

## **Singing through the pain**

### **The story of John Loxterkamp**

In June 1998, I hit my finger with a hammer; a good full swing hit! I woke up the following morning swollen in every part of my body with hot, red, achy joints and almost incapable of movement. Unable to get an appointment with my family doctor I visited the local clinic where the doctor told me to, "Rest a few days, and take Tylenol." This was the start of four months of doctor's appointments, x-rays and blood tests. Unable to work, I was diagnosed as having 'some sort of reaction to the hammer blow.'

Late September brought me a lucky break. I visited a locum doctor who took one look at me, asked a few questions and said, "You have a classic case of Psoriatic Arthritis"! I was 46 years old. Another three months passed before I could see a rheumatologist. That began two years of drug experiments trying to find the medications my body would tolerate while controlling my arthritis. Every joint from my toes to my nose is affected.

As with most people who suddenly develop severe arthritis, the change to my life was drastic. I was working full time, attending night school, teaching night school and I chairing several committees. I was a 14 hours a day, six days a week kind of guy.

The hammer blow in June 1998 stopped all that. I was unable to work, almost unable to dress myself and walk to the toilet. I was unable to go to night school, as I could not concentrate. Of all my conditions I think 'mind clouding' was the worst. For over two years I sat in my chair depressed, while I attempted to find some sort of work that I could do as my company refused to retrain me. I watched as my wife and children took on 'my work', cutting lawns, taking out the garbage, carrying the heavy stuff etc. For a long time I felt I could not do anything, even sleeping was painful. To sum it up, I could no longer support my family, and the changes my family was forced to endure were dramatic.

I have been hospitalized 8 times over the past five years, due to 'flares' causing me tremendous pain. Dealing with my local hospital has been a nightmare. Although there is a standing order at the hospital about me, no emergency room doctor or nurse will abide by it. I normally have a four to six hour wait before I receive pain relief. During my 'normal' five-day stay every nurse questions my pain medications, and phones my doctor for confirmation, thereby delaying my meds to the point that I am once again in agony. Every nurse says "Why doesn't your doctor do \_\_\_?" And they proceed to tell me what my doctor should do. A few times I have been delusional 'due to my pain' once to the point where I somehow left the hospital and my wife, by lucky chance, found me wandering around on the street outside!

It took years for me to accept the reality that although I couldn't clean the house, I could clean one room; that although I couldn't cut the entire lawn, I could cut one section; that I could peel 3 potatoes in the morning and three potatoes in the afternoon. It took years for me to realize that nothing was as important as regular rest periods each day no matter what had to be done. And it took even longer for me to realize that some days nothing would get done at all. It took years to find a hobby that I enjoyed (barbershop singing) and I now run our chapters' website. It took years for me to realize that I was now one of Canada's 'poor'.

I have my life somewhat back together, and am more comfortable with my cane, wheelchair and scooter. Having these tools available has given me freedom and allows me to contribute at home and in my community. Finding new hobbies is great too. – It energizes me and ensures I get out of the house to meet new people

P.S. Barber shopping is fun for men of all ages. Share your hobby stories on the Discussion Board.