage, still singing ‘our’ song.

Keeping her face to the wall, Mam joins in: ‘My my my, Delilah! Why why why, Delilah?’ We sing our hearts out, each of us as lonely as the other.
Carers UK Patrons, Tiggy and Johnnie Walker MBE have had some real highs and lows over the years, but none more so than their recent escapade trekking the Great Wall of China, raising funds for carers along their way.

“Walking the Wild Wall section of the Great Wall was frequently as testing as going through chemotherapy – and often more frightening”, Tiggy Walker declares as the group of trekkers land back in the UK with exhausted legs and weary feet. The Walkers, along with 13 of their friends and Carers UK’s athletic Head of Fundraising, Jeremy, completed a six-day trek of the Great Wall of China, raising an astonishing £60,000 for Carers UK.

“Carers are utterly selfless people and they make a wonderful contribution to their fellow man, so we wanted to do something challenging to raise money for Carers UK, to give carers some much-needed support. We had never heard of an
overseas charity trek and thought we were a few years beyond marathons and survival races. Inspired by a volunteer at Maggie’s Centre in Manchester who completed a similar trek, we thought this would be the perfect challenge for us to raise money to help support carers.”

At night, they would retire back to the barracks where host William Lindesay OBE gave fascinating talks about the history of the Wall, while the group ate traditional Chinese dishes and they rested their bodies for the next tough day of hiking. “We loved spending time together in the common room, warmed by a wood-burning stove and listening to adventure stories of the Great Wall.”

Now that the team are home, they hope that the money raised will help the lives of carers. Fellow trekker, Michael Cole, says “I’ve witnessed both my parents and parents-in-law suffering from age-related diseases resulting in the need for care, much of the responsibility resting with family. We hope that our fundraising will raise awareness, as well as the vital funds.”

A huge thanks to our Patrons and their team of trekkers for not only raising their own travel and accommodation funds, plus lots more money to support our work, but also physically pushing themselves to the limit.

Fundraising thanks

While the sun was still shining over London back in July, our **Ride 100 team** of three avid cyclists overlooked the saddle sores to race the capital’s streets, out to the rolling hills of Surrey. Completing the 100-mile course over seven and a half hours, the team raised £1,551 of vital funds for Carers UK.

The **Toyota manufacturing plant** hosted a **Pop the Kettle on** in August, the most successful Pop! in the event’s recent history. Through delicious cakes and well-brewed teas the organisation raised more than £1,300.

In much need of a cup of tea were colleagues at **Broadgate Search** after completing the gruelling **Bear Grylls Survival Race**. Jumping haystacks, wading through water and running 10K, the group of eight were muddy but ecstatic to receive their medals at the end and in the process raised a fantastic £700 to support carers up and down the country.
Working with Carers Trust and funded by the Department of Health, we have launched a website to help organisations in different sectors to develop Carer Passport schemes.

Essentially a Carer Passport is a record which identifies a carer in some way and sets out an offer of support, services or other benefits in response. The better the offer, the more difference the Carer Passport will make for carers.

In this project, we’re focusing on Carer Passport schemes in hospitals, employers, communities, mental health trusts, schools, colleges and universities. None of those organisations is required to run a Carer Passport scheme. While running a scheme can be a big undertaking, the benefits of doing so – to carers, to the organisations themselves, to the wider community – are huge.

Get involved
Find out if there are any existing Carer Passport schemes (or similar schemes) which you could benefit from. See below for ideas about how to find this information out. If there aren’t any existing schemes which are applicable to you, then why not send our Carer Passport Guide to a relevant organisation so they can read about the benefits for themselves? You could be the reason they set up a scheme which could benefit thousands of other carers!

[carerpassport.uk]

Employment
If your employer has a Carer Passport, it should be listed among your organisation’s caring policies or staff benefits.

