However caring affects you

Our vision for 2021
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Our vision for 2021
This wasn’t in the plan

Until my daughter, Daisy, was born prematurely in 2004, I was a driven, ambitious, marketing professional, a mother-of-three working full time and worrying about childcare, global warming and the best route to get to work.

When Daisy was diagnosed with a rare genetic condition – Costello Syndrome – I was confronted with a situation which was not in the plan. My career went out of the window and I found myself a stay-at-home mum. As well as a family plate spinner, journalist, carer, nurse, spokesperson, campaigner and marathon runner (actual as well as metaphorical).

Ten years after Daisy’s birth, Andy, my husband and partner of 27 years, was diagnosed with cancer. He deteriorated rapidly and died in December 2015. Losing the father of my children, my rock and soul mate, was certainly not in the plan. It left me and my family with a gaping hole in our lives.

My life was never going to be entirely predictable but as Andy always said, it is what it is: it’s how you respond which makes the difference.

“Caring for Daisy is still bone-achingly exhausting. It’s not just physical work, it’s emotionally and psychologically draining. “

Caring for Daisy is still bone-achingly exhausting. It’s not just physical work, it’s emotionally and psychologically draining. But we get on with it, focusing on what we have, not what we don’t have. I can’t pretend it’s all plain sailing but we make it work and above all we don’t sweat the small stuff anymore!

It is very important for me to make space for myself. I had a life before children. I had a life before becoming a full-time carer. I am more than mother, wife, carer, widow: I am me. I have been pushed to my limits in many ways but I am determined not to let it define me. I want my children to have a life and happy memories, regardless of everything that has happened to us.

My life went spectacularly off script at quite an early stage. But even if our lives are going swimmingly, sooner or later we will be affected by caring. Sooner or later, we will face the challenge of helping someone we love get the most out of life, without losing sight of who we are in the process.

When we face that challenge, it’s so important Carers UK is there with a plan to make sure we’re respected, valued and supported.

– Steph Nimmo
However caring affects you

It wasn’t in Caryl’s plan for her husband’s health to decline so rapidly. Or for the caring to become so difficult that she could no longer look after him at home.

It wasn’t in Palwinder’s plan for his widowed mother to develop dementia or need the kind of round-the-clock caring that he gave up his job to provide.
Our vision

Sooner or later, most of us will face the challenge of caring for family and friends who are older, disabled or seriously ill.

But it’s rarely in the plan.

We’ve created a vision for the world we want for carers by 2021. For Steph, for Palwinder, for Caryl, for everyone looking after loved ones right now and for the 6,000 who start caring for someone every single day.

In the world we all want, carers are respected and recognised for the huge contribution we make to our families and communities. In that world, carers feel valued and supported. The care we provide is not taken for granted.

Without carers, the UK’s health and social care system would completely fall apart. As our population ages and people live longer with illness and disability, carers are becoming more and more important.

We have been striving to create a better world for the past half-century. We’ve won some important rights for carers in that time, but there’s so much further still to go. Far too many carers are stretched to the limit looking after loved ones, while also having to worry about making ends meet. This cannot go on.

We want a world where carers are supported not only to cope with the challenges of looking after someone, but to build a life of our own too. A life which includes caring but is not overwhelmed by it.

This matters to all of us. At some point, we will all care for family or friends who are older, ill or disabled, or we will need that care ourselves. At that point, we will realise how important it is to make a better world for carers. For there is nothing more human than looking after loved ones, and no more pressing social issue than making that care possible.

Shaping that world means taking action now.

We have created a vision and plan inspired by the experiences, frustrations, passions and commitment of our members and supporters. We believe our plan can create a world where the right help and support is there, whether caring starts gradually or takes us completely by surprise.

The vital ingredient for delivering that plan is you. We’re building a movement of carers and everyone who recognises the importance of caring, so we can unite behind this vision and plan and work together to make it happen.

