DEMENTIA
CARERS COUNT

What if… I'm not there to care?

Sharing the experiences of dementia carers

3 in 4 dementia carers have no alternative plans in place if they aren’t there to care

Meet some of the carers behind these numbers

What if… there's an emergency?

> **I care for mom with mixed Alzheimer's and vascular dementia. Mom has no friends or family to step in. It's just me 7 days a week. I feel like I could have a heart attack with stress and anxiety.**
>
> *Lou, dementia carer*

1 in 2 dementia carers
say there is no-one else available to care

> **“I was struggling to stay conscious at this point, but had to find some care for my mum.”**
>
> *Elaine, dementia carer*

My mum, who has also always been my best friend, came to live with me in 2019, when her vascular dementia was clearly interfering with her ability to continue living safely in her own home. Despite my having to work in a very demanding job, and having no additional support, we managed.

However, in May 2021, I became very ill and was told I had to go to A & E, where I was diagnosed with septicaemia and told I would have to be admitted. After pleading with the duty doctor, I was allowed to return home to put my mum to bed and settle her and to explain to her that I would have to go to hospital for a little while.

After a scan, I was told that I had a liver abscess and kidney abscess which had caused the septicaemia and that I would have to be admitted.

I was struggling to stay conscious at this point but had to find some care for my mum.

I was told that she wouldn't be eligible for social care. All they could do would be to admit her to hospital too, so that at least she was safe.

I will always remember how awful it was to be feeling so very ill and so very, very worried about my mum.

> **“We staggered along. A disabled woman, no longer able to drive, dodgy health, caring for a husband living with advanced dementia.”**
>
> *Unity, dementia carer*

I suffered a silent heart attack and ambulance crew took me, plus my husband living with dementia, to hospital. On the way they called his next of kin son who took care of his Dad for a couple of nights. Then his daughter cared until I got home.

When time came for my heart bypass surgery I used a live-in care company, booked for two weeks to allow for overlap of staying before surgery and a few days after surgery to ease me home.

Things did not go to plan and I had a stroke coming off the bypass machine. My husband's son arranged a further two weeks care for his father.

Lurching around on a zimmer, I got home in time for Christmas, but no care for my husband.

I could not afford more than the £8,000 it had cost already.

We staggered along. A disabled woman, no longer able to drive, dodgy health, caring for a husband living with advanced dementia. We struggled until his falls required hospital attention and he died.

What if… I wasn’t so terrified of what might happen?

> **“I worry about what will happen to my wife if I become ill – there is no fallback plan.”**
>
> *Anonymous dementia carer*

1 in 3 dementia carers can see a time ahead when they will no longer be able to care

> **“After some experiences with people we know being put in unsuitable care, we are so scared of the future when we may be unable to manage.”**
>
> *Betsy, dementia carer*

Me and hubby care for my sibling with Downs Syndrome and Alzheimer’s(6 years since diagnosis). He has lived with us for 23 years and is 60 now. Everything was good at first but now, with Alzheimer’s progressing, it's getting hard.

We do have day service five days, a week 9 til 4, which is really supportive and is helpful to us. Hubby is in his mid 70s, I'm slightly younger, but it's hard.

The options for respite for young onset dementia are non-existent, as are facilities that cater for learning disability and Alzheimer’s. Staff are not trained and the only option is dementia care, where the majority of people are in their 80s. This just isn't suitable and the future scares us. After some experiences with people we know being put in unsuitable care, we are so scared of the future when we may be unable to manage.

We have put our lives on hold. We are now unable to go on holiday with my sibling due to advancing Alzheimer’s. We are exhausted and tired, but feel we have no option but to continue to care for him at home.

I don't think any of the policymakers or government understand, and are quite happy for us as unpaid carers to carry on regardless as they know we will.

> **“I worry a lot about what would happen if I become ill - in fact I lie awake for hours on many occasions because of this.”**
>
> *Angela, dementia carer*

I care for my husband who has middle stage mixed dementia and third stage bowel cancer. We live in a rural situation which I think would be described as a hamlet. We do have a few kind neighbours within walking distance but like us they are all elderly.

We no longer have a car but a neighbour can usually be found to take us for my husband’s hospital appointments and one or other of them will come and stay with him for an hour if I need to see a doctor, for example.

Luckily, up to now I am in good health as I am my husband’s sole carer. We have no family close by. Our daughter lives in South America.

I worry a lot about what would happen if I become ill - in fact I lie awake for hours on many occasions because of this.

An alternative care plan would be wonderful, the sooner the better for me.

> **“If it was me in hospital, who would look after my wife and would they look after her properly and not leave her on her own?”**
>
> *John, dementia carer*

I have recently lost my wife, she was diagnosed with mixed dementia in 2020. I was her sole 24/7 carer and have my own mobility issues.

While I was caring, I cancelled eye surgery, a colonoscopy and physiotherapy sessions, as there was no-one available to look after my wife.

