

Annette McKinnon

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After enduring progressive symptoms for two years, when I was finally diagnosed with RA at 32 it was a life changing event. It led me to build a rewarding career in market research over the past 25 years. For the first few years of dealing with the RA I felt alone: isolated and in the dark.

Once I joined the online world I found communities and support to be plentiful. I also discovered that I liked to share my experiences with others in ways that I hoped would be helpful. That motivated me to become active — both online and in real life — talking about support, advocacy and sources of information.

Now I share my experiences through my blog "Your Gold Watch – Rheutired". It's about being a patient and having a chronic disease in a general sense that could

apply to almost any ailment.

I hope that my efforts will help patients to deal with challenges they face in healthcare, and enable them to become self-managers of their health issues and active participants in bringing change.

Here are some of the ways I have learned about being an active patient.

I'm a volunteer member of Patient Partners in Arthritis. This group provides trained patient volunteers who facilitate an increase in the understanding of all aspects of arthritis. This is accomplished through small group sessions led by a trained patient(s) that includes not only a technique for a musculoskeletal (bone and joint) examination but also real life narrative of experiences of living with the disease.

As a member of Board of Directors for The Sjogren's Society of Canada I try to help to raise awareness of Sjogren's Syndrome which is a disease that not enough people have heard of. I set up the Twitter account @SjogrensCA and try to Tweet relevant information at least once a day.

I volunteer as a model patient for The Arthritis Society.

As a Health Mentor I meet with students in various health care professions for the Centre For Interprofessional Education, University of Toronto. I've done this three of the past four years and think that this interdisciplinary course is part of the future.

I was trained as a Peer Mentor for Dr Mary Bell's ongoing study called "Peer to Peer Mentoring For Individuals With Early Inflammatory Arthritis" I expected to be sharing information with others who had a new diagnosis of inflammatory arthritis. I did not count on learning so much myself.

I've been the moderator of a Yahoo RA group called RA-Factor for the past 5 years and a member for 5 years before that. There are so many useful and friendly support groups to help with almost any problem.

Also during the week I take time to be an active participant in several health care social media tweet chats. It's a great way to learn more and meet and connect with people.

The movement to empower patients to work with their doctors and the health care system and to gain easy access to health data is gathering momentum. In an age of increasing costs, where a great deal of money is used by patients with chronic disease I would like to offer input and advice on self management of chronic conditions and help advance patient centered health care and the personal data revolution.

Patients should not be left out of the healthcare equation!