It’s a wonderful vision – join our movement and help us create the world we all want for carers.
Our plan

We’ve got a plan to make sure that however your life is affected by caring, you get the support and recognition you need.
In the world we all want, carers feel valued and supported for the huge contribution we all make. The care we provide is not taken for granted.

2021 isn’t far away, so we are focusing on three priorities to create the world we want for carers.

1. Battling for greater understanding and support for carers in our society.

2. Being there for carers with information and advice, right from the start.

3. Building a network of carer positive employers.

In order to deliver on these three priorities, we will also focus on:

- growing income streams so we can increase our impact year on year
- being a great place to work and volunteer, where everyone knows the difference they make
- making the best use of technology to work effectively and respond to changing behaviours
1. Greater understanding

Our society cannot keep taking carers for granted. We will battle for greater understanding and better support.

Over the years we’ve secured landmark rights for carers throughout the UK, from the first ever legal rights for carers in 1967 to the Care Act 2014.

How

• Producing research which builds an irrefutable case for better support for carers
• Campaigning for carers’ rights and leading the way in achieving lasting change on the issues that affect carers most
• Creating a movement of carers and people who are passionate about caring to speak out powerfully about the world we want
• Supporting the development of the global carers movement and collaborating with international partners to increase recognition and support for carers around the world
• Pushing the reality of life for carers much higher up the political debate and into the hearts and minds of the general public

Vision 2021

We’ve already built a strong platform – over the years we’ve secured landmark rights that our founders would never have dreamed were possible.

We have five key campaigning priorities to deliver better support for carers, and we will keep fighting, publicly and behind closed doors, until we bring that world about.

By 2021, we want a world where we can all look after loved ones without putting our own lives on hold.
Speaking powerfully about the world we want

Paul

Paul came to a Carers UK Parliamentary event to talk directly to MPs about his life and what needs to change for carers. His story shows the importance of being heard.

“My son Harrison was delivered in a frank breach position and spent most of his first year in and out of hospital with doctors shaking their heads, not knowing what was wrong. He has an unknown genetic neurological condition and a cocktail of other complex health issues.

Helen has a condition called fibromyalgia which causes widespread severe pain and exhaustion, which has become gradually worse since Harrison was born.

Over the years I gradually took over more and more of Harrison’s care and started doing more and more to help Helen. When I gave up work I thought it might be for a year or two, not the eight years it currently stands at.

Yet caring for Harrison and Helen isn’t the hard part – having to fight for every scrap of support is. That’s what I told MPs at a Carers UK Parliamentary event.

I spoke about my experience of applying for disability benefits and getting the system to understand the challenges families like mine face – it’s emotionally complicated, time consuming and utterly draining.

““It’s not the caring that’s difficult so much as the continuous fight for services."

For me, coming to the House of Commons to speak to MPs is about having my say. I want to be able to put my story across and talk frankly about the difficulties that my family and I are facing.

I’m just one story – there are thousands like mine.”

We will amplify these stories to push the reality of caring up the political agenda.
However caring affects you

2. Timely information

The right information at the right time makes a world of difference for carers. We will be there with expert help and advice, right from the start.

Caring is part and parcel of family relationships, so many of us don’t look for support until we reach breaking point. We want carers to be able to access expert advice and information services much earlier.

As soon as you start looking after someone, we want you to know that you are not alone, that you are part of our supportive community where every question, feeling and experience can be shared and where answers can be found.

How

• Working with partners to create a much more responsive, comprehensive support service, based on carers’ experiences, improving our digital capability so the answers are available for everyone who needs them
• Enabling carers to connect with other carers for support and understanding, both online and in local communities
• Mobilising our employer and volunteering networks to reach carers early

Vision 2021

We’ve already built a strong platform – we’re already reaching a million people a year with our expert information and advice.

We will make the most of digital tools to reach a wide audience, while being there at the end of the phone or in local communities for everyone who needs us.

By 2021, we want to be reaching two million people per year with expert information and support.
Answers for everyone who needs them

Emma

Emma, together with her grandad and brother, looks after her 74-year-old grandma who has dementia.

