



Rheumatoid arthritis - a long term condition

Adapting to life with rheumatoid arthritis

After diagnosis there was the whole living with rheumatoid arthritis and knowing it wasn't curable, that was quite a big thing, and doing the day to day coping with it and finding out what that actually meant. I was introduced at the hospital early on to Arthritis Care, they help you with self management, it's very much run by people with various forms of arthritis, I went on the course, the Challenging Arthritis course. That was so helpful, I can't tell you, and I became a trainer on the Expert Patients course later, which is modelled on the same basic framework, so I learnt a lot of self management stuff. And that was a nice thing, that was something I could positively do, rather than avoiding things, that was something positive. But that was necessary because it wasn't straightforward. I mean okay, I wasn't you know waking up really stiff and barely able to move, and in lots and lots of pain and that real ill, ill, chronic illness scenario to the same extent but there was plenty of that still going on, I was getting really tired, which was, which was the worst thing, I think, and has remained the worst thing. I mean it's called fatigue and to me that doesn't begin to cover it.

I would have to say no to things that I would have liked to have done, or I would do them and, and be shattered, I would have to sleep loads the day before, I wouldn't be able to do anything else, and then I would be exhausted afterwards, I remember there was a group doing singing in West Oxford, so not immediately locally, during the school day there were groups of people with learning difficulties, which was a bit of a departure for me and, and I was thinking oh, this is too many things, I'm trying to do too many different things, I can't do it, I had to rush back to collect my son from school, it wasn't going to work. So after about three goes I pulled out and in pulling out I found out that people had been really enjoying it and when they went back to their day centre they were singing songs and I thought oh God, maybe I'm even good at this and I'll never find, I don't know, no I can't do it and I went, so my lack of confidence was exacerbated by the fact that I would be in pain, that I would be tired, that I was struggling to find a way of earning a living and being a mother, and being ill. So it's like having arthritis was like having another part time job on top of the various work that I was trying to do. The more I tried to build it up, the riskier it felt.

There is of course economics aspect to all of this which is that my partner became the breadwinner, I was working a bit here and there, but nothing very lucrative, nothing continuous, I like to think that I had a significant earning capacity that, you know, I only hadn't manifested because of arthritis, though I don't know that that's even true, but my whole working life was, was shot to pieces by having the disease.