



## Speaking from Experience Young Adults with Arthritis

### Transcript for chapter 6 of 9: Relationships

**Sharryn (developed juvenile arthritis at 16 months):** My arthritis does impact on my partner because they also have to put up with the pain that I go through. They have to be patient. They have to put up with your bad moods.

**Judi (developed rheumatoid arthritis at 27 years):** There were times when we were invited out on a Saturday night and I was in pain so we couldn't go. So he misses out as well. But that time I didn't see that he was missing out - it was just me, I was in too much pain. So it has affected him in a huge way but we've got through that with me communicating to him on how I feel.

**Heidi (diagnosed with fibromyalgia (FMS) at 22 years):** I don't think my partner thought I was making it up but I don't think he really understood how much it impact on my every moment, and that one minute I can be really quite good, and then the next minute I can just be a bad tempered, emotional person.

**Judi:** He feels helpless. And I suppose a big issue is he's always scared that he's going to hurt me, if he gives me a hug.

**Peter (diagnosed with ankylosing spondylitis at 30 years):** It put a lot of pressure on our marriage, because all of a sudden I didn't look like I was going to be in a situation where I could always be the bread winner. The fact that I could be sick a lot of the time, made things a little bit tense at home I think. But over time my wife has adjusted to the fact, and she has seen that I have been able to take a reasonable amount of control over my life as well.

**Kim (developed lupus at 23 years):** He has been fantastic and really boosted my self esteem when I thought that there wasn't much to live for - at one stage I was pretty much down in the dumps. Same with my parents, they've been very supportive and have always encouraged me to keep going and keep my spirits up.

**Judi:** We dearly wanted to have some kids so we just thought, well even if we have one child. It was really difficult. I knew I had to come off the medication, and I had to work very closely with my rheumatologist and GP. And because I did have to come off a lot of the medication, therefore I did flair up with the rheumatoid. Fortunately with my first pregnancy, I became pregnant quite quickly. Then I went into remission with my rheumatoid while I was pregnant and the nine months were wonderful.

**Sue (developed rheumatoid arthritis at 12 years):** Because I've come off medications before and it has just been horrific, all of that sort of stuff is really scary. There's really not a lot of information out there about it, because no one knows how each individual is going to react. Sometimes you can go into remission during pregnancy, or often women do, but a lot of women don't.

**Sharryn:** It is a genetic thing in my family, not that any of my siblings have it. But maybe it will skip a generation, I don't know. By that time they might have a cure. I still want to have a



family, but I'm quite scared about the effect it might have on my children. If I could deal with it, then I feel that maybe they could too.

**Judi:** The arthritis has definitely impacted on parenting. I look now at the way I do things with my two children, and I look at the ways other people do it and it's totally different. But that's OK.

**Peter:** The issue of having young children bothers me because of the fact that I sometimes look at things like playing football with the kids, or something like that, and that when they get to an age of twelve or fourteen, I'm hoping I can still do that.

**Sharryn:** When I was growing up my brothers were very protective of me, knowing that I did have arthritis. They still wanted me to be normal and to do other things that other kids could do. So I guess they took more time in teaching me how to kick a football, for example, and how to play cricket. They knew that I had to go to see medical people and health professionals when I was younger. They were quite patient with the time that my parents had to spend with me.

**Judi:** At the beginning with my initial stage, I didn't tell any of my work mates and I didn't tell many of my friends. I told my family. But it was just too difficult at that stage to tell them, because I hadn't accepted it myself.

**Andrew (diagnosed with psoriatic arthritis when at 14 years):** I don't care now. When I was young I used to care. I didn't really want people to know. But now I couldn't give a hoot - I'll tell anyone, it doesn't worry me. If I've got arthritis, it affects me, but it doesn't affect what I do that much.

**Kim:** Sometimes you really do have to justify yourself and I find that if you tend to say lupus makes you extremely tired, then people tend to say that everyone gets tired. But it's a different sort of fatigue with lupus to normal fatigue. You still have to give your doctor's certificates to prove it.

**Peter:** Because of the nature of arthritis, it has times when it's quite aggressive and you're suffering from it, and there are other times when it completely leaves you alone and you have no outward signs. You look perfectly healthy, you look perfectly OK. I think that sometimes people can perceive that there really isn't much that is wrong with you and wonder why are you like that today when yesterday you were perfectly fine. And they tend to think that you're putting it on, and that you might be using the arthritis as a convenient way to get sympathy or something.