ARTICLE • MS • PSORIASIS

Living with Invisible Illness: 4 People Share Their Stories

By Lauren Krouse

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Often, when people think of chronic disease, they think of someone who "looks sick" or uses supports you can see, like a wheelchair or cane. But millions of people are living with invisible conditions, like depression, chronic pain, endometriosis, diabetes, lupus, multiple sclerosis, and arthritis, among others.

Living with an invisible illness means many of your day-to-day symptoms and frustrations aren't really apparent to other people. Often, they're not easy to talk about for the same reason. But opening up about your hidden struggles can be a path to getting the help you need, educating others, combating isolation, and feeling better.

To draw attention to the things people are going through that often go unnoticed, we asked four people with invisible diseases to share their hard-earned insight and tips for others facing similar challenges.

My Lifestyle Revolves Around My Disease

Kara Skorupa, 52, Miami Beach, Florida

"As an attorney with multiple sclerosis (MS), I have limitations, which forced me to look at the aging process a lot sooner than my contemporaries. For example, my family just downsized from a big family home to a condo. Part of the reason we did this was so I wouldn't have to use stairs or drive to work anymore—tasks that can lead to significant flares of extreme fatigue.

"I'm an admitted control freak and am constantly planning ahead, but this does come in handy when it comes to coping with MS. I have to be super careful about everything because if I push myself too hard, my hands could start to shake, or I may have trouble moving. Where something might be an inconvenience for an able-bodied person, for me it's way more than an inconvenience.

"This morning, walking two blocks to Whole Foods, you could look at me and wouldn't think there's anything different about me. It's a little funny when I tell people I have a disability and certain needs, because I can see it on their faces: *What? You?*

"It really is a just-under-the-surface thing. Even my friends sometimes struggle to see or understand certain decisions I make, like this recent move. But just being in a new building, I've already had to talk to the management company and my neighbors about my disability and emergency preparedness for my own well-being.

"I've learned that self-advocacy is key. When I was first diagnosed, I read every book on the planet, and I'm a member of an MS support group. My advice? Learn as much as you can and don't be afraid to ask questions of others with disabilities, like how to manage a trip to the beach with mobility concerns. There's a real wealth of information in communities of people with lived experience."

I've Learned to Take It Easy When I'm Not Feeling Well

Bridget Shirvell, 35, Mystic, Connecticut

"At 19, I was diagnosed with ulcerative colitis, an inflammatory bowel disease that causes ulcers to form along the lining of my large intestine. When I'm having a flare, it's definitely hard. On the outside, I look and feel fine, but I'm really struggling.

"Plus, symptoms can really vary. Sometimes it's just a feeling of utter exhaustion, where even putting on socks makes me want to take a nap. Other times, I get really achy. And then there's stomach pain and an urgent need to go, which can make me nervous about finding a bathroom.

"For me, an important coping tool is communicating what I need and setting clear boundaries. For example, as an independent journalist, there are times when I've had to push back a deadline because I wasn't feeling well. In those instances, I normally simply say I've been sick and will have the project by X date. Most people are more than respectful of this.

"When it comes to my personal relationships, most close friends and family are aware of my illness, so I can say something like, 'Hey, I'm not up for dinner out, but I'd still love to see you. Would you mind coming over to me?'

"With people I'm not as close to, I used to keep it vague, or sometimes it would be my way of then telling that person about my illness if it was a relationship I wanted to deepen or keep. But the pandemic has made me more cautious, so I've found myself telling more people about my underlying condition and then asking if they've been vaccinated.

"When you're first diagnosed, it takes time to get your bearings. But I don't think of it as making adjustments anymore; it's just my life. There are some days I might do less work if I'm not feeling well. But I know I'll make up for it another day."

It Took Me Years to Start Speaking Up for Myself

Jenn Lloyd, 44, Los Angeles

"After 38 years of searching for a diagnosis, I was finally diagnosed with Ehlers-Danlos syndrome, hypermobility subtype, an inherited connective tissue disorder that causes loose joints prone to dislocation and chronic pain, among other symptoms.

"It's difficult because not only do I have a condition that others can't see or tell I'm affected by, but it's also a condition most people, doctors included, haven't heard of or know very little about. I often encounter people who don't believe I'm in as much pain as I say I'm in because I'm young, or they think I'm just a 'hysterical woman.'

"My advice for others is to be as open and honest as you can be about your condition. As a TV comedy writer, I spent so many years trying to hide my illness and the severity of my pain for fear that my co-workers would see me as incapable of doing the job. But my

experience in opening up has actually proved the opposite. I've connected with empathetic people who have my back and support me if and when I need accommodations at work.

"I feel much more comfortable in my own skin and less stressed since coming out about my illness, but disclosing your condition is a personal choice that may not be right for everyone. A few things that helped me were connecting with a therapist who's familiar with chronic illness and following disability rights activists and organizations online, like Incight and All Walks of Life.

"Having these resources has helped me speak up for myself. I've learned how to communicate my needs and limitations in a professional manner. And I've stopped putting my body in peril to prove I'm worthy of a job."

I'm Forced to Put Myself First

Denise Lani Pascual, 47, Greenwood, Indiana

"Over the years, I've been diagnosed with migraines, bipolar disorder, psoriatic arthritