



ADDRESSING THE BURDEN OF PSORIATIC ARTHRITIS: MOVING BEYOND THE JOINT PSORIATIC ARTHRITIS

PATIENT EXPERIENCE: DEANE

DIAGNOSES

I was 57-years-old when I was diagnosed with PsA. I was a jogger. I used to go jogging every day after work, and it got to the point where I couldn't jog anymore. The more I jogged, the worse it got. So, a business associate recommended a rheumatologist to me, and I went to see him. And when he looked at me, he suspected psoriatic arthritis right away because I had a rash on my forehead at my hairline. He did some blood tests, and they came back and proved that I had psoriatic arthritis. At the time, he also told me, I think you may have some osteoarthritis in your knees, but we weren't worrying about that. There was soreness in my hands, my right hand in particular, and my knees, and my feet. And it got just progressively worse and, in fact, it even became a chore to walk. That's how bad it had gotten in a short period of time.

TREATMENT

The initial treatment was methotrexate and prednisone, plus some cortisone shots. But I was on the methotrexate and the prednisone for 4 years, and then I changed doctors. I went to another rheumatologist, because the first one retired. The second one continued the methotrexate and the prednisone and added REMICADE (infliximab). He explained to me what a biologic was, and after a couple of treatments with the REMICADE I felt real improvement; but I was concerned about what it was. I did some research on my own. I went to Janssen's website and read about it, and I read some other websites about it. And I didn't like the way the doctor's office was administering the REMICADE. They weren't weighing me, and the way they put the REMICADE in the saline bag worried me. It didn't seem to follow the Janssen protocol.

I asked my primary care doc for a referral. And I got a referral to a rheumatologist who I have been with since the year 2000. She's marvelous. She continued the REMICADE, but I would get it as an infusion at a hospital where they would weigh me first, and then the hospital pharmacy would prepare the dosage. I got some hand strength back, the swelling went down, feet improved. Didn't do anything for the knees.

I stayed on the REMICADE, methotrexate, prednisone combination until July of 2017, when the blood test came back. With the new doc, every time I had REMICADE, I would have a full set of blood labs done. She would monitor the results, and the creatinine level came back very high. She sent me to a nephrologist. He ordered a kidney biopsy and that came back showing damage to my kidneys from the methotrexate. We discontinued the methotrexate and continued with REMICADE and prednisone, and a little later added the leflunomide (Arava).

As of March 2019, I'm off the REMICADE because of the kidneys. Now I am just on prednisone and Arava. The blood tests revealed the only side effect that I experienced, which was the kidney damage, or high creatinine level. Other than that, there were none. I was very fortunate that I didn't experience any. Never had a problem with the prednisone, never had a problem with the REMICADE. The only thing that was a problem was the methotrexate, which we stopped.

EMOTIONAL WELLBEING

I'm a recovering alcoholic. I was in rehab in November of 2013 and haven't had a drink since. But that taught me a lot about myself, and I went to a psychologist when I came out of rehab, every Monday night for 2 years. He was also a recovering alcoholic and he helped me in my recovery and also to develop a positive attitude. AA is a very spiritual program, the psychologist is a very spiritual person also, and so that's played a big part of my life. But going to AA meetings is a support group, it's not an arthritis support group, but you're there with people having a



struggle. You're helping them and you're getting outside yourself. That to me was more important. I did hook up to a couple of arthritis groups and, to be honest, I couldn't handle the negativity. "Woe is me, what am I going to do," that sort of thing. My glass is half full and I need to be happy. My wife is a happy person, a glass half-full person. But I think what I learned being a recovering alcoholic helped me deal with the arthritis pain because it's all about having a positive attitude. And there were days when they weren't so good. Back in January of 2017, I fell off the bed. My wife was in the hospital recovering from a heart attack, and I fall off the bed, land on my left hip, break the implant and break my femur. So, I was in rehab for a long time, and I was having a tough time emotionally with it. And then a friend of mine recommended a book called *Joni: An Unforgettable Story* by Joni Eareckson Tada. It's full of hope, and I haven't had a really bad day since I read that book. Even with this dialysis. I have diabetes, type 2, which is under control. Also, I had most of my stomach removed in 1980 due to bleeding ulcers, so now I don't have any stomach problems. And I had Hodgkin's lymphoma in 2000, and I had that fixed with surgery and chemo. And then the following year I had prostate cancer and they removed my prostate, with no follow-up, and that's been fine ever since. And the Hodgkin's has never returned. So, I'm a true cancer survivor.

As the patient, I had to be, as I said earlier, my own advocate. And talk to your doctor. Once you develop a relationship with your doctor, I think that that is a huge help in managing whatever your disease is, and I've been very fortunate. All my docs are associated with one hospital, so they can all see the electronic health record. They don't have to go and get permissions and all that sort of thing. I like that.

I'm very comfortable. Everybody in the same place. And it's been a wonderful that I have great doctors, so I'm very fortunate to have good people all under the same roof.

POSITIVE OUTLOOK

You have to have a positive mental outlook to go forward. And I'm fortunate in that, [as] a recovering alcoholic, going to AA meetings. When I was in rehab, I turned my life over to God and I read the Bible constantly. I go to a Bible study class. It's all part of my being, of having this positive attitude and just not being down on myself.

It is what it is. I am what I am because I am not what I used to be. And, I'm happy here today. I'm happy with what I've got, and I don't look back, it's history. Tomorrow's a mystery, so let's deal with today. And I think if you can get through the PsA, you can get through osteoarthritis or rheumatoid arthritis if you've got a good attitude about it. If you're in charge, then you have a chance. And there's all kinds of places to get support. The Arthritis Foundation, your family, your church, wherever. But you need to be around positive people.