If you cannot find evidence of it, you could simply ask whoever manages human resources at your organisation, attaching our Guide to Carer Passports so they can see the benefits for themselves.

Hospital
If you are not sure whether your hospital offers a Carer Passport, you could check with your local Patient Advice and Liaison Service. They might already have some schemes in place to identify carers. This would include John’s Campaign for people caring for someone with dementia, the Butterfly Scheme, and there are a few others. Don’t forget that they might not be called a Carer Passport but might be called a Carers Card, etc. Even if there are existing schemes, a Carer Passport can really help draw these schemes together.

If they don’t have an existing scheme, could you make contact in person, or via email or social media, drawing attention to our Guide to Carer Passports to help them get started or develop their support for carers?

Community
In some areas Carer Passport schemes are called something else, such as a Carers Card or Carers Discount Card, etc. In some areas a Carers Emergency Card acts as a Carers Passport and offers discounts when a carer shows the card.

There is no requirement for any region or authority to issue a Carer Passport, though they can be a really helpful tool to improve carer identification and support.

Your local carers organisation or local authority is the best place to check whether there is already a Carer Passport operational in your area. Check our local support directory if you are not sure where to start.

[carersuk.org/local]
Caring through a lens

Special feature: Photography competition 2017

This year we opened our Creative writing competition up and asked for your photography submissions, as well as poems and short stories. We had a great response and photographer Bella West judged the entries, here, we take a look at the winners.

1st PRIZE

Alexandra Davey

“I selected this image as my overall winner as the connection is so special between the two children. I am assuming that in reality they are good friends or siblings - there is a visible loyalty from the older child. I’m sure a lot of attention is given to her sibling. The masked girl could have rushed in from a party or she’s been entertaining her sibling until they fall asleep together. It’s an image full of unequivocal fun, love and devotion.”

– Bella West

How the photo was taken:

“Benjamin is my middle child, when I took this photo he had just come out of an operation and was in the children’s ward of the hospital recovering. It was Father’s Day so we went to visit him. Benjamin was

“when I took this photo he had just come out of an operation and was in the children’s ward of the hospital recovering.”
Sarah Nicholls

“There is a strong devotion visible here from both subjects, they seem unaware that they are being photographed – caring at its most genuine. I also like how the rim light creates a halo around the two subjects.”
– Bella West

born with complex needs as his brain didn’t develop properly in the womb. He was given such a terrible prognosis before he was born, that when we brought him home we were relieved. However, he is non-verbal, non-mobile, incontinent and is fed through a tube. Day to day his care is non-stop, I give him his medication, do his physio, check his airway and give him suction if he needs it and either push or carry him from A to B. My husband works, but we split the caring when he’s around. We’ve both fought tirelessly to get Benjamin a carer that takes him to school two and a half days a week, and is with him throughout the day.

He loves preschool, so it was a shame he’s missed a lot of time being in hospital – but since this operation he’s been much better. The other child in the photo is his older sister, Jackie. I’m not quite sure why she was wearing a mask. Both Jackie (5) and my youngest, Caitlin (18 months) love Benjamin and always want to kiss and cuddle him, so I guess this was just Jackie’s natural reaction to seeing her brother in his hospital bed. When he gets home from school they cuddle him and although they might miss out on certain things because of how consuming Benjamin’s needs can be, they certainly aren’t aware how hard all of that was. Everything is worth it in the end.

To read more, head to Alex’s blog: thelongchain.wordpress.com

“but then he comes home and everything is fine for a while and you forget about how hard all of that was.”

Our 2nd Prize winner

CarersUK.org

14
Karen Arthur

“Clearly a fun afternoon in the pub for this young man – aided by his friend or maybe his daughter – showing a resilience that despite his disability, he and his family are dedicated to enjoying life.

It also outlines the practical support and love involved in caring.”

– Bella West

Highly commended entries...

Jim White

Dan Johnson

Fran Bridgewater

Continued overleaf...

