



## **Rheumatoid arthritis - a long term condition**

### *Diagnosis*

Well despite my earlier experiences of things being a bit just dismissed, I did start going back to the GP erm in the summer of '97. There were locums, it was holidays, I thought oh let's see someone who I haven't seen before and let's get a new angle on this, I don't know if that was a good idea or not, but that's what I did and so I was having blood tests, I think I even had x-rays at one point of my hands, and nothing came up, and because I knew nothing about rheumatoid arthritis that's the other thing that didn't help. And I'd started reading a bit by then and going oh symmetrical, oh fluctuating between the joints, that's funny, that sounds like me and yet because I don't have rheumatoid factor, I'm one of about 10% or so who don't show it on the blood test, so every time they did a blood test it came out that I didn't have rheumatoid arthritis, and I'd got to the point where I was thinking well what, what have I got then? And there was a point when one of the GP's said he could refer me according to my subjective symptoms, I think that's the term, but at that point I discovered this very good osteopath and now I laugh, but back then it felt to me that that sort of thing could be the solution, and so I said oh no, let's just see how I do.

So that would be, I don't know, about the October I think, and then I was getting so run down, my feet were swelling up, there was one pair of shoes I could still wear, which is a very normal symptom again of rheumatoid arthritis, but I didn't know that, so by the December we were in such a state as a family, it was having such an impact on everything, that my partner came with me to yet another GP to ask to do something, and we didn't actually know what that would mean, but what that meant was to be referred to the rheumatology department up at the Nuffield orthopaedic centre. I was feeling pretty bad, I was not happy the whole time by this point, and in huge amounts of pain, and also very ill and getting infections and sinusitis and really, really rundown, and so I just let myself cry very easily and, and thought well that might help, and the fact that he came with me, and was pretty forceful about it, uncharacteristically, I got a referral to the Nuffield which was for, you know, I don't know a couple of months ahead, during which time I deteriorated further and further and further, of course, because it was galloping by then.

We went up to the Nuffield, I had to be driven close to the entrance 'cos I found it so difficult to, to walk any distance, 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 rather weird, bruised-looking, purpley, reddy-purple colour, and they were hot to the touch. He was, you know, shocked it had taken so long, saying well you know we can sort this out, it never has to be this bad, you know we can do something about this, which was the first I'd heard. So that was good to know but of course it was all drug-related and up until that point I had been totally wholemeal, East Oxford, vegetarian, alternative, healthy diet, the works and I wouldn't take an aspirin, you know I was that kind of a person, so this was a bit of a shift for me, I was pretty desperate.

I do think now that if I'd been diagnosed right at the outset I would have refused the drugs because I hadn't been through this process of finding out how bad it could get so I wasn't exactly rejecting the drugs, I was just nonplussed that that was, that was the solution, I hadn't known that until that point.

They suggested that that I go in 'cos then they could, you know, sort everything out but, given our lack of childcare and my son, there was no way, you know my partner was off to London several days a week, we had no-one around to do childcare, we couldn't do it, so, so we said no to that and it's possible that that is why I got a letter a couple of days later saying I would have an appointment in six weeks' time to discuss my disease and my drug regime.

Well given how irritable and negative I was, I got so furious, and I was two guns blazing for the next six weeks, I was so angry at feeling kind of known and not known, and neglected really, didn't think of going to the GP and saying give me something in the meantime, didn't know how to deal with that other than going on an exclusion diet, without any supervision, and because I didn't eat fish I didn't eat any protein for a week which now I realise was a mad thing to do, to see if the symptoms went if you cut out everything and lived on courgettes and sweet potatoes, and whatever it was. Well they didn't go and I was in such a weak state by the end of that, and I just started eating pretty well normally again and reckoned, possibly rightly but, you know, it's not triggered by certain foods.

So that was in the February and various family members came to see us and were really worried, my mum couldn't get the hang of it 'cos it wasn't obvious really what was happening and she was really trying to encourage me to take the drugs and I was going well I would but they haven't offered me any, 'cos by that time I was getting so desperate. My left ankle in particular got very, very bad and that has been sort of pretty well permanently damaged by the whole process as far as I can judge it though, you know, I cope pretty well, that is a, a vulnerable point.

So beginning of March went back to the hospital with my partner and we went back to where we were and realised we should have been in a different part of the hospital, and I remember that being an issue – could I actually manage to walk from the outpatients department over to the specialist nurse's office?

I went in to see this woman, all totally miserable and in a terrible state, and she was great. And she just talked me through it and, and somehow I felt heard, I felt seen, I felt understood, and then she said oh well you go away and think about it, you know about taking the drugs, I said no, give me something now, give me something now, I was that desperate.