



Two in three of us will care

What you should know about unpaid caring:
perspectives from five different carers

Contents

About this guide	3
Carer experiences	4
Hitesh	4
Wyn	7
Jaycee	10
Barbara	13
Michael	16
How we can help	19



About this guide

Every day, millions of people are caring, looking after family members, partners or friends with varying disabilities, conditions or illnesses.

Saving the economy £132 billion a year,¹ unpaid carers play a vital role in looking after people and propping up the health and social care systems.

If someone close to you has an accident or sudden illness, you could become a carer overnight. Or you might gradually slip into the role, incrementally taking on more and more caring responsibilities as someone's health worsens.

Some people don't think of themselves as carers, but caring will most likely affect us all at some point in our lives. With our population ageing, increasingly many of us will need extra support in later life.

Two in three of us will care and there's a 50:50 chance that any one of us will become a carer by the time we reach our 50s.²

In this guide, five individuals share their own personal experiences of caring, shining a light on what support is available and the different ways you can help fulfil your own needs as well as meeting the needs of those you look after. Whatever your circumstances may be, it may be useful to explore what sources of support are available to help.

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50:50

chance that any one of us will become a carer by the time we reach our 50s.



1. Valuing Carers 2015 – The rising value of carers' support. Carers UK report, 2015 [carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015](https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015)
2. Will I care? The likelihood of being a carer in later life. Carers UK report, 2019 [carersuk.org/images/News__campaigns/CarersRightsDay_Nov19_FINAL.pdf](https://www.carersuk.org/images/News__campaigns/CarersRightsDay_Nov19_FINAL.pdf)

Hitesh's experience



Hitesh has channelled his positivity and energy into enriching his mother's life, supporting her as well as many others with his dedication and compassion.

“ I had been looking after both my mum and dad for many years previously, but when my dad passed away in 2014, that's when it got intense. I didn't know where to look for help or information on how to cope with all this. So, I just carried on day after day, firefighting to tape it all together and make it work.

The big problem was that the stress and depression crept up slowly. That meant while I was trying to care and extend my mum's life, I'd be losing the quality of my own life. In time my whole life changed; it took up every second of my mental minutes just to keep my head above water.

The first 18 months after my dad passed away, I had to do everything for my mum. We both went into depression and needed bereavement counselling as there was no support from family during this time. This was probably the toughest challenge I had in my life.

At that point I realised it was just Mum, me and the tortoise (Rocky). My mum suffers from chronic kidney disease, osteoarthritis and short-term memory loss due to dementia.

“This was probably the toughest challenge I had in my life.”

“Mum loves the garden so will be out in nature as much as possible.”

As well as having to do the cooking and cleaning, it means I have to keep an eye on her diet, ensure she’s doing some exercise each day and take her to her doctor’s appointments. I also have to help her navigate all the many confusions and issues that arise with dementia.

I wasn’t prepared for the work-life balance and mental challenges I’d be facing. From handling doctors’ appointments, Mum’s tantrums and short-term memory loss, to following up with the chemist for delayed medication, grocery shopping, cooking, cleaning, filling in online forms, handling financial bills, the list goes on...

How I keep positive

First, I have a nutritional drink to keep my immune system in good shape. Then me and Mum do some HIIT exercises. I created a YouTube video of this to inspire other carers looking after their elderly parents.

My mum enjoyed watching how many people viewed it and it inspires her to help others. I believe in giving your elderly parents a purpose to lift their spirits. So now Mum occasionally joins me and volunteers to feed homeless people.



After exercising, we hug and say the Ho’oponopono phrases: “I love you, I’m sorry, please forgive me, thank you.” Ho’oponopono is an ancient Hawaiian healing system. It is essentially about complete freedom from the past. We then have breakfast.

Mum loves the garden so will be out in nature as much as possible. In April we planted some sunflowers seeds, and they grew to 8ft, which put a smile on our faces. I wrote a letter to some friends and put the seeds in there, so they could plant them and experience the joy of nature and pay it forward too!

