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Speaking from Experience
Arthritis in Childhood

Transcript for chapter 2 of 9: Dealing with it

Jennifer, 19 years, has Fibromyalgia (FMS): When you're in pain you kind of hold yourself in a particular way, so the muscle tension caused by that sort of thing also causes its own pain.

Conrad and Doune have a daughter, 7 years, with arthritis: We've just really been noticing the way Claire does deal with it and encouraged her to do what she has found naturally. She really likes drawing. She's a really active kid, she'll always want to be doing something – she'll be wanting to muck around with other kids, or draw, or play some game. It's partly, I think, just how she distracts herself.

Peter and Toni have a daughter, 14 years, with arthritis: She does experience pain, but it's mainly that she gets limited movement of her joints. Provided she just doesn't overdo it, she doesn't experience a lot of pain. So I guess she has learnt to manage it, in terms of what she can do and what she can't do.

David and Michelle have a daughter, 5 years, with arthritis: Sophie doesn't talk a lot about the pain.

David and Michelle: Probably a mood swing lets us know that she's not really good. She'll get very arcky on us, won't she? You can't look at her otherwise she'll snap at you. Might be the red hair that does it to her.

Conrad and Doune: At night, just telling her stories to try and distract her when she's actually lying still and she's actually probably a lot more aware of the pain than she has been when she's moving around.

Sharryn has a son, 12 years, with arthritis: He just powers on and does whatever he can do, and tries not to let anyone know that he's having trouble.

Conrad and Doune: When she's feeling a lot better, or when her medication is under control, or when she's on a medication that's not causing a lot of side effects, and she's happier. She may not necessarily be pain free but she is actually managing a lot better, and then it is actually a lot easier to cope with her having arthritis.

Peter and Toni: Melanie's attitude has changed over the year. Like because she was diagnosed so young, it has always been a way of life for her, and so she doesn't know what it's like to be a child without arthritis. She has had to do everything with the disease.

Conrad and Doune: Knowing that Claire's been limited from doing some things that other kids just take for granted, there's some sadness about that.

Robert, 18 years, has Polyarticular Arthritis: Everything's new, still, to me. And it's really hard to know that you can't do something that a lot of your friends may be doing. You just find it's really frustrating. Why me?

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Conrad and Doune: I spent, I think, a few years just hoping that Claire's condition would... that she'd get over it really quickly, that therefore she'd go on to lead a completely normal life.

David and Michelle: I always say to Sophie, "I don't know how you feel." Because I think it's important that you let them know that it is their pain. You can't fob it off and say it doesn't hurt, because you don't know how they feel. I think she gets comfort from that actually.

Conrad and Doune: Our attitude and our response is, I think, really important for Claire. We actually stay reasonably on top of things and don't collapse and let her see that we're really upset about her condition.

Peter and Toni: As a teenager she's becoming more defiant if you like, or more assertive, and it's hard to tell whether she's playing on the disease or it's genuine. But generally we believe her when she says that she's had the disease that long that when she does say that she has a problem with her wellbeing or she's not wanting to do something, we generally accept that.

David and Michelle: You can't get everything right. But you've just got to be firm, and not let them get away with more because of their illness than you would if they didn't have it. You need to be aware that it can make difference but you still want nice children as well.

Sharryn: His grandparents probably mollycoddle him more than I do, and I let them do that because that's their role. But I need him to be able to get on with things himself and find ways of coping. That sounds harsh but it's probably good for him in the long run.

David and Michelle: That can be changing from one day to the next. They can be jumping out of their skin one day and the next day they're really lethargic and tired. And it's important when they're well to let them be doing what they want to do, and when they're not well, they're the days that they rest.

Conrad and Doune: I'm now realising that there are times when it's a lot better, and I have to keep telling myself when there are a few bad days, or something like that, that she will get better, it can be a lot better than this, and try and sort of motivate myself like that.

Jennifer: I have horrible days where I just feel so alone. I guess that's the worst thing – feeling so isolated from other people. Because people who aren't in pain can't understand what it's like for someone who is in pain, because it's not visible either.

Robert: It's very hard to open up to people, to explain. You're in fear that they may think you're an outcast, or a freak at the worst.

David and Michelle: Dave tells everybody.

David and Michelle: I've got no restrictions at all who I tell. They ask, they find out.

David and Michelle: I still mostly to family members. Dave deals with his things by speaking them, and I'm a bit more private than that. Plus I don't need to tell them if Dave has already told them.

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Jennifer: I don't tell that many people really. I don't tell my lecturers at uni – there are two lecturers who know. I just want to be judged because of my achievements, and not because I'm sick.

Robert: When I was in primary school, trying to describe to the kids what arthritis was, was really hard. It really was frustrating because they really had a short attention span and either wouldn't believe you or would tease you about it. That really hurt to a degree. But as you get to older kids, I guess they're more understanding and respect you for it. And then the adults either don't believe you again because they've never heard of it or they're over-sympathetic to you, which frustrates you even worse.

Peter and Toni: You can't just explain it in a few words. To make people understand you really have to sit down and really go through the whole process of what has gone on and what is going on. And a lot of people don't want to hear all of that.

Robert: Going to the arthritis camp really opened up my eyes. I really saw that I'm not the only one with this. Because previously I knew no one, as a young people with arthritis.

David and Michelle: Just talking to all of the different parents and talking to the kids and seeing the kids play – there's actually no restriction on the kids at all. And to be able to see that the kids can live a normal life – even though they're in pain – they're still running around and jumping on a trampoline. They accept it so well. They seem to accept it better than the parents actually.

Conrad and Doune: There was a time too, when Claire was really starting to learn what it meant to have arthritis in a wider sense. She came home from school one time and she said, "How come other kids don't have it?" So that was really good for her to meet other kids with arthritis. It meant that we had another context for talking with her about it. We could say, "You know that kid who..."

Jennifer: For cello lessons, I usually play for more than fifteen minutes. In fact, we sometimes play for an hour and a half and that makes me flare for a long time. And I have to go home and rest and put an ice-pack on my arm for the rest of the afternoon, and that sort of stuff. But I think it's worth it, because I love the cello. The enjoyment I get out of playing it surpasses the pain.

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