“After completing Carers UK’s Upfront guide we realised my grandad is entitled to a carer’s assessment. This has allowed him to support my grandma with specialised respite care, so he can get a well-deserved break. We previously assumed he wasn’t entitled to anything.

Caring day-in, day-out for my Grandma, dealing with her high support needs and aggressive behaviour, terribly affects both our health.

Without this small amount of respite that my grandad now gets, I believe we would have hit breaking point.”

“Without this small amount of respite I believe we would have hit breaking point.”

We will reach out to carers early, because timely information makes a world of difference.
3. Positive employers

Enabling carers to combine work with care is better for business and better for everyone. We will build our network of carer positive employers to light the way.

Three million people in the UK combine work with caring for a loved one. But without support, we can find it extremely difficult or impossible to continue with both roles. Far too many have to give up work altogether.

Progressive employers are already waking up to the benefits of supporting the carers in their workforce. We will find and champion those employers across all sectors to create carer positive beacons and inspire others to follow suit.

How

• Building on the strength of our employer networks to create a powerful movement of progressive employers committing to providing carer positive workplaces
• Bringing together all our employer services into a single, integrated approach for maximum impact
• Working with business groups, unions, local authorities and others to reach employers of all shapes and sizes with an inspiring business case for supporting carers in their workforce.

By 2021, we want a world where no one has to give up work to care.

Vision 2021

We’ve already built a strong platform – we’ve established a big-hitting network of employers who completely understand the importance of supporting carers.

We will work with them to spread the message that supporting carers makes complete sense for businesses as well as families.
Developing carer positive workplaces

Hugh

Hugh works for a company which belongs to our Employers for Carers business forum. His story shows what a difference the right support can make – both to families and to businesses themselves.

“I started caring in 2003, when my dad was diagnosed with Lewy Body Dementia. At first mum cared for dad at home, but as dad’s condition developed, it became harder for mum to cope.

It got to the stage where dad was in hospital, having fallen into a diabetic coma and later contracting pneumonia and MRSA. We were told he had two days left to live. He pulled through, but was bed-bound and doubly incontinent. We decided a care home was the best option.

We visited dad in the care home almost every day for the six and a half years he was there.

Routine was really important to dad – having us visit at the same time each day really mattered. My manager and team were incredibly supportive, allowing me to work mornings, visit dad in the afternoon and then make up time in the evening.

I had a handful of comments from colleagues – “Another half day again, Hugh?” – but the organisation knew that keeping carers in the workforce really mattered, and people soon learned that everything that needed to be done would still be done.

“The organisation knew that keeping carers in the workforce really mattered.

One day I overhead two colleagues talking about their caring responsibilities. I joined in their conversation, and we went to talk to HR about setting up a Carers Network.

When people first come to a Carers Network lunch, they often think they’re the only ones going through it. Many of them haven’t spoken to their colleagues about the effect caring has on them. And they apologise for needing to have a moan about it all. That’s what the Carers Network is here for. We’ve all been there, and we know what a difference it makes when you can talk about it to people who understand.”

We will create a world where we can talk openly about our caring role at work, knowing that our employer will understand.
We need your help, in all kinds of ways.

The issues that affect carers are the issues that affect us all. A better world for carers is a better world for everyone.

If we achieve our vision, we will:

• radically improve the lives of millions of carers and those we’re looking after
• create stronger, more supportive and resilient communities
• help many return to work and reduce the stresses and strains for those already juggling work and caring responsibilities
• increase our ability and readiness to deal more effectively our ageing population
• recognise and celebrate the role of carers in our society, cultivating greater understanding and better support.

Join our movement for change and be part of creating the world we want – where we are respected, valued and supported to look after our loved ones and build a life of our own.
Every day 6,000 people become carers, looking after family or friends who are older, disabled or seriously ill.

However caring affects you and your family, we’re here.

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carersuk.org

For expert advice and information about caring, contact the Carers UK Adviceline.

T 0808 808 7777   E advice@carersuk.org

Open Monday to Friday, 10am to 4pm.