If I’m not helping Mum, I’m coaching and creating useful content for family carers. I have recently created a free caregiver roadmap. I also have a five-day challenge coming up to help carers create a more balanced lifestyle in achieving more by doing less:

hiteshdaudia.com.

Looking after someone guide

Covering everything you need to know when you become a carer, from benefits to services: carersuk.org/looking-after-someone



“I know many carers experience loneliness, as they feel they can’t talk to people about their individual circumstances.”

New direction

I’ve stopped working 9 to 5 as I needed something that allowed flexibility. So, I decided to focus on working from home on my own projects. This allowed me to help Mum out when needed.

We, as human beings, need that interaction with other people so working on your own can feel lonely and I know many carers experience loneliness, as they feel they can’t talk to people about their individual circumstances.



You must be organised otherwise the whole day will slip away, and you feel you haven’t achieved much. We need to take care of our wellbeing because if you fall ill as a carer, you will not be able to care for the person who needs your help. I’m currently a coach and mentor other carers, too; it’s given me my freedom and sanity back. ”

Managing someone’s affairs

We have a whole host of ways to do this from putting a contingency plan together at: carersdigital.org/mybackup to getting the most from services: carersuk.org/managing-someones-affairs

Wyn's experience



Wyn has been caring for her husband for over 30 years and generously shares her knowledge to support other carers. We are grateful that she shares her experiences with us.

“ I first met my husband, Colin, at a New Year's Eve party when we were 18 and we have now been married for 56 years. When we met he was a motor mechanic and played in a band most evenings – I suppose I was a bit of a 'groupie'. Changing from motors to music was a natural progression for him, especially using his skills as a mechanical engineer. We set up our own hi-fi manufacturing company, employing about 10 people and exporting all over the world. We were on the up. Then in 1990, Colin suffered a subarachnoid haemorrhage, followed

by a massive stroke; we were then only 46. He stayed in hospital for almost a year and during that time, not only did I, with the help of our oldest daughter, have to decide what to do with a business, but we also had to deal with Colin's disabilities.

Our GP was fantastic at giving me support and information, especially on the Stroke Association. They in turn put me in touch with a family support worker, who guided me through the systems I had to encounter. This was to prove invaluable when he came home and in later times.

“In terms of maintaining your identity and wellbeing, it’s important to keep connected with your friends and family.”

I would say to anyone, get help when it’s offered. Seek out advice from carers’ centres and Carers UK; they have great expertise in many areas.

At first, we had 24/7 care from both the health and social care systems and knowing how they work has helped through the years. I identified as a carer early on. We need to be called carers; we need a label so we can be recognised and find the help we all need. I urge carers to join Carers UK – it does not cost anything to get the help you need.

I have never been too proud to accept help – we have had a social worker for many years. I know people shy away, but they are not there to cause problems; they are there to help you.

We have personal assistants through the direct payment scheme for 30 hours a week to help me with Colin. They provide most of his personal care. He is a permanent wheelchair user and has very little lower body strength, so we have a moving frame to help him move around. The one thing I am grateful for is that he is a happy person. That was the biggest challenge to me, accepting that he is not the same person he was before.



He sometimes lives his life through me. You have to try to shield your family and keep some normality in your life as much as possible. It is difficult to accept your life has changed. I would say to new carers who might be daunted about the future: look for the humour or silver lining in every situation.

My life is so different but I have grabbed it with both hands. Getting involved in the voluntary sector has kept me focused, helped retain my sense of identity and wellbeing, and given me things to achieve with carers always being at the centre.

Finding aids and equipment

The right technology or practical aids can provide more independence and freedom. See our online sources of guidance: carersuk.org/tech

“As independent as I am in spirit, I do know that I cannot manage without help.”

I have helped set up a carers’ centre and a stroke club in our local area, and been to parliament and spoken to a select committee on health and social care. I have met some wonderful people who I would never have met. Being part of Carers UK as a volunteer and sitting on the local carers partnership board gives me great satisfaction.

