



Speaking from Experience Young Adults with Arthritis

Transcript for chapter 8 of 9: Impact on lifestyle

Kim (developed lupus at 23 years): I can still play sport, I play basketball as well. I still love snowboarding. You can still appreciate those things in life. I think that's what brings you real enjoyment.

Sue (developed rheumatoid arthritis at 12 years): I can live with the limitations, but it doesn't mean that I like it. So you fight it, and I think that's a really positive thing to do. I don't think I'd be as healthy as what I am, with the disease that I have, if I didn't have that sort of attitude.

Andrew (diagnosed with psoriatic arthritis when at 14 years): It's not worth not doing things. I can understand how it's different for some people. But for me, it was worth putting up with the extra pain for the fun of it all. If I couldn't play sport or anything, I'd go mad, or if I couldn't go out and enjoy myself.

Sue: It's the extra things that are the hard things. Dealing with ignorance from people around you can be really hard at times. Or just dealing with the changes that have happened to you, the thought that you won't be able to do those things that you wanted to do - or that you thought as a child you would be doing at this stage of your life.

Kim: You have to balance your life so that you don't trigger off a flair. You can't push yourself too much, and you have to really listen to your body. So if your body's saying you're tired, you pretty much have to go and have a rest.

Sharryn (developed juvenile arthritis at 16 months): Socially I have found of late that I can't stay out as long - maybe by two o'clock in the morning, I know that I've got to get home, and I've got to get these legs to bed.

Andrew: If I went out and rode my horse and I said "Oh I'm sore from riding my horse" and I had school the next day, my mum and dad would kick me straight out of bed. They'd go "You know the consequences of what you're doing. Don't let it affect what else you've got to do."

Kim: I've found that lupus has pretty much impacted on my independence, especially when I couldn't walk at one stage. I needed people to help me to get around, I couldn't drive. I couldn't walk so I needed my boyfriend to carry me around, and him to drive me around everywhere. Sometimes when I felt like going shopping I couldn't, because I just didn't have the energy to walk around, I couldn't walk around. At one stage I was in a wheelchair, and I always had to get someone who could be bothered to push me around.

Judi (developed rheumatoid arthritis at 27 years): The financial side of it is really a big issue. My husband jokes about it and says he has to do two jobs just to support my disease, because my chemist bill is huge.



Heidi (diagnosed with fibromyalgia (FMS) at 22 years): I find it really hard living with FMS and managing on the amount of money I get as well. Because I don't take normal medications and I don't see normal practitioners, I don't get any rebates or anything. I spend a lot of money on massages and vitamins.

Sue: It's all those other costs that you need to carry that never go away. Like your health benefits - will people allow you to have health insurance because of a pre-existing condition? All those concerns about if I need hospitalisation will I be able to pay for that, will I be able to get it? Having a condition where your strength and mobility is limited, you need to have good transport, and you need good things to help you do just ordinary things around the kitchen, etc.

Judi: My look on life has changed considerably. The little things don't matter anymore, and I'm enjoying educating other people about this disease. I'm co-leading a self-management course for people with arthritis. I'm running a young women's support group because I really believe in mutual support. With a disease like this I think mutual support is really important so that you can just run things by other people in a similar situation.

Sharyn: I guess living with arthritis has made me a stronger person. I've had to deal with the ups and downs of having arthritis, so therefore, it makes other things in life seem so much more simple.

Peter (diagnosed with ankylosing spondylitis at 30 years): I do a lot of work on my house, and that's another priority of mine. I'm trying to do as much now as I can, because it's experience that I might not be able to do at a later age when I'm not as mobile. There's probably not a lot of things I can't do but there's a lot of things I feel I need to do now because I mightn't be able to do them later.

Andrew: I met a lot of people, especially younger people, who are a lot worse off than I am, and people who are a lot better off than I am - all with arthritis but in different stages. When you get down to it, they're just normal people who are trying to do their best. That's it.