Bella’s comments on judging the competition

“This was possibly the hardest photography competition I’ve had to judge, in respect that this was not about all the qualities we look for in a professional portrait image, it was all about the content – a penetrating statement of the reality many carers face and such a pleasure to look through.

Photography, as with all art is subjective, so my choice of winners is defined very much by the emotional value the images had on me and what I read into them. That in no way lessens the impact of any of the other entries, and the entire collection contained humour, sadness, devotion and love. It was such a pleasure to view all these wonderful photographs.

A clever narrative within a photograph or portrait, is one that invites the viewer in, to read their own story – the winning image definitely held this open invitation.”
“It is an illusion that photos are made with the camera... they are made with the eye, heart and head.”

– Henri Cartier-Bresson

Images clockwise from top left: Amanda McLellan; Loren Dixon; Karen Arthur; Christine Jones; Claire Stoneman; Dawn Hart
Carers coming together

Each autumn carers in all four UK nations attend our AGM and summits to reflect on the past year and make plans to achieve change.

Carers Northern Ireland
On Tuesday 10 October, we held our annual Carers NI Summit in Lisburn, where Carers UK Chief Executive Heléna Herklots launched the NI State of Caring Report 2017. This detailed study of what you told us about what it’s like to be a carer in Northern Ireland will form the basis of our policy and campaigning activity over the year ahead.

BBC Radio Ulster covered the event, interviewing Heléna along with carers Michael Downes, Anne McAllister and Margaret Field about their experiences of caring. More than 80 carers and health and social care professionals attended the Summit where we explored together the areas we would want to see included in a future Carers Strategy for Northern Ireland.


Carers Wales and Carers Scotland
Cardiff and Glasgow will be kicking off Carers Rights Day activities this year with the All Wales Carers Assembly and Carers Scotland Summit taking place on 24 November.

Both events will bring carers from across the nation together with Parliamentarians and other senior leaders to discuss the issues affecting carers, including the implementation of The Social Services and Well-being (Wales) Act and the coming devolution of certain benefits, including Carer’s Allowance, to the Scottish Government.

Find out more at carersuk.org/Scotland/CarersSummit and carersuk.org/Wales/CarersAssembly

Carers UK
On 18 October 138 members gathered in London for Carers UK’s Annual General Meeting and Members Conference.

The AGM is an important part of our governance, where we report back on the activities and achievements of the last financial year and present the company accounts. We’re ending this year in a strong financial position, largely thanks to a generous legacy received from one of our long-standing members, Rosemary Watt. Read more in our Members’ Report, pg 20–21.

Following the Governance Review which concluded last summer, the Nominations Committee put forward four new Trustees who were unanimously approved by members at the AGM. These individuals were selected to ensure the Board had the right skills and experience – including experience of caring – to lead the charity.

Read more about our new trustees at carersuk.org/trustees
One of the central themes of our Members Conference this year was the power of telling our stories.

That’s how our movement started 52 years ago, when Reverend Mary Webster shared her personal story of caring for her parents with absolutely no recognition or support. It was this story, simply told in a letter, which caught the attention of a national newspaper. All over the UK, others recognised that her story was their story, too. Each story unique in its way, but coming together to form a powerful narrative which brought caring out of the shadows.

What started with an individual story became a national movement.

As the story has developed over the past half-century we’ve seen new rights, changing attitudes and major demographic shifts which have made caring feel very different now to how it was in the beginning. But it’s the same story.

Caring for our loved ones is right at the heart of what it is to be human, yet for the 6,000 people who become carers every single day, it can still feel like being thrust into a completely separate world.

The veil between these worlds is paper thin – no one is more than an accident, an illness, a gene mutation away from becoming a carer. Yet it can feel like a huge gulf in understanding.

Whether in person, in writing, on film or however we choose - by telling our personal stories as carers we can help to close this gap and open up the reality of what our world is like.

