



Rheumatoid arthritis - a long term condition

Liz's story

Liz

My name's Liz Hodgson and I have rheumatoid arthritis. I've had it since at least the summer of 1996, possibly longer, it's hard to tell. There wasn't a day when it started exactly, it was a sort of process that gradually became more normal. I thought oh actually my knees are a bit bad today, oh not, they're not so bad today, oh my wrists are hurting or my knuckles seem a bit hot. It was very gradual and it kept shifting, so it wasn't like I had a sore knee that got worse, like osteoarthritis would be. It's not like that.

And I remember how I felt, sitting there, a sort of stuck feeling. I suppose part of the problem is that I wasn't going out more than I absolutely had to because it hurt, and I was thinking that woman, she must think I'm horrible 'cos I'm yelling at my son to stop him running ahead of me, and I'm limping along and looking like death warmed up, and clearly quite irritable. This isn't really how I am but I couldn't stop and say actually I'm quite a nice person and I don't normally limp.

We went up to the Nuffield and went to the outpatients and saw a rheumatologist who looked at the colour of my knuckles and said well, you know, this is inflammatory arthritis, there's no question, 'cos my knuckles were a rather weird-looking bruised, purply, reddy-purple colour, and they were hot to the touch. It was getting on for a couple of months after I was diagnosed that I was prescribed Sulfasalazine, and then that did kick in and make a real difference, so I could function and do things, but it didn't completely suppress the disease and you can get these fluctuations where the disease will flare up, and that's referred to as a flare. My left ankle in particular got very, very bad, and that has been sort of pretty well permanently damaged though, you know, I cope pretty well, and that is a vulnerable point.

When I used to take my son to nursery school, so he would be four, and we'd get to the crossing and press the button, I couldn't wait for the green man so we had to start the minute the traffic had stopped, and I wouldn't have finished crossing the road by the time the lights changed. So they would hoot at me because it wasn't obvious why I wasn't crossing the road, 'cos I didn't have a stick, and I didn't have a stick because it would hurt to hold anything that I didn't have to hold, and I couldn't possibly put my weight on my hands 'cos they were so painful. So that was a horrible thing that used to really wind me up and make me feel even worse in a very public way about what was going on.

There was the whole living with rheumatoid arthritis, knowing it wasn't curable, that was quite a big thing, and I would get really tired which was the worst thing, I think, and has remained the worst thing. I mean it's called fatigue but to me that doesn't begin to cover it. This wave of exhaustion that would visibly come over me sometimes, and people wouldn't see me when I was like that. And I remember one occasion when all the school parents, and there was a fireworks party at somebody's house, and this was going on into the evening and I was completely shattered, and normally people wouldn't see me when I was like that. I remember sitting on a sofa sort of away from the fireworks, just waiting for people to start to leave and just kind of oh knocked out, and one of the fathers turned around and saw it, said Liz, what's the matter? I said well I'm often like this, you just don't normally see me. 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, and the more I tried to build it up, the riskier it felt.

Jonathan, Liz's partner

Sometimes it felt like walking on eggshells a bit and just, you know, try and keep going and at the same time our son was quite young and at that sort of age where he was out and about,

needing to do things, and I think it sort of derailed something that we'd hoped to have which, you know, was a fairly balanced equal relationship.

Liz

'Cos I mean you did everything round the house and of course, in a way, it can be, you can exploit that and someone as kind and driven as you can be really exploited, and I know I did that some of the time and that's not healthy.

Jonathan

I very much felt it was down to me and I was sort of coming home after working, and having a strong cup of tea, carrying on cooking...

Liz

Oh and washing, yes.

Jonathan

All that sort of thing, it was quite driven, it was quite driven, and I think some of that stayed with me. I think I haven't, even though now Liz is a lot better, I think there's, I still have that instinct to do stuff. Well, I think that's one of the things I found a bit hard was the sort of parenting aspect of it, and I think on the one hand feeling I needed to make up for what Liz couldn't do, so I think I sort of tried to put extra in, but also when, you know when there was, when Toby was upset or Liz was upset with Toby, sort of not wanting to be on either side, or wanting to be on both sides.

