



Rheumatoid arthritis - a long term condition

Early stages

I did have the symptoms briefly in 1994 because I'd had some septicaemia around my son's birth in '93, and there was some liver damage and various sort of knock-on medical problems, so I was having joint pains but they all went and I thought no more about it, then they came back in the summer of '96.

Because I'd had this brief incidence of joint pains before I thought oh that's funny, that's how it was before, oh-er, I don't know why that should be happening and then, and, and because it wasn't debilitating or disabling at that point I was just sort of very, and it just came on very gradually and it was just coming and going and there was no way you could have a label, no way there was anything clear to be done 'cos it wasn't acute enough really.

I mean I didn't go and see a doctor until October '96 when it had been happening on and off since the summer. And then unfortunately the GP was a bit dismissive and saying oh well, just have hot baths and take Nurofen and, and really didn't seem to acknowledge what could be going on, and didn't seem to think it needed exploring and that made me quite cross 'cos obviously you get more and more crabby, yes, I think it's a symptom really, in a way, that sense of just feeling everything's not right, and so I didn't go near a doctor for a long time until the, oh the following autumn, I think, which probably didn't help.

I didn't have much of a social life because I was too exhausted and it was, it was really unsatisfying knowing there was something wrong and that no-one was witnessing it. And the job that I had in a hospital, weirdly, was a very isolated job, I was just managing the volunteers, so I wasn't involved with the day to day, it was just a few hours a week, and it was off in one of the little towns outside of Oxford where I didn't know anybody, so I was really on my own quite a lot of the time or else, you know, trying to be with my son, and trying to sleep. I was so exhausted by that time, by that point; by the summer of '97 I was getting him extra nursery places whenever I could, just so that I could do nothing and that's now how you see people, that's not how you connect a network, and get known and seen by people. So there was a huge psychological problem around that, that I felt very lonely. The nature of the condition is that it's invisible. Wasn't going to carry a stick because that would hurt too much, 'cos my hands were so affected, so that just carried on.

There was no-one around who'd said, what's happened, why are you limping, for instance, which was a very visible change. But of course once you've got that condition, and you're feeling really dreadful and you're not doing very much, and you're resting a lot, you don't see people anyway. So those two factors in a way made the whole thing very private, which wasn't good.