This is precisely what drove Carers UK member Steph Nimmo to start writing about her experience of caring for her daughter, Daisy – trying to help others grasp what life is like caring for a life-limited, fragile child. Trying to be heard and understood.

Sharing what it’s like to be bone-achingly exhausted yet have no opportunity to sleep. What it’s like to be responsible for administering the intravenous infusions that keep your child alive. What it’s like to see your child in the hold of a violent seizure and have no idea when the next is coming.

“by telling our personal stories as carers we can help to close this gap and open up the reality of what our world is like”
“all of our stories demand to be heard. Each is extraordinary in its way. Together they illuminate what it is to be a carer”

And in the midst of all the challenge, the exhaustion, the grief, what it’s like to hold onto a sense of who you are as an individual. What it’s like to create precious memories and live life for the present, when both your daughter and your husband are terminally ill.

We may not all have a story which can captivate an audience, as Steph’s did at the Members Conference – but all of our stories demand to be heard. Each is extraordinary in its way. Together they illuminate what it is to be a carer and bring to life our call for better support and services to make this care possible.

**Tell your story**

We’re creating a space on our website to tell and share your stories.

Not just because every story is worth telling, but so those with the stories can connect with each other too and share understanding. It’s part of being a supportive community.

By adding your story, we will ask you to take one more step and share it – with your friends on social media, as a letter to the editor of your local newspaper or radio station, or to your local councillor or MP. So we can spread these stories far and wide to help improve understanding and effect change.

We are starting with Carers UK members and then, once the map is alive with your stories, we will launch it more widely, inviting carers everywhere to tell their stories.

Just go to [carersuk.org/wecare](http://carersuk.org/wecare) and follow the steps to tell your story.

“we can spread these stories far and wide to help improve understanding and effect change”
Every autumn we report back to our members on what we’ve achieved together during the last financial year, from April 2016 to March 2017. Our annual report and accounts were presented at our AGM and are available online to give you a full picture, but here’s a snapshot for you:

We help

19,864 enquiries handled by Adviceline

94% of people that read Caring magazine said it made them feel part of a supportive community

1,704,430 people accessed help and information online

We campaign

2016 was an extraordinary year in the courts for carers as we won hard fought rights for carers. We worked with our members and supporters to provide support to three key issues: the benefit cap, attendance allowance and the bedroom tax.

Protecting Older People’s ‘Attendance Allowance’: We campaigned successfully to stop Attendance Allowance becoming a post code lottery and protected essential sources of practical and financial support both for older disabled people, and for carers.

Exempting carers from the benefit cap: 2016 started with government announcing it will change the law to exempt all carers entitled to Carer’s Allowance from the ‘benefit cap’. The announcement is their response to an amendment tabled by Carers UK Vice-President, Baroness Pitkeathley and follows a landmark ruling from the High Court in November 2015 which found that the Government was unlawfully discriminating against the claimants by capping the benefits of their carers.

Exempting carers from the bedroom tax: Carers UK members, Paul and Susan Rutherford put forward – and won – their legal challenge against the ‘bedroom tax’. In November 2016 the Court of Appeal accepted that the ‘bedroom tax’ unlawfully discriminates against disabled children requiring overnight care, as it does not allow for an additional bedroom for their overnight carer and a further case also allows a second bedroom where it cannot be shared for medical reasons. This is the culmination of 7 years of campaigning to highlight how the bedroom tax ignores the needs of carers.

Thank you so much for all your help and advice I am so grateful. It has been a big decision to give up my job to become a carer but it’s definitely the right thing to do. Thank you for all the useful contact information, you are an amazing source of support.
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 2018. You too can help us achieve this, find out how by visiting: carersuk.org/how-you-can-help

View the annual report and accounts in full at: carersuk.org/about-us/what-we-do

We connect

\[4,328\] hours of volunteering by carers and others who share our mission

On average \[8,000\] people engaged with us on Facebook each month

\[1,000\] local groups signed up to Carers Rights Day – reaching thousands of new carers with information on their rights

\[130\] Employers for Carers members with a reach of over a million employees, plus 68 Carer Positive organisations in Scotland

Over \[52,000\] now follow us on twitter

We innovate

\[3,049\] people downloaded Jointly

11,131 new members joined Carers UK

It is always good to feel you have contributed and in turn helped to raise the profile of Carers UK.