Both Carers UK and Carers Trust are brilliant organisations. They have carers at the heart of what they do and they listen which is so important. In all I have done I have always felt valued and listened to. These are all the positives for me; there is a good side to caring.



As a carer, you really do need to look after yourself. Who’s going to look after the person you’re caring for if something happens to you? As independent as I am in spirit, I do know that I cannot manage without help. People worry about getting help because they don’t want others to interfere, but they’re only going to give you as much help as you want. Nobody is going to force you to do anything.

So many people don’t claim the benefits they’re entitled to. You can email Carers UK’s Helpline to check if you’re entitled to any benefits and it doesn’t cost anything. It doesn’t cost anything to join Carers UK so what have you got to lose?

All you’re doing is joining an organisation where you might be able to find some help at some point when you need it.



Joining Carers UK

Joining Carers UK costs nothing and provides access to helpful sources of support. Find out more on page 19.

Jaycee's experience



Jaycee is a carer for her 92-year-old mother who has reduced mobility due to a spinal condition. Four years ago, Jaycee quit a 30-year nursing career to care for her mother full-time.

“ I consider it a privilege to support my mother to be as independent as possible and enjoy a comfortable quality of life.

As well as managing her ongoing healthcare needs, providing emotional support and dealing with day-to-day household responsibilities, I love assisting her with her favourite activities: cooking, gardening and going on community outings. Even through the tough times, our connection and respect for each other has grown deeper.

Since becoming a carer, my biggest struggle has been dealing with my emotions. When I first became a carer, I experienced a huge emotional upheaval that came with the sudden change of circumstances. My way of coping was to suppress my feelings and pretend that everything was okay, when it wasn't.

“Since becoming a carer, my biggest struggle has been dealing with my emotions”

“I felt alone in my caring responsibilities and invisible to the outside world.”

I felt shame around admitting I was struggling, experiencing feelings of guilt, frustration, and resentment. But more than anything, I felt alone in my caring responsibilities and invisible to the outside world.

I have since found wonderful outlets for expressing my emotions through dancing, writing poetry and sharing how I feel with other carers.



Being able to access support through organisations such as Carers UK has been a lifeline. In the past year, I have participated in over 30 Carers UK online Share and Learn sessions, ranging from craft workshops, community singing groups, mindfulness and yoga, to creative writing.

Not only have these sessions given me an opportunity to switch off and enjoy uninterrupted time for myself, I have also made new friends, gained new skills and established new support networks.

As a result, I feel more empowered not only in my caring role, but also as an individual in my own right and for that I am extremely grateful.

Share and Learn

Hosted by Carers UK online via Zoom, regular instructors, artists, performers and experts offer free sessions for unpaid carers. From arts and crafts to Latin dance, yoga and marital arts, there is something for everyone. See the latest programme here: carersuk.org/share-and-learn

“Through connecting with a positive network of support with other carers, I have gained strength in knowing that I am not alone.”



As a carer, I received no training on managing difficult emotions and coping with the ongoing pressure and responsibility of caring for loved ones.

But through connecting with a positive network of support with other carers, I have gained strength in knowing that I am not alone. ”

Carers UK Forum

To use this, you just need to sign up to become a member, which is free. See page 19 for more details.

Volunteering links

To find out more about our various volunteering opportunities, see carersuk.org/how-you-can-help/volunteer

Barbara's experience



As well as caring for her daughter, Barbara devotes her time to setting up support for other carers and volunteering. She is keen to convey how self care is paramount to help carers keep going.

“ In August 2011, our family was on a beach playing quoits and other games when my 28-year-old daughter complained of unbearable pain down one side.

That was the beginning of my caring journey, although it took two to three years to realise I was a carer.

It can be a natural instinct to become a carer for members of your family, as you are doing what anyone in your situation would do. This is how carers may not see themselves as carers. After a couple of years of being told by the surgeons that Tamsyn was ‘fine’, we knew she was far from this.

She had suffered a brain injury, following a complication with her neurosurgery that wasn't addressed at the time it was found.

