

Rebecca, former NHS Project Manager.

About my caring roles

I began caring for my husband 29 years ago, when he started losing his sight. Shortly after he was diagnosed with Parkinson's and then early-onset dementia. Around 15 years ago, he had four strokes and now suffers from diabetes, epilepsy, heart disease, liver disease, and kidney disease.

I also look after my daughter, who has been disabled since she was 17. Then I have my stepdad and my mum, who moved down in 2011, shortly after they were both diagnosed with dementia. I cared for them both until I put alternative care in place, due my husband's growing needs.

Two years ago, my sister moved from Yorkshire because she was diagnosed with terminal pancreatic cancer. The 18 months before, I was going back and forth to Yorkshire every weekend, to be with her at the hospice until we moved her down from Yorkshire to Cirencester.

What has been your experience of working and caring?

I worked as a project manager, at the NHS for 20 years, and never told my employer I was caring. I never thought about it, being the manager, I just worked in the evenings and brought my work home.

Originally, I was full-time, but gradually reduced to 20 hours as working part-time helped. I didn't tell my employer why, I just said that I wanted to cut my hours down. I wasn't aware of any support in the NHS for unpaid carers. Even now, I wouldn't know of any.

Eventually, I gave work up because it got to the stage where I realised that I was working to pay somebody to look after those I was caring for. It didn't seem logical, paying out more than I was earning. I started thinking, "Why am I paying somebody to look after them, while I'm working to pay for it?"

When did you first identify as a carer?

I knew I was a carer in a vague way, but I just got on with it. It seems a bit silly now, but I suppose I must have been a carer a good 15 years before I really thought, 'Maybe that's what I am.'

Was your employer aware of your caring role?

My employer probably was aware that I cared, because my daughter was in the hospital where I worked. But carers didn't seem to exist, as far as my work was concerned. **Even when I had appraisals, I was never asked.**

Now I'm a chair of a charity, where we do appraisals every year, asking if someone is supporting someone is always one of the first questions we ask, including our volunteers. We ask if there is anything in the workplace, we can adjust for them if they need it. From my personal experience, as the person that does the appraisals, I know how to ask those questions.

The other thing is a lot of people are afraid to tell their employer that they're a carer. If it's a child that's poorly or disabled, maybe that wouldn't be an issue. I think it's when it becomes the adult you're looking after. They put crèches into hospitals so you can leave your children there, but how many hospitals would consider putting on a daycare?

What challenges do you face as a carer?

Social needs assessments

I've struggled with the social services needs assessments. One of the things that my husband needs is another day in daycare. My carers assessment pays for him to go to daycare once a week, with Crossroads, that's all-social services will provide.

Recently, I came out from the hospital due to my own health needs and the doctor said I had to have some extra care coming in at least while I'm recovering. Yet I was told by social services that because I was home, I could look after him.

They said, 'You're home now, so you'd be able to look after your husband.' I said, 'No, the doctor said I've got to have some care. I really need some help, I'm struggling to look after my husband, and am struggling to cook, clean, etc.' She asked, 'Can you dress? Can you wash?'. I responded 'Yes'. She said, 'You can't get any help from us, because you can wash and dress'. I had just gotten out of the hospital, and I already struggle with my own health and disability.

Eventually, we got an extra hour. But that's not the point. My daughter has been waiting for two years and had four assessments to get support. Only when she put a complaint in, did the social worker come out within two days to assess her. I've never received, or been recommended for any advocacy support.

Legal paperwork

After my sister passed away, I looked for support to make arrangements to sort her estate, but nothing existed. The local carers centre supported me in respect to having someone to talk to, but there wasn't any specific support for things like probate.

For a period, I looked after my aunt with Alzheimer's who is now in a home. I'm in the process of navigating selling her home to pay for her care costs. Again, there's been no support available to help me with this.

Luckily, I suppose I'm more clued up than some people about these things. But for those who aren't as capable, I can imagine they must think 'Where do I find a solicitor? How do I do this? How do I find an estate agent?'

Social security - Universal Credit

What I had great difficulty doing, was dealing with Universal Credit. When my husband reached state retirement age, despite not being able to work for a long time, suddenly, all our money stopped. They didn't tell me until a week before, so we didn't have money for a month.

After phoning the local Carers Hub, all they could suggest was to go to the CAB to see what I personally was entitled to in my own right. I'm sorry to say, but CAB weren't that useful. They told me to make an appointment at the Job Centre, and you've got to do everything online. That's okay, but I don't do things online.

Eventually, after an hour and a half on the phone trying to sort it out, a follow-up appointment was made to go to the Job Centre with my ID. But because I did it over the telephone, they don't open a folder online. Which meant any forms/letters from the Universal Credit, I don't receive. DWP said they couldn't do anything about it, but eventually, I'll get a letter to say, 'Why haven't you filled this form out?'

We were a month without any pension, or any other money coming in. When I said, 'I need some money to keep us going,' they said, 'You can apply for it, but having just started the application you can't get any money in advance.'

This is the sort of thing that carers need, there's not that much information about what benefits you could be entitled to. The carers centre said to phone CAB, and CAB said until I got Universal Credit, they couldn't help. After I received Universal Credit, I was told I can't get any other support.

Bereavement is the same. I spoke with another carer, whose father sadly passed away. She didn't know anything about claiming funeral expenses. I think carers, should be more supported.

If you're a working carer who recognises some of the experiences in the story above then contact us today!

Crossroads Care Gloucestershire can support you with adult respite and information about your rights and those you look after.



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For more information or for an informal chat call Jessica on: 01452 933503 or email: workingcarers@crossroadscareglos.org.uk

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