The great thing is that now as a member, I’m in a position to offer encouragement and understanding to other carers, and that feels good.

thank you
A Carer’s Guide to: Positive thinking

Sometimes it’s hard to stay positive when we’re caring, and we’re confronted with the reality of life not going to plan. Carers UK member Steph Nimmo has had to work harder than most at finding the positives. Her daughter, Daisy, born with a rare genetic disorder, passed away last January, just over a year after Steph’s husband, Andy, died of cancer.

Still caring for her two sons who have autism along with another teenage daughter, Steph has managed to turn the most difficult of stories into a book which is both life-affirming and uplifting.

“With Christmas just around the corner this will be a hard time of year for many of us”

We parents of children who were born to be different in some way are always being told we are amazing, we are so strong, we are told that you couldn’t do what we do – well guess what? Sometimes we want to turn around and instead of smiling angelically and saying something like ‘Well you just have to get on with it, they are my child no matter what’ we want to tell you ‘It sucks, I hate it and quite frankly I want to run away!’

There are days when the Glad Game, famously played by the fictional character Pollyanna, just does not work for me. How could I be glad when my work load just kept increasing, when I saw constant deterioration in my child’s health, when her bedroom looked more and more like a hospital room every day? How could I, when every hard won battle for independence and time off got taken away by yet another medical curve ball?

Caring is rubbish at times. The times when you’ve just changed the bed for the millionth time and then her stoma bag leaks all over it. The times when she hit you as you leant forward to kiss her goodnight because the seizure activity going on in her brain made her confused. The times when your other children were on the receiving end of your stress and didn’t deserve to be shouted at for the smallest of misdemeanours. The times when the nurse agency messed up the care rota so by day three of being awake most of the night you are incapable of stringing a sentence together let alone caring for four children.

With Christmas just around the corner this will be a hard time of year for many of us. It’s supposed to be a time of thanks and gratefulness. Last year, Christmas came after the year from hell, which began with my husband’s funeral and ended with Daisy’s health in a desperately worrying decline.

I’m so glad I gave in to Daisy’s demands to put the tree up in November and went all-out to make it super-special. I’m so glad I trawled the internet trying to get hold of the
“My ability to see the positive in every situation is irritating even to me at times!”

Baby Alive doll she kept watching YouTube videos of. I’m so glad she dressed up in her Christmas hat and visited friends, delivering cards and presents. Because this year I’ve got the Christmas that part of me was wishing for last year, where I also get to sit down and relax and enjoy the festivities. I wish I didn’t. I wish Daisy was still here to sweep me up (and wear me out) in her festive enthusiasm. Of course, like many carers, I will make the best of it. But sometimes we lose at the Glad Game and that’s totally OK. 99% of the time I am a Pollyanna. In fact, my ability to see the positive in every situation is irritating even to me at times. However for the remaining 1% of the time I want to strangle Pollyanna. She can take a running jump.

If you find yourself struggling to think positively, here are some tips which I’ve found useful:

**Steph’s tips for positive thinking:**

1. **It’s not the cards you’ve got, it’s how you play them**
   My life was never going to be entirely predictable but as Andy always said, it is what it is: it’s how you respond that makes the difference. For me, that’s about focusing on what we have, not what we don’t have.

2. **Do things for you**
   As well as writing and live music, I love running – it keeps me sane and allows me to eat cake. I have run several marathons and an Ultra marathon and have raised around £10,000 for our hospice in the process. I’m branching out into open water swimming and cycling... Some call it a midlife crisis, I call it an alternative to prozac!

