



## Speaking from Experience Arthritis in Childhood

### Transcript for chapter 7 of 9: Have a life

**Jennifer, 19 years, has Fibromyalgia (FMS):** Each of the areas of social life and school life and health - all those sorts of things influence each other. So for example, if I ignore the health aspect of myself (and it's the same with other people as well), then the rest of it suffers. I'm not well enough to go out and have a life.

**Robert, 18 years, has Polyarticular Arthritis:** I found the balance basically by over-doing it, having to deal with that, and then knowing my limits from that.

**Peter and Toni have a daughter, 14 years, with arthritis:** She's learned to self-manage the pain I suppose. After a netball game she'll put an icepack on a joint that's hurting. She's prepared to do that. So we've sort of left that up to her, to tell us when she's had enough - but she seems to be managing that quite well.

**Sharryn has a son, 12 years, with arthritis:** He does alright at cricket and he does alright at football - he's taken some 'speckies', I think the term is. And I think people are just as excited about that, who know Craig's condition, as me. And they come and tell me "Craig took a great mark at football, you know."

**Peter and Toni:** She'll even go into things like cross-country runs or for walks and things like that. She will exert herself and she knows she'll suffer for the next day or so, but it's important to her to be in with the group or not to be seen as too different.

**Sharryn:** I encourage him in things I know he can do, like swimming, which is non-weight bearing and good for him for a start. And that he can achieve things in, so that he can feel up with everyone else.

**Peter and Toni:** We talk it over with the doctor and specialist as well, and we make sure... we get advice on the direction we need to go. For instance, her continued involvement in netball, we talked with the doctors about that and discussed with Melanie. There's a bit of a risk there, in hurting herself, but she enjoys the game that much.

**Robert:** It has really limited my sport. I'm now interested in playing table tennis and billiards - more of a easier game to play; not as active and less stressful on the joints.

**Peter and Toni:** As a family, when we decide to do something, whether it's a career move or moving house or travel or something like that, you always consider Melanie's condition. The change you make - you always think of the impact that may have.

**Sharryn:** I guess I've had to have some understanding employers. It's not something at an interview when you go for a job, like say "By the way, my son has arthritis."

**Conrad and Doune have a daughter, 7 years, with arthritis:** It's the appointments. We both work, so it's working out how we can juggle around who's going to do this one, is this one we both need to go to, is this one... you know, getting a balance. Earlier on, last year, it



took me a while to realise how serious it was and how much I'd need to be involved in it. So Doune was really carrying a lot more of the load.

**Sharryn:** I make sure that Craig's appointments are at five o'clock. Or he has blood tests on Saturday mornings, when I can take him.

**Conrad and Doune:** Sometimes I feel I go into this weird situation when I've had an absolutely difficult morning getting Claire ready for school or she's been really unwell. And yet I've actually managed to get her to school. And I go into this sort of surreal environment at work, where I walk in and I just pull myself together. And I think this is amazing - no one's got any idea of the two hours I've just gone through. But then again, I feel that I would be too emotional if everyone at work was asking me all the time "How's your daughter." I just wouldn't be able to deal with that.

**Sharryn:** I get my mum to pick Craig up from school, take him to the doctor, so she's sitting there with him, and I get there right on five o'clock. So I've taken as little time off work as I can, I've taken ten minutes off to get there. Then I can go in with him. I don't miss out on that contact. I feel it's very important that I hear what's going on. I don't want to hear it second hand from mum.

**David and Michelle have a daughter, 5 years, with arthritis:** Probably the only thing it has affected is friendship-wise, you know with people we're friendly with. We're still friendly with them but we don't see a lot of them now. By the time we get home from work, we do what we have to do with Soph, and then look after the other two kids, your time just runs out. It's fairly time consuming looking after them all. And that extra bit of time it takes to look after Soph.

**Robert:** It really changes the way you look on life. You have an open mind towards life. A much better understanding of life and caring for people.