

Speaking from Experience Arthritis in Childhood

Transcript for chapter 3 of 9: Finding the balance

Jennifer (19yrs, has fibromyalgia (FMS)): Finding the balance is the biggest issue, with regards to treatment. A balance of exercise and relaxation, having fun and medication.

Michelle and David have a daughter, 5yrs, with arthritis: It's hard to know whether we've done the right thing or not. But we've always been pretty firm in, this is what you need to do, and I think then it becomes more like a daily routine, rather than a drama.

Conrad and Doune have a daughter, 7yrs, with arthritis: The Physiotherapist, for example, was very happy to come to the crèche and talk to the staff, really help to work out ways to do exercise. You're talking about an 18 month old child, you know, you're not going to sit down an 18 month old and say, this is what you need to do. You've actually got to work out how you're going to get the ankle to move around a little bit. So, just working out the best way of doing that.

Michelle and David: Actually to do physio without them knowing that they're actually doing it. The other night we sat on the floor and did all the stretching exercises, but you get them out riding their bike and lift their seat up so that they've got to stretch their legs to get to the pedal. They can ride all day and they don't realise that they're actually doing all the exercises they're supposed to. They're stretching their legs and they're working their legs. It's not pounding on their knee. Take them off to the pool and let them run around and jump in the pool. They can jump as much as they like, because the water is taking the weight of their body and they're not jarring up their joints and they can swim and do whatever they like.

Conrad and Doune: We've developed a really good relationship with our daughter's rheumatologist. There's no problem now, if we need to contact her on the weekend or, and she's very happy to be paged and she rings us at home.

Michelle and David: It is very important that you give the doctors a bit of credit and give the medication a fairly good go. It's no good – especially if they're not getting any reaction to it – if they tell you it takes a month to get through their system, you've got to try to give it a month. On the other hand, if it's making your child sick, or they're getting some reaction, speak to your doctor and say, "well, it's not agreeing with her, is there anything else we can try?"

Conrad and Doune: Last year was the hardest year, in terms of her arthritis. It's been the worst it's ever been. Also, the amount of treatment and side-effects of the treatment has really made it a very demanding year for us.

Robert 18 yrs – has Polyarticular Arthritis: I'm prepared to try anything. I really want to deal with this the best way I can.

Conrad and Doune: Probably over the past two years she has been really unwell, not just from the pain of the arthritis, but from the side-effects of the medication. She dealt with months and months of nausea.



Sharyn has a son, 12yrs, with arthritis: If you read the list of side-effects, you'd just say 'no way!' You've got to tossup between what's, you know, what's right and what's wrong...

Conrad and Doune: It's really hard, because you know what's causing it is something that you're actually giving her and encouraging her to take the next day. And that's really hard to do that.

Michelle and David: We felt that there's room for the modern medication and naturopath. So, we just combine the two. But, we wouldn't give her naturopath medication, without speaking to a rheumatologist to make sure it's not affecting the medication that they're giving her and make sure they don't react together.

Robert: I've spoken to my rheumatologist about all the natural therapies I've tried over the years, and basically they're... give anything a go. I can't recommend or guarantee anything for you. But, different things can work for different people.

Peter and Toni have a daughter, 14yrs, with arthritis: With her medication, if she's feeling well she doesn't think that she needs it. But then I'll see her, if she's been to a party and danced all night, I'll see her the next morning going for her medication. She knows mum's right, 'I do have to have it. I am sort of hurting'.

Robert: I think about not taking the drug sometimes, but I know of some people who have done that from some previous arthritis camps, and they've ended up worse for wear. So I've tried to lower the medication down myself and I really end up wearing it and I have to boost it up even higher than the original dose to try to control it. So, I realised that is not an option.

Michelle and David: With Sophie's medication, she has tablets and we let her take them herself now. She takes them out. So, she has some kind of control over it, it's not just us in control. And she's only 5 ½ but she feels really important if she's taking out her own tablets.

Jennifer: I've taken complete control, practically, I suppose, of my treatment. I decide which specialists I see, which tablets I take. What sort exercise and relaxation programs and everything I do. That's been a real empowering thing. My parents aren't really aware of half the things I do to treat my FMS.

Michelle and David: When she hasn't wanted to do her physio, just recently she's started saying, 'I don't want to do it'. OK, well don't do it, and you just see how you feel tomorrow. If you feel a bit stiff, or whatever, and explain the consequences of not doing it, and let them have charge in some ways.