Later, following several major brain operations, it became clear that my daughter and granddaughter, who was just a toddler, would need extra help. We tried agencies and au pairs, but none of this worked for us and my daughter's unique needs.

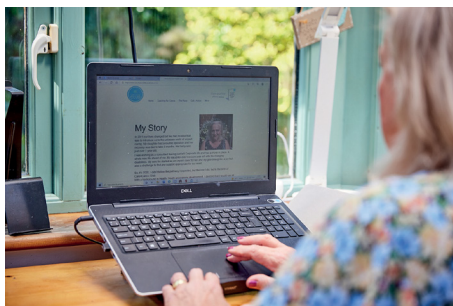
“That was the beginning of my caring journey, although it took two to three years to realise I was a carer.”

“I found Carers UK by trawling the internet and was amazing by everything on offer.”

I decided to give up my consultancy and charity work to care for them full-time. Previously I had worked in the corporate world, developing and implementing positive health programmes.

I supported both my daughter and granddaughter physically and financially full-time. My pot was empty and I called Action for Family Carers who within two days had a social worker knock on our door and things changed from that point.

I found Carers UK by trawling the internet and was amazed at everything on offer. I became a Carers UK Ambassador and had many interesting and satisfying projects to assist with.



Then 2020 arrived and didn't we know it! I again found myself doing a lot more supporting and following a conversation with my GP, I founded the Care4Carers Club in the middle of lockdown, offering online coaching and community for carers.

Over the past few months, I have become an expert in juggling, prioritising and delegating at the drop of a hat! I do find that sharing the experience and knowledge I've gained from caring and from my training background helps a lot.

Leaving paid work to care

Some helpful points to consider if leaving paid employment to care full-time:
carersuk.org/help-and-advice/work-and-career/thinking-of-leaving-work

Financial support

For guidance, see carersuk.org/help-and-advice/financial-support

“We all have unique lives and we are the only ones who can decide which path we would like to follow.”

As well as running sessions with Care4Carers Club, I was delighted to be invited to present at Share and Learn sessions with Carers UK in February 2021.

During these sessions, I spoke on devoting time to ourselves by learning and practising tips around keeping a healthy mind and body.



“I believe that during the pandemic, we unpaid carers have never been so overlooked.”

I believe that during the pandemic, we unpaid carers have never been so overlooked.

We all have unique lives and we are the only ones who can decide which path we would like to follow. As carers, we have our cared for to consider and I certainly don't have all the answers. But I do know by allocating a little time to pursue where our path is leading to, and by spending a few moments on ourselves, we might just start heading in the right direction. ”

Letting your GP know you care

See our guidance at: carersuk.org/your-gp

Michael's experience



Michael has dedicated much of his life to caring for his loved ones. He now cares for his daughter who has complex needs.

“ At first in 1999 I cared for my mum, who was in her 80s, helping my dad with the caring routine whilst I was working full-time. After my mum passed away, I started caring for my dad until 2007 when he moved into a nursing home due to his Alzheimer's. I also cared for my eldest daughter for three years as she had a mental breakdown in 2017. It was a difficult time as I was also caring for my youngest disabled daughter, Suzie.

I lost my three children for eight years following a very difficult divorce. Then in 2006, I received custody of them when they were aged 10, 11 and nearly 13. This

meant that I had to give up work to care for them, especially Suzie who was born with microcephaly.

Now 26, Suzie has very complex needs. As well as having cognitive and speech difficulties, she has other underlying conditions including cerebral palsy, epilepsy and asthma. She is also doubly incontinent and needs to use a wheelchair.

I do all the household tasks as I'm a single parent, but I also have personal care assistants who come in through an agency and look after her personal care needs. I try to entertain her and keep her occupied and safe as she has no spatial awareness.

“The best advice I can give is to ask for help, which unfortunately, as a man, wasn’t my strong point.”

All the help has come from Carers UK in terms of support that I’ve had for my morale. I’ve regularly attended the Care for a Cuppa and Share and Learn sessions online.