3. **Upbeat but real**
   I’d always been optimistic and upbeat about Daisy’s health but Andy and I always chose to be very open about what was going on with Daisy and to share her story, good and bad because we felt it was important for people to have a window into a world that they probably knew nothing about.

4. **Make it happen**
   This has become a mantra for how I try to live my life: deciding what I want to happen, and doing everything within my power to make it so. I wanted to be the best mum I could be for Daisy, I wanted to make sure that our other children did not miss out on childhood, I wanted to ensure our marriage survived.

*Was this in the plan?*

Steph’s book *Was This in the Plan?* is published by Hashtag Press, and available to buy or download on Amazon.

Reader reviews:

“Wow. What a lady. Proof that a positive attitude and a glass-half-full attitude can triumph over the greatest adversity. A heartbreaking but uplifting memoir.”

“I read this book in one sitting. It had me laughing out loud and made me cry but most of all it reminded me to seize the day and enjoy the journey.”

@carersuk @carersuk
My father has recently been awarded Attendance Allowance. If I make a claim for Carer’s Allowance for looking after him, could it affect his Attendance Allowance payments?

If you claim Carer’s Allowance for looking after your father, then his Attendance Allowance wouldn’t be affected in any way. If your father is receiving a State Pension or an occupational/personal pension then these payments wouldn’t be affected either.

However, if your father is receiving any means-tested benefits, then your claim for Carer’s Allowance could affect these. The means-tested benefits that could be affected are:

- income-related Employment and Support Allowance
- income-based Jobseekers Allowance
- Income Support
- Pension Credit
- Housing Benefit
- Council Tax Reduction.

If he is receiving the severe disability premium (called the severe disability addition within Pension Credit) as part of his means-tested benefits, he will lose this if you are paid Carer’s Allowance for looking after him.

The severe disability premium (or severe disability addition within Pension Credit) is £62.45 a week, and might be included in your father’s means-tested benefits if he meets all of the following conditions:

- he gets a qualifying disability benefit (which includes the middle or the higher rate of the care component of Disability Living Allowance; either rate of the daily living component of Personal Independence Payment or either rate of Attendance Allowance); and
- he lives alone (there are some exceptions to this - such as if he lives with other people who also receive a qualifying disability benefit they will all count as living alone); and
- no one is paid Carer’s Allowance for looking after him.

Therefore, if your father is getting this severe disability premium (or severe disability addition within Pension Credit) as part of his means-tested benefits, these payments could be affected if you apply for Carer’s Allowance.
My Nan is undergoing palliative care. I’ve always been close to her. I’m getting so many mixed messages from others and from Nan. I am trying so hard to understand end of life, because if I can understand the ‘process’ - I can accept it. Is she really dying? How can you know a time frame? I’m so confused!

I am so sorry you are having such a hard time. It does sound as if your Nan is at the end of her life. My only advice is to sit with her and talk to her, even if she seems to be sleeping. Say all the things you want to say, how much you love her and so on. Be strong.

Is anyone going to be around to help with this at all? If not, feel free to ask us anything you’d like to know. Lots of us here have been through it. Finally, and most importantly of all, your Nan is very, very lucky to have such a kind and loving granddaughter. Feel proud of what you are doing.

Precisely when that [her passing] will be is hard to say – the doctors can give their prognosis, but not always accurately, as each person is different. As others are saying, it’s wonderful that she can be at home, with her family, to end her long life, with all those who love her around her.

Get involved
You can talk to other carers who understand 24/7 at the Carers UK Forum – visit carersuk.org/forum to get started.
I Care: Emily

Emily has cared for her husband Neil since she was 24. She talks about the challenges she’s faced as her husband’s health has deteriorated...

