

Sophie works at a local school as a teaching assistant.

About my caring roles

Back in October 2020, my mother-in-law moved in with us. She has advanced Parkinson's and couldn't stay at home any longer. A year ago, she had a series of three bad falls and ended up with a subdural hematoma, which means that combined with her Parkinson's her mobility is now very limited. She has to be held and transferred to go to the toilet, so needs increasing levels of care. If I'm not here, then someone else always needs to be.

This is just one of my caring duties. My son has been diagnosed, with autism, ADHD, and a number of sensory issues which means that he needs additional support and care. He's now got an EHCP and attends a specialist school. Only last week, we had a few wobbles with him not being able to attend school. If I'm not at home, there needs to be someone in the house, in case he can't go to school.

When my son started school, I worked as a self-employed childminder part-time sometimes working full-time hours but over condensed days. Then I started work at a school, keeping part-time hours because that's what they offered and full-time I knew was just too much.

When my son went to senior school it started getting harder and harder. I was trying to take him to school, he wasn't able to get on the bus. Last year, there was an opportunity to take on a maternity cover position for my boss. At almost full-time hours, I knew I couldn't even contemplate it due to my caring role. Currently, it costs us more as a family unit for me to work.

When did you first identify as a carer?

It was during the COVID vaccines rollout when carers were allowed to have them first. I thought hang on, we're carers. Because we had my mother-in-law living with us, it was quite important, I quickly got vaccinated to protect her. We then found out how to register at the local carers centre and the doctors.

I had never considered myself as a carer with my son, I'd just seen myself as a mum. It's really hard as a parent to identify yourself as a carer because your role as a parent is in a caring role. It is tricky to acknowledge that you are in a parent carer role and that your child has considerable additional needs.

What challenges do you face as a parent carer?

Where to go for help

I knew my son was struggling and having real problems at school and that there was something that needed a bit of extra help, but others weren't seeing that. Being told nothing was wrong, I think played into not seeing myself as a carer. In the end, we had to go private to get the necessary assessments.

I was so concerned, that years before he started at secondary school, I was talking to the SENCO.

We got an educational psychologist to assess my son in primary school but realized afterward that it wasn't an educational psychologist that was needed. **This is the thing; you don't necessarily know the route to go down.** I asked the health service for help and was told to go via education. I asked education for help and they said we have to go to the health service. At which point I realised, there wasn't any help.

Unless I'd had a friend who has a law degree, who understood and had already done EHCP, then I wouldn't have had a clue about navigating special needs education and the health system and I've done SENCO training. I needed to make sure that there was a report or an OT report, or a speech and language report, all sorts of things. And it's just very hard to do.

Universal Credit form

Then there's filling out the DLA form, there is no support for that, and it is a soul-destroying form. A friend told me, that after she'd filled in that form on behalf of her child who's got Down syndrome that she felt incredibly down.

Help with form filling, that's especially important for people. I'm fortunate, I've got people that have helped me hugely through this. But there are lots of people that don't. And those children whose parents don't understand the system, they're just going to lose out. Those who can't afford private reports, we've gone to the wider family for help.

I've got lots of friends who should really be claiming it, but aren't. One friend is a single mum with two children, who have severe SEN needs, one of them stayed in a room for four weeks. But to actually get to the point where you feel you can fill in the DLA form is a different thing, there needs to be an acknowledgment that it is hard. If you're at the bottom of a black hole, you're not going to be able to access the support you need.

Carers rights

I have no idea what my rights are. I had a carers assessment; they kindly gave me 3 hours a week for my mother-in-law. Someone will sit with her, which is brilliant, but they won't look after my son. I receive no support for my parent's carer, part of my role.

Challenges at work

Acknowledgment of care roles

I never said I am a carer to my employer, but they know that I have my mother-in-law living with me and they know my son has additional needs. The receptionist at my workplace is one of my friends. Unfortunately, quite often my son will ring into the school, and although it's not in her role, she's willing to come and find me and relay messages.

My employer hasn't mentioned a carers policy, or carers leave, nor have I sat down with the manager and asked how they can support me.

Fears over job security

Last week, we had a little wobble with my son, struggling to get into school. His support worker was supposed to pick him up from a house, and he refused. I was lucky enough, I said to my manager "I need to leave and get him into the car". My manager let me go.

After I said, I might need that to happen twice a week for the next couple of weeks. First off, it seemed like that might be a possibility, but they've come back and said that I would have to put a formal request in.

I'm on a permanent contract for some of my hours, whereas I am on a fixed-term contract on my two long days. Those are the days I would potentially have to ask to go in at quarter past nine. **I worry that if I ask for that time, it will affect my employers willingness to renew that contract next year.**

Barriers in career development

Although I'm employed from 8.30, it would be handy if I were there earlier to help set up everything, but I can't do that. We get the paid carer in from 8 am and there's always a bit of me needing to settle someone in or hand over.

There was a maternity cover job opportunity, which effectively would have been a promotion that I could have applied for. But I couldn't even contemplate applying for it, because I can't give enough to the role.

It might have been nice to do it full time, but I know I can't at the moment, because there's just too much needed of me at home. **There is only so much energy to go around everything. Effectively, caring has meant that I don't really have a career.**

Is there anything your employer could do differently?

The difficulty with it being a school, is that there isn't that flexibility to work from home occasionally. At the same time, I need the school time working hours because of the care responsibilities, you're then tied into needing to be on-site and that can be quite tricky.

My employer hasn't mentioned a carers policy, or asked how they can support me. Yet we've got policies for almost everything else.

My original role was covering my boss on the two days that she didn't work. When my boss went back on maternity leave, my employer said they felt they had to offer five days for a replacement because they didn't think that they would get somebody for three days. Effectively I then had to go into less senior position, because I couldn't stay as a supervisor, effectively taking a pay cut.

If my employer had offered a job share that would have made a difference. Initially I was sort of job sharing already, as I was looking after the day-to-day on the days when my boss wasn't there. On those days, if anything went wrong the responsibility sat with me.

What support would be beneficial in your local area?

A guide on how to fill in the forms, and what you're entitled to. The support that's out there, is only going to work if you're feeling able to access it, or know where it is.

My support was very much from people I knew. My friend helped me do my DLA, so it wasn't as dreadful for me. You know, just having someone sitting there going - 'don't forget you've told me about this and you've told me about this. You need to put this down'.

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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