

# Please Hear Me: How Effective Provider-Patient Communication Improved My Psoriatic Arthritis

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## Background

I was diagnosed with psoriasis (PsO) followed by a diagnosis of psoriatic arthritis (PsA) at age 30. Initially I was not able to achieve well-controlled disease. I had pain, swelling, fatigue, and brain fog. I am now 38 and want to share my experience with navigating the healthcare system to get the care I needed so that others can learn from it and be inspired to advocate for themselves.

A three-pronged approach helped to get my PsA under control:

- 1** Researched for scholarly articles regarding my PsA & suspected new diagnosis
- 2** Asked for referrals from other medical professional
- 3** Found a new rheumatology practitioner & made a new patient appointment

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## Intervention

- RESEARCHING. I reviewed medical studies and articles online about PsA with fibromyalgia and medications. I discovered that PsA and fibromyalgia are comorbidities and that switching biologics can cause flares. What I was experiencing aligned with symptoms of uncontrolled PsA with a few overlapping fibromyalgia symptoms.
- ASKING FOR REFERRALS. I also looked for other rheumatologists. I consulted with the Dean of Rheumatology at my state university who confirmed that I did not have fibromyalgia. Rather, my symptoms were likely due to uncontrolled PsA. She gave me the name of another rheumatologist, who confirmed the same.
- FINDING A NEW PROVIDER. In a rheumatology desert, with few options, I thought I might have to travel out of state. Fortunately, I stumbled on a practice new to my area that employed nurse practitioners with rheumatology specialization, and I made an appointment. The first thing my new provider said was that she expected me to be a collaborator in my health journey. I was the captain of my ship, and she was there to support me. She read my notes prior to our visit and ordered extensive labs. We scheduled a follow-up to review my labs and discuss next steps. I felt understood and hopeful.

## Patient Communication Principles

Before the Appointment	<ul style="list-style-type: none"> <li>• Bring a list of all current medications, frequency, dosage, and what they are for</li> <li>• Write questions/thoughts you have before the appointment including about your symptoms and how they are affecting your daily life.</li> <li>• Be specific with how you feel including how many days a week you feel your symptoms.</li> </ul>
During the Appointment	<ul style="list-style-type: none"> <li>• Clearly state your goals for the appointment</li> <li>• Carefully listen to your provider and their recommendations</li> <li>• Advocate for yourself                             <ul style="list-style-type: none"> <li>○ Get your questions answered to your satisfaction</li> <li>○ Take notes, record the appointment and/or bring a trusted person</li> </ul> </li> </ul>
After the Appointment	<ul style="list-style-type: none"> <li>• Research your provider's recommendations about treatments, further testing, any new diagnosis, and find out the standard of care for your condition</li> <li>• Follow up with your provider about what you learned through your research</li> <li>• Get a second opinion</li> <li>• Be prepared to find a new provider if you do not meet your goals in a year</li> </ul>

## Quality of Life

Since 2021, my health has improved, and my life has become my own again. Gone is the constant fatigue and brain fog and aching swollen joints. My CRP levels are lower than they've been since my PsA diagnosis. I re-started graduate school and have been volunteering in health advocacy in my state. The time and effort that goes into having a chronic illness has also become less burdensome: I don't need to travel to doctor's appointments as often and I spend less time on the phone with my doctor's office and insurance company.

This has all been possible because of the collaborative relationship I now have with my rheumatology provider. I communicate with my provider about my needs and PsA goals and she listens and provides constructive feedback. To maintain our collaborative relationship, I wrote up patient communication principles based on my experience (Table). If I need to change my provider again in the future, I know I can do so with confidence using the steps in my Guide to Changing Providers (see figure below).

## Guide to Changing Providers

