



Ceinwen Giles

Director, Shine Cancer Support

Trustee, The Point of Care Foundation

What is your role at work?

At the moment I've got quite a few roles. I am a founding Director at Shine Cancer Support, a charity that supports adults in their 20s, 30s and 40s who have experienced cancer. I also do freelance work on patient involvement. And I'm a Trustee of the Point of Care Foundation. Read the full profile.

How did you get into this type of work?

It's not something I planned! I worked for about 13 years in international development and worked all over the world, from Vietnam to Sierra Leone. In 2010 I was diagnosed with an advanced form of blood cancer and spent six months in the hospital receiving high dose chemotherapy. I'd just had a premature baby. So, having never spent any time in the hospital at all, I suddenly was dealing with all kinds of doctors, from paediatricians to haematologists. While I was recovering, I felt like there was scope to contribute to change in the health service, given what I'd seen and experienced first-hand. I began volunteering as a patient representative but I found a lot of the work really dispiriting. I didn't think that the way patients were worked with was very creative or very meaningful. From my previous work I'd learned a lot about community development and began to think about how we could apply principles of community development to healthcare in the UK. And that's how I got here!

What's your favourite part of the job?

I love working on patient involvement when you can see it's made a difference – when both the patients and people working in the healthcare system develop new solutions to old problems because they've been able to work together in new ways. I also love my work with Shine. When people tell us that we've changed their lives and made them less lonely, it makes everything worthwhile.

What's the most challenging part of your role?

I find some attitudes towards patient involvement frustrating. In some cases, people don't understand what it means. But in a lot of cases, because it means sharing power with the people who use health services, it makes people uncomfortable. I get that – but it can be frustrating when you hear excuses about why it's too difficult and you know that there has to be a way around it.

Tell us why you think patient experience matters

At the most basic level, being a patient can be terrifying and I think we have an obligation to treat people with respect and to help them feel safe. But I also believe there are clear links between patient experience and patient outcomes; if you have a better patient experience, you can have a better overall outcome. As a patient, you're certainly more likely to listen to someone who is giving you advice if you've had a good experience of being treated by them.

What is your greatest achievement in your role?

I'm not sure I've got there yet! But I'm very proud of the way that The Point of Care Foundation has grown over the last few years and its commitment to opening up new conversations, and new ways of working with both healthcare practitioners and patients.

If you could be anything else, what would it be?

Probably some combination of an adventurer and a trapeze artist. But I've got pretty poor upper body strength so the trapeze artist part is unlikely to be realised anytime soon.