



Rheumatoid arthritis - a long term condition

Treatment

The first thing they offered was a steroid injection, so I had to go to the GP's, I left my soon at a little friend's birthday party and limped over to the GP's and they hadn't got the right drug, so I had to go to the pharmacist to fetch it and come back again, which was outrageous really. It was a mad, mad saga, and he injected this into me, said well it might make you put on weight but that looks like a good thing really because I was very underweight, I was really stick thin by then, and nothing happened so I went back to them or to somebody saying you know I can't even remember the whole thing now, but I went, I said 'give me more steroids' and they wouldn't, which was fair enough. So they started me on Sulfasalazine. At that point they started me on one or maybe two, it was a gradual dose of Sulfasalazine and of course that wasn't going to kick in for a while, if it did. Now it did kick in but in the meantime I was still in exactly the same state I'd been in before, so one day, I don't know exactly when, I went to the original GP and I remember whipping you know this one shoe that I could get my feet into, whipping off my shoe and my sock and saying look, I have a small child, I can't function. I shoved my foot in his face pretty much, poor man, and so he gave me what turned out to be a magic pill, which was Indomethacin, it's a vicious anti-inflammatory. So I took two that night, woke up in the morning, not stiff, not in pain. I couldn't believe it, so I took two at lunchtime and two in the evening, and I coincidentally went to somebody's leaving do that night and there was a photo of us all sitting round the table and me kind of with this strange expression 'cos I, and that is the first day that I hadn't been in pain for about a year, and it was wonderful.

So I carried on taking six Indomethacin a day and then I thought ooh, well I can cut back a bit now and see what happens, so I cut back and cut back and nothing happened because by then, this was some weeks later, the Sulphasalazine had kicked in.

The Sulfasalazine wasn't controlling it completely so every time I went back to the hospital which was, you know, every few months initially, they would try and put me on to Methotrexate and Methotrexate, they had to tell me, was a cancer drug but it wouldn't make your hair fall out and there was all this stuff about it back then, and I was very resistant because I was basically functioning and I could see, you know, that my knuckles were swollen, they were red, they were hot, I would get really exhausted, I'd have to cancel things, say no to things I might have said yes to, and that was normal for me. I was managing to move, I wasn't limping, I wasn't in lots and lots of pain, I wasn't stiff like I had been and so I didn't want to pursue it really, I had stopped being desperate, but somehow they did manage to convince me.

I did go on Methotrexate eventually and then they gradually persuaded me to up the dose to the point that by 2008 I was on was it 17.5g a week. I take seven little yellow pills on a Tuesday evening, and I haven't had a flare for a long time, I'd say maybe five years, which is fantastic, and of course I hadn't realised that for a while. But 2008 was a significant year in the family. There were lots of problems with my mum having to go into hospital, having to go into care, a lot of family tensions, I'd got neuralgia, I was run down, I was very stressed, but I did not get an arthritis flare. So at that point I, I reckoned things were pretty stable, and so I didn't have Indomethacin any more, I don't need to do anything like that, and the Methotrexate seems to be controlling it.

So a few months ago when I went for my annual appointment with a nurse, 'cos that's the sort of status I have now, she did a few calculations and said I am in drug-controlled remission, which is a rather nice label to have and I'm very happy with that.

So now I'm gradually tailing off the Sulfasalazine, have been doing that very slowly. I've been very grown up about it, I could possibly stop taking it today and nothing would happen, but I'm you know doing it progressively, a few months at a time, reducing it, so I'm taking less pills

every day, which I love, and then the Methotrexate has been at that dose that it's been at since about 2007 and that seems to be doing the job.