In the six months before her passing, it was a huge concern of mine that:

1. My wife could be admitted to hospital, where she would be confused not having people she knew around her

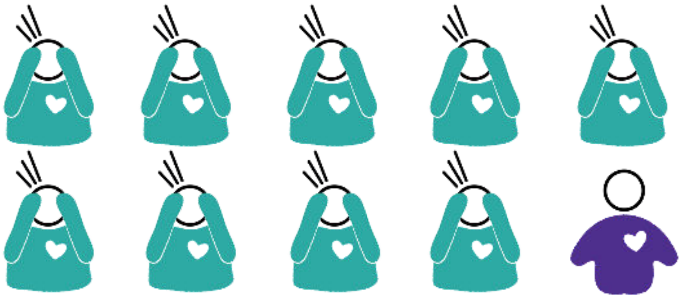
2. I might be admitted to hospital myself, leaving her at home on her own or being taken into care

3. I might die before her, leaving her on her own and having to go into care

If it was me in hospital, who would look after my wife and would they look after her properly and not leave her on her own?

What if... I can’t care?

> **“Caring has resulted in burnout. I am now on anti-depressants.”**
>
> *Anonymous dementia carer*



9 in 10 dementia carers have reached crisis point

> **“Two days after Dad's sudden death, my siblings and I were taking turns sitting with Mum in Accident and Emergency for over 28 hours, waiting for her to be put into a mental health facility. It felt like mum was being punished for having dementia.”**
>
> *Helen, dementia carer*

We'd had such little outside support, that when Dad was diagnosed with cancer, we just automatically kept muddling on.

Dad was mum's main carer, and her dementia had advanced to a stage where she couldn't safely be left alone. We'd only just started having someone to come in to give Dad a break for two hours a week.

We quickly developed a plan to support both our parents. This involved as many family members as possible at short notice covering getting Dad to his chemo sessions and looking after mum, while juggling jobs and families, with only one of us living in the area. This loose arrangement fell apart completely when Dad died suddenly a few weeks later.

Mum was placed in a residential care home, but it was arranged in a rush and the home was inappropriate for her needs. On her first night there, she became panicked and disorientated and tried to escape. They refused to continue her care and insisted she was sectioned.

Two days after Dad's sudden death, my siblings and I were taking turns sitting with Mum in Accident and Emergency for over 28 hours, waiting for her to be put into a mental health facility.

It felt like mum was being punished for having dementia.

What if... my own health didn't have to suffer?

> "I had to drop going to A&E with spinal issues because I couldn't get cover to take my mum to her appointments. This made my condition worse."
>
> *John, dementia carer*

1 in 5 dementia carers can't access the health treatments or appointments they need

> **“I’ve an auto immune condition myself and just have to get on with caring however I am feeling.”**
>
> *Debbie, dementia carer*

I’m a full time carer for my husband who has had Alzheimer’s for 6 years. He’s now at the stage where he panics if he doesn’t know where I am. He needs help with feeding, washing and toileting. He wakes up throughout the night and has to be put back to bed.

I recently had a very bad and painful case of shingles - I was receiving anti virals. We have no family other than my son who was working away. This meant there was no way I could rest.

I had to continue my caring role despite being in severe and constant pain in my back and feeling extremely ill and fatigued.

The same situation happened a year ago when I had covid. I’ve an auto immune condition myself and just have to get on with caring however I am feeling.

I also need surgery on my knee but haven’t been able to arrange a date as I won’t be able to take time out afterwards for recovery.

> **“After breast cancer treatment (goodness, and wasn’t that the mother of all challenges with him!) I’m left with fatigue, brain fog and some heart damage.”**
>
> *Lynne, dementia carer*

My husband has Alzheimer’s Disease. After 5 years he is now at his most confused, forgetful, anxious and frail. I’m with social services, who provide a once a week day centre and a couple of respite weeks for me each year.

But my health is not good. After breast cancer treatment (goodness, and wasn’t that the mother of all challenges with him!) I’m left with fatigue, brain fog and some heart damage.

If I have hospital appointments he has to come too. I have little time for self-care or for the exercise and home cooked food that’s supposed to reduce cancer recurrence.

My children help out with domestic issues some weekends, but looking after him, the house, the domestic chores and the finances is exhausting.

If I was ill, or I went into hospital, I’d have to ask them to help and then see if social services could find him a place to stay. This may not be possible and anyway would cost me. It’s very hard.

What if… you implemented a national carers’ strategy?

> **“Each nation must fully implement a carers’ strategy which outlines carers’ rights and what support they should receive.**
>
> **“This should include provision for regular, proactively offered and frequently reviewed, assessments of carers' needs and plans for contingency or alternative care.**
>
> **“All adult social care must be sustainably resourced to enable delivery of personalised support. What exists on paper must be delivered in practice. ”**
>
> *Helen Pyper, Head of Policy and Campaigns, Dementia Carers Count*

The statistics in this report are from our 2024 survey of dementia carers **What if I'm not there to care?**

About Dementia Carers Count

Dementia Carers Count is a small but mighty charity, powered and inspired by dementia carers' experiences and insights and driven by the urgent need for change. We are here to listen, to support and to help unpaid dementia carers look after themselves as well as the person they care for. We provide free, personal and confidential practical advice and emotional support. Every day our team of specialist advisors supports carers across the UK.

dementiacarers.org.uk

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