Liz

There was this huge build up of frustration that I had and in the end I did have a very public outburst one time which was just terrifying really, I really frightened myself, but that did lead me into some years of therapy which actually was a good idea. And I'm not saying that that's helped me go into remission exactly but it's taken a lot of the heat, a lot of the anger out of life for me really, and I didn't know for a long time that if you had exhaustion one of the things you should do is exercise 'cos that does seem a bit counter-intuitive. Once the drugs kicked in and I got that I could do things again I remember the feeling the first time I swam here and it was like I could be powerful again and that was just worth it just for that. I can get out of breath, I can push myself without damaging my joints, and I don't know of other ways of doing that, that is quite a problem. I can't go running really and, you know, but swimming is brilliant. So I've got more confidence in my body which I felt up to then had really betrayed me. It was just, you know, not something I liked living in, but that was a really, really good feeling.

When I was on the Challenging Arthritis course you had to do a little action plan every week. I will do something really manageable, you know three days a week, and one of the things I did was I will walk to the allotment and back, and pull up a weed while I'm there. So that was part of, you know, advancing the exercise. Do you remember that day when I ran downstairs and you said I thought I'd never that sound again?

Jonathan

Yes, yes.

Liz

That was an amazing moment. That must have been, I don't know, '98, '99, some sort of time like that 'cos I was, you know I was getting used to being able to move around, and I'd been to the gym a bit or whatever, you know, things had got better and you suddenly heard that sound. That was amazing, wasn't it?

Jonathan

Yes, yes.

Liz

I loved that. So now a lot of people I know have no idea that I have this disease, and so I can choose how much I say, and I don't actually need to tell people now, most of the time. I did used to tell people when they said what do you do? And I would find myself saying oh well,

you see I have, I have this disease, I have rheumatoid arthritis, it means that I can't work full time, and then they would start to make suggestions and recommendations, and I've been through that process of understanding that people do that because they can't bear chronic conditions. It's horrible, they don't want someone to be permanently ill. You want them to get better, and you want to help, and so it's out of courtesy as much as anything else. People say oh, have you tried aloe vera? Or have you, oh of course well you don't eat cheese, do you, or you don't eat tomatoes, do you, or apparently there's this wonderful osteopath in London or all these things that people say out of the best will in the world, and it's so horrible because either you say no, or you say that's a lovely idea, I'll look into that, or they give you leaflets for some product completely untested, un-researched, whatever, and there's part of you that wants it to be true, there's part of you that wants to come off all these drugs and do this thing, whatever it is, but probably, generally costs loads of money and has no real testing or real science behind it.

And there was a very sweet acupuncturist I went to for quite a while and I don't think it made any difference at all, and he was all for, you know, the Chinese don't eat salads, they don't eat anything raw, and I probably shouldn't eat bananas, and this and that and the other, and there was a point when I just thought oh this is, well I like bananas and I'm going to eat salad, and to hell with it. I want to find the things that are good for me, so with diet I would go on the positive rather than trying to cut things out all the time. Cutting things out is awkward, I'd rather eat cake with my friends, you know, than worry about how much wheat I should have. I'm not saying that what I have done is why I'm in remission. I'm not recommending anything particularly, I just know that there've been ways of dealing with it that have worked for me.

It's been quite interesting to reflect on that and get the perspective of how bad things were. I don't mean necessarily just between us, where they were difficult and fraught, I would say, and because, very much because of the impact that the disease had on us, and because that impact has receded, you know, we can emerge, and all that positive psychology stuff as well, that's come in there and been a lovely element in our lives, and when the drugs kicked in I had that sense of the person I really could be, had a chance again, whereas before I felt that however clever and talented, whatever I was, and all the things I knew and all the things I could do, it wasn't going to happen.