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Journal of Dermatology for Physician Assistants



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FROM THE PATIENT'S PERSPECTIVE

How To Talk To Your Loved Ones About Your Psoriasis

By Sabrina D Skiles

The National Psoriasis Foundation (NPF) offers many resources for patients with psoriasis. They offer ways for people newly diagnosed with psoriasis to connect with others who have experienced similar journeys. They have an online patient navigation center and options to connect one on one with NPF mentors. Sabrina Skiles has had psoriasis for fifteen years and is an NPF mentor as well as an online blogger. She shares ideas ranging from living with psoriasis, health, and fashion. She shares with the JDPA readers her experience in talking about her psoriasis with her now husband while they were still dating and offers tips and suggestions on how people dealing with psoriasis can talk with loved ones.

Your friends and family are around you everyday. They know everything about you, and psoriasis shouldn't be the exception. You may not know why you have the disease, but you can understand the science behind the disease and share that with your loved ones. Here are a few things I've learned that loved ones can express with their partners to help them open up about psoriasis.

Why do we go to concerts by your favorite band? Or loyally buy clothes from your favorite store or designer? Why do we take our kids to the best cheerleading or

basketball coaches around? One of the major reasons may be that we confide in and have confidence in those leaders in their respective fields because they are the best at what they do. That being said, we know what we are going to get when we invest in these things. But the same can be said for anyone who has psoriasis or a chronic disease. You too can be an expert in how psoriasis affects you. How exactly can we get there? It's time to start confiding in those around you. Opening up about having psoriasis can be difficult. But I have come to realize that talking about your condition actually makes opening up so much easier. For me, it didn't happen at first, it took practice, a lot of practice, as well as truly learning to confide in those around you. But it is possible, and I'm here to help those with psoriasis learn to open up to others as well. The more you know about the disease, the more confident you will feel and will want to tell the world about this chronic disease. When I was first diagnosed over fifteen years ago, I didn't have all of the resources that there are now. Because of that reason, I was scared to death to talk to my now husband about this chronic disease that didn't make me feel sexy at all. However, hearing the following phrases from him made all the difference in helping me to learn to confide in him about my skin. "I'm not dating you for what you look like." I remember to this day exactly where we were. We were standing on a deck at a restaurant in Galveston, Texas. Despite the muggy weather, I was wearing a quarter length black shirt and jeans to hide my elbows and legs. My husband and I were talking about what a great night we were having with each other and opening up about a lot of things. Now was time to tell him. I first asked if he knew anything about psoriasis. He said no. I explained to him that it was a chronic autoimmune disease with no cure yet. I told him that it affects the immune system and appears as red/flaky patches on the skin. I showed him my patches. I told him what treatments I was on, and how it affected my quality of life. He was extremely



The National Psoriasis Foundation (NPF) is a non-profit organization with a mission to drive efforts to cure psoriatic disease and improve the lives of those affected.

Founded in 1966 from a tiny classified ad in a Portland, OR newspaper, the Psoriasis Foundation has evolved to become the leading patient advocacy group for the 7.5 million Americans living with psoriasis and psoriatic arthritis.

As emerging research continues to demonstrate the serious, systemic effects of these chronic autoimmune diseases, our highest priority is to find a cure.

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NPF BLOG

The P is Silent, but We are Not!

understanding. He could tell that opening up was hard on me but was grateful that I was showing him this side of me. He was also thankful that I was teaching him about something he didn't know about yet. One thing he said to me that has stayed with me was, "I'm not dating you for what you look like, I'm dating you for who you are."

Loved ones should remember this phrase when showing support to someone with psoriasis. Similarly, those with psoriasis should remember this when opening up to family, friends, coworkers, or significant others. Loved ones are not there to judge you, but instead care for and accept you for who you are. To further help you on your journey of opening up about having psoriasis, here are some prompts, questions, and psoriasis statistics that can help you when talking to those around you:

- "Do you know anything about psoriasis or autoimmune diseases?"
- "Psoriasis affects the immune system and appears as red/flaky patches on the skin." (*Now would be a good time to show your patches*)
- "It is not contagious."
- "Psoriasis affects more than 7.5 million Americans and about 25 percent of people have a genetic predisposition to getting psoriasis." (*You were just one of the lucky ones!*)
- "There are different types of treatments out there, but here is what has worked for me.... I've also tried (*insert what treatments you've tried*) but they didn't help, and it really made me feel (*explain how it makes you feel*)."
- "Psoriasis affects my quality of life because..." (*it's extremely itchy, it can be embarrassing, hard to talk about, etc*)
- "What questions do you have for me?"

Have you opened up recently with your family or friends? What has helped you? What is stopping you? 🗣️



Photo by Todd Spoth Photography.

Sabrina D Skiles is a lifestyle and psoriasis blogger who has had psoriasis for over fifteen years. She is the creator of Homegrown Houston, the online website where she provides inspiration from living with psoriasis to fashion, career, love, family and health (www.homegrownhouston.com). She enjoys being an NPF mentor, Psocial Ambassador, and online influencer to raise awareness for psoriasis

Homegrown Houston

BECAUSE COMING HOME NEVER GOES OUT OF STYLE

Everyone needs a little inspiration today whether it be on fashion, career, love, family, or health – which is what Homegrown Houston is all about. Think of this as your 24/7 inspiration source where I share my love for fashion and advice on how to lead a healthy, balanced, and fashionable life while managing psoriasis.

I have a classic, sophisticated yet down-to-earth style and I want to bring daily fashion inspirations to you to make living with psoriasis just a little easier! I'm also a health and nutrition consultant with simple tips on how to eat better on a daily basis. I am a volunteer mentor and coach for the National Psoriasis Foundation, living with psoriasis for over fifteen years, providing guidance to those newly diagnosed. I have been with my husband for six years and married for three of those, so I feel like I know what's important in a marriage and how to make it stronger everyday. I am also a mother to a 9 month-old son so I offer tips and advice on managing psoriasis during pregnancy as well.

I am always open to suggestions on what my next post should be, who to feature, how much you like (or don't like) my website, and everything in between.

Take Home Points for Derm PAs:

By Steven K. Shama, MD, MPH, FAAD

1. As clinicians we diagnose and treat conditions of the skin. Sabrina is reminding us that we need to help patients to adjust to chronic diseases, both physically and especially, socially. Whether we do the counseling ourselves or help our patients connect with someone like Sabrina who is a mentor for the NPF, this referral may very well be as important as the treatment itself since better-adjusted patients are more likely to be compliant with caring for their skin and have better clinical results.

2. Sabrina suggests ways of introducing her condition to others, by asking certain questions. When was the last time you suggested an approach similar to

Sabrina's for your patients to take, in order to ultimately make lighter their private burden of having psoriasis? Whether we train our patients in specific approaches or not, at the very least we should be asking our patients with any skin disorders, "How does your skin condition affect you socially? Would you like me or someone else to help you in learning how to talk to others about your condition?"

Perhaps many of us have rarely given our patients the gift of caring about them as a whole human being, in addition to caring for them by simply treating their skin condition. In giving this "caring about" gift, we give ourselves a gift too, that of being a complete clinician.

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