

## Speaking from Experience Young Adults with Arthritis

## Transcript for chapter 5 of 9: Medication, side effects & solace

**Sue (developed rheumatoid arthritis at 12 years)**: Your relationship with health professionals is just so important. To blindly follow anybody, when you're dealing with a chronic illness - it can't be the right thing to do. You've really got to let them know what's going on inside you as much as you can, so that together you can make those decisions.

Kim (developed lupus at 23 years): I wish I didn't have to take a lot of the medication that I do but I think it is necessary for my pain to be controlled. I actually do a bit of meditation, and find that it really helps to reduce my stress levels. I think stress is related to developing lupus.

Andrew (diagnosed with psoriatic arthritis when at 14 years): For months I'll be alright - I've had three months where I've had nothing, so I just don't take any drugs. If the pain comes back, I'll go back on the medication and see a doctor and say can you give me something? It's usually the same drug all the time, because it works, it doesn't give me stomach ulcers or that sort of thing.

**Sue**: Medications have been great for me in that it certainly helped me with pain levels and with keeping me mobile. I've sort of learnt through coming off them and finding that it was just such a huge impact that it's not worth it.

Sharryn (developed juvenile arthritis at 16 months): When I was about seventeen I decided that all the medication I had taken when I was a child and all the effects that I felt it would have - internally, such as stomach ulcers - I just felt that I didn't want that extra burden in years to come. So that's when I made the choice to take any more medication and to just get through the pain by my own means.

**Judi (developed rheumatoid arthritis at 27 years):** I have been on a lot of medication, on and off. I'm lucky I haven't suffered a lot of side effects but I am still concerned about the side effects. For example, the secondary effects, like I am more at risk of developing osteoporosis. One particular drug I'm on at the moment makes my hair fall out gradually. Another medication did change my appearance; you know the pimples that you thought you got rid of sixteen came back.

**Kim:** I just blew up like a balloon. My face sort of expanded and my midriff grew. A lot of people that I've come in contact with that I knew before I was diagnosed with lupus, some of them haven't even recognised me.

**Peter (diagnosed with ankylosing spondylitis at 30 years):** Without the medication the quality of life isn't there. There's nothing saying that this drug isn't going to do any severe damage to you, but the point is that if you don't take the drugs, the arthritis will do damage.

**Sue**: I've been very ill with some side effects recently, but for me, I've come out of that and either changed the way I've been taking my medications, or changed my routine, or something.





**Peter**: I always have the hope that something is going to happen in the future. You don't shut those doors. I always think that maybe there'll be some new drug that will come out that will alleviate a lot of the pain or the degradation. One of the reasons I try to look after myself now is that I've got that option.