



Speaking from Experience Arthritis in Childhood

Transcript for chapter 1 of 9: When it all started

Robert, 18 years, has Polyarticular Arthritis: I first noticed that I had a limp in my leg and I thought it must be a sports injury or something like that. But after a few weeks it was only getting worse and it really got me worried. Being young I tried to hide it from my parents and friends, but my parents soon picked up on it and took me to the doctors, which really scared me. That's when it all started.

Sharryn has a son, 12 years, with arthritis: I really sort of watched Craig and he was limping and I said let me look at your knees. They were obviously swollen and I sort of felt guilty and thought why didn't I notice this before?

Conrad and Doune have a daughter, 7 years, with arthritis: Once we got to the orthopaedic surgeon he re x-rayed her, took one look at the x-rays and said "You're in the wrong department. You need to go and see a rheumatologist." It had been going on for probably three or four months before we got a diagnosis.

Peter and Toni have a daughter, 14 years, with arthritis: She went into hospital and went on a drip for two weeks. In that time that doctors hadn't told us what the problem was, so we really didn't know what to expect. It wasn't until the end of that twelve weeks that they sent us on to a rheumatologist and he told us that he suspected it was arthritis.

Michelle and David have a daughter, 5 years, with arthritis: It was blood tests and other tests to sort of see. And then it was still really active, so from there he said that we can't do anymore, we'll head to the children's hospital. And that's where we got the official diagnosis.

Jennifer, 19 years, has Fibromyalgia (FMS): Fibromyalgia, which is what I have, is a problem with the pain system. It doesn't mean there's actually anything wrong with you, which is good in some cases, because it's not degenerative. But it's bad in other ways, because it's hard to diagnose. They have to rule everything else out, so that they know that the pain system is sending out false signals I suppose.

Peter and Toni: The diagnosis was a bit of shock and it was something that we thought would go away. We didn't realise that it was a chronic illness that was going to be with us for a long time. We didn't really comprehend what the future was.

Sharryn: I just thought, "But he's just a little boy, he's my boy. He can't have something wrong with him that is chronic. And how can he have arthritis when he's just a kid?"

Conrad and Doune: Looking back, I don't think we had any idea what it meant, what the implications were. Obviously the biggest thing for me was the sense that it wasn't just a temporary condition anymore, that it wasn't something that she was just going to get over.

Jennifer: Naming it is a bigger step than I thought at the time. I think the biggest thing that it helped me to do was that it gave me some control back, because I felt that my body was doing all these things and I just could not control what I was feeling.

Peter and Toni: My own experience with arthritis is that it's what older people get, and how crippling that can be for older people. So it had me quite terrified.

Conrad and Doune: Not knowing about that sort of stuff is pretty unsettling.

Peter and Toni: Your whole focus is on making that child well and so we did that rather than looking for information. We just honed in on Melanie and tried to make her feel safe and comfortable. It wasn't until later on that we thought, well hang on, this is here to stay and we really need to look for more information.

Michelle and David: That's just where you get a thirst for knowledge. You really want to read everything you can and talk to people. That was one thing that we'd said - you need to talk to people, and then you think, "It's not so bad." People who have been there, it's really important.

Conrad and Doune: They wanted to put Claire straight onto the medication and we just felt that it was all happening too fast. We really wanted to get another opinion - not necessarily to get confirmation about her condition, we understood that - but just as to which way to proceed with medication.

Peter and Toni: I knew that it was not curable to any extent. I knew it affected her life from that moment on. I knew it wasn't going to go away easily.

Michelle and David: Your first response is "Are we going to have a daughter who is crippled and in a wheelchair? Just how far will it go?" So there's a fair bit of fear involved in the deformities she's going to get.

Peter and Toni: You look through your family relatives, etc. looking for signs of arthritis. You're looking for a link; you're looking for a reason. Because from our understanding there isn't really a link from juvenile chronic arthritis and the adult arthritis. We were searching for this link that wasn't there. So you do look for reasons.

Conrad and Doune: We've got a video of her when she was about eleven or twelve months and she was at a children's birthday party. About a year after she had been diagnosed, we were sitting down watching it, just to have a look at the video when they were little. Claire's sitting there, and we can see her left ankle's all swollen up. And you're thinking, "Has it really started that early?" We never noticed it because at eleven months, they're just starting to walk and you don't look for a really perfect way of walking. And we just never noticed the swelling so there was a bit of guilt associated with that - that it took us six months even to notice what was going on.

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