My daughter received a needs assessment as part of a transition plan when she left school. They allocated respite and services for her for five days per week. She’s allocated 15 hours a week, one to one. I get an extra personal care call and they come to change her. I’ve also just managed to get dual funding between continual care and the local authority (NHS continuing healthcare based on medical needs).



The best advice I can give is to ask for help which unfortunately, as a man, wasn’t my strong point, but it is now. Suzie qualifies for Personal Independence Payment. I had a professional to help me with all the paperwork with applying from my local Scope branch.

In addition, I qualify for Carer’s Allowance and it’s topped up by Income Support because I’m on the old benefits system and my daughter is on the old ESA benefit as well.

Care for a Cuppa

Hosted by Carers UK online via Zoom, this is a chance for carers to come together and share thoughts and feelings over a cuppa, see: carersuk.org/cuppa

“The second piece of advice I would give is to ask for a carer’s assessment. It’s your legal right.”

When I started caring, I had to change my whole concept and admit I needed help. Don’t be scared to ask for help because at the end of the day, they’re just people. They’re just social workers and they’re not there to make you feel wrong and belittle you. They’re there to help you. A lot of us feel like our loved ones will be taken into care or they’re going to say I can’t cope and nowadays I like to think that that concept has gone.

If you’re struggling, admit you need help. Get in touch with social services and ask for a bit of support. The second piece of advice I would give is to ask for a carer’s assessment. It’s your legal right and if it turns out that your council don’t do it, they will signpost you to one of the carers’ service organisations.



Let them do it and if it doesn’t meet your needs, seek advice from Citizens Advice or Carers UK’s Helpline. Don’t bottle things up; just ask for help.

And you can always challenge decisions you don’t think are right. There’s always someone higher up you can take it to.



Getting support

For guidance on requesting a carer’s assessment, see carersuk.org/carersassessment. For details of our Carers UK Helpline, see page 19.

How we can help

Carers UK Helpline

The Carers UK Helpline provides support and guidance on a range of caring topics. Whether you're having difficulties with understanding the benefits system or not sure where to start with accessing services, we're here to help point you in the right direction.

Email advice@carersuk.org for more detailed enquiries or call 0808 808 7777 (Monday – Friday, 9am–6pm).

Looking after someone guide

A starter's guide to caring, covering everything from wellbeing to financial benefits. This is available online and in print in five versions (England, Scotland, Wales, Northern Ireland and Welsh).

carersuk.org/looking-after-someone

Being Heard: a self-advocacy guide for carers

This guide offers valuable guidance on how to communicate effectively with professionals and assert your rights. It also offers plenty of tips on how to deal with the complex emotions that can prevent you from getting your points across or heard.

This is available online and in print in five versions (England, Scotland, Wales, Northern Ireland and Welsh).

carersuk.org/self-advocacy

Join Carers UK – for free!

As a member, we will keep you informed with helpful developments including updates on events, research and campaigns.

Other benefits include being able to connect with other carers via our forum and access to our quarterly *Caring* magazine.

Find out more: carersuk.org/join

Our website

This has an abundance of helpful information. Here are just some resources:

Carers UK Forum

An online community for Carers UK members, accessible day and night. Visit carersuk.org/forum

Carers UK local directory

Find carer support centres and services in your area: carersuk.org/localsupport

Listening Support Service

Find a supportive listening ear by signing up to calls from our trained volunteers: carersuk.org/listen

Online meetups

Meet other carers who understand in our weekly online chats at carersuk.org/cuppa, or sign up to our free activities and talks at carersuk.org/share-and-learn

Want to get involved?

If you would like to support carers by fundraising, volunteering or helping campaign for carers' rights, we would love to hear from you: carersuk.org/how-you-can-help.

We are grateful that this guide has been supported by the London Freemasons and Masonic Charitable Foundation



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We would welcome your feedback on this guide.

Please email comms@carersuk.org

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX.

Publication code: UK9052_1608 © Carers UK, September 2021.