Being a younger carer can be isolating. I’ve been caring for my husband Neil, since I was 24. Most other carers I meet at our carers centre are over 60, they’re very friendly and helpful, but I find it harder to relate to them.

My husband, who has just turned 51, started feeling very ill around eleven years ago. He became too weak to walk to the local shop, which was so close you could see it from our house. The GP wasn’t sure what was wrong with him and when he was sent for further tests, he collapsed. He was rushed to hospital and admitted. After a week in hospital the doctors suspected renal failure, which was confirmed by a specialist shortly after.

Neil was in hospital for quite a while and had to give up his job as a driver for a fruit and vegetable company. He made applications for PIP (Personal Independence Payment) and ESA (Employment and Support Allowance). Without Neil’s income, we fell behind with our rent payments and, unfortunately, we were evicted from our home. We were placed in a bed and breakfast and eventually we qualified for a one bedroom flat. It was a very stressful time.

The housing trust made a referral on our behalf to social services and we were allocated a social worker and occupational therapist. We were awarded housing and council tax benefit and ESA and Neil was awarded PIP two months later. Up until this point I had continued working as a cashier at ASDA, however, when we started claiming ESA, it became clear that it would be better financially for me to leave my job and start claiming Carers Allowance.

I found the social worker friendly and helpful, however, we’d been on our own with no help or advice on how to manage the situation for six months. Although I had heard of social services I had no idea what they were, so it never crossed my mind to contact them. The social worker suggested that we employ my brother in law as Neil’s driver. She also got us an electronic bath chair that Neil could use to get in and out of the bath.

After a few months of living at the property, Neil’s health had declined and the one bedroom flat was no longer suitable. Neil couldn’t get in and out of the bath even with the chair. We had been given an NHS wheelchair for Neil, but the door frames

“eventually we qualified for a one bedroom flat. It was a very stressful time”
It is important to me to have a life of my own.

The next problem we faced was... the bedroom tax... it’s been a difficult journey but we’ve kept fighting.

were too narrow for us to move it anywhere. I was also sleeping on the sofa when Neil wasn’t well. Our social worker helped us secure a two-bedroom bungalow, which is fully accessible and has a wet room. The next problem we faced was fighting the bedroom tax. We were initially turned down for Discretionary Housing Payment (DHP) to help with the bedroom tax. However, after contacting our local MP we have been awarded DHP. It’s been a difficult journey, but we’ve kept fighting.

Since then Neil’s health has declined even further, he was diagnosed with autonomic neuropathy, Barrett’s Oesophagus, and has suffered a couple of mini strokes. Dramatic problems with his blood pressure affected his sight and he’s now fully blind. He has dialysis in hospital three times a week, and is hoping to lose enough weight to be put on the transplant waiting list.

My caring role mainly involves giving Neil help when he asks for it, running errands, such as going to the shops for him, guiding him or pushing him in his wheelchair, and helping with his communication needs or filling out forms. Neil likes to be as independent as possible and most of the time he can do things like wash and dress himself unaided.

We have a Carecall alarm system in our house so that in an emergency Neil can get help via his pendant if he’s on his own. This gives me great reassurance, so that I can leave the house. I like attending a weekly photography group, and I sometimes go on day trips with the local Carers Centre and I’m taking driving lessons. It is important to me to have a life of my own, obviously Neil’s my first priority, but he says himself he doesn’t need a nanny.

I’m quite passionate about trying to improve things for carers and disabled people, so I like to attend local groups such as our local disability forum to try and give carers a voice. I will never forget how difficult those first six months were, everything changed we were thrust into a new world we knew nothing about.

Looking back on it all, it was quite stressful. I am determined to try to make sure no other new carer goes it alone and gets access to the help they need.

“It is important to me to have a life of my own”
“Every piece of writing contained in this anthology is a testament to belonging – a reminder of what it is to be human, and what each one of us has to offer the other.”

– Cheryl Moskowitz, Carers UK creative writing competition judge

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