



## Speaking from Experience Young Adults with Arthritis

### Transcript for chapter 3 of 9: Personal impact

**Andrew (diagnosed with psoriatic arthritis when at 14 years):** It's an on and off thing. Like at the moment, my hands are fine, my feet are fine. But my hips, pelvis - it all feels stuffed. So I could probably go out and catch a ball and hand pass it, not a problem, and it wouldn't worry me. But I might regret it three days later because I've knocked them around.

**Kim (developed lupus at 23 years):** I've had sore joints and sore muscles and just absolute fatigue. I pretty much spent three months in bed at one stage. But as the treatments have sort of become more intensive, I've been able to pretty much lead a normal life.

**Sharyn (developed juvenile arthritis at 16 months):** Living with juvenile rheumatoid arthritis is just a part of life to me I guess, because I don't know what it's like to live without it. But it's challenging, painful, mind-draining I guess... it takes a lot to just get past the pain, and then to get back on track.

**Sue (developed rheumatoid arthritis at 12 years):** The symptoms of my disease have changed quite dramatically over the years. I've had my arthritis now for twenty four years. It has been a fairly destructive disease in my case. I've had a lot of joint surgery.

**Judi (developed rheumatoid arthritis at 27 years):** I grieve for the sports I used to play. And listening to your peers and hearing them talk about how they went to the gym, or aerobics, once again I think "Ouch that would really hurt."

**Peter (diagnosed with ankylosing spondylitis at 30 years):** It doesn't do your confidence the best, because I find that I have enough problems with self-confidence anyway, and then to think that you're hunched over... there's always that sort of negative... you know the Hunchback of Notre Dame sort of attitude.

**Sharyn:** I guess it has changed my appearance in terms of my legs - my knees are quite puffy and they turn in. But since I was young I remember that they always did turn in. I guess it puts me off wearing short skirts and shorts, for example, because my knees to me are quite ugly.

**Peter:** If you're having a bout or a flare-up, you tend to be very down and negative, because you're looking at the point where, if I'm like this now, what am I going to be like when I'm older? And also frustration, because you're trying to do something, and you can't do it because the pain is interfering.

**Sue:** There's certainly an emotional impact to having arthritis. It's not just a physical condition. At different times, it will be a bigger impact than what the physical one is.

**Sharyn:** I did go through the stage of "Why me? Why couldn't it have been one of my brothers? Or why couldn't it have been someone else?" But as I grew up, I came to terms



with the fact that I had it, and had to deal with it, and still made the most of what I had. You can still get positive things from having arthritis. You get to meet a lot of people.

**Sue:** I feel that I've got a fair degree of control over my life. I don't feel totally in control of it, because I'm really not sure what's going to happen in the future. Or even a few days from now, you know I don't know what my condition will be like. But I feel that I have the skills to manage whatever comes.

**Peter:** With the initial onset of arthritis I didn't have control, and I was basically at the mercy of the arthritis. But I've been able to take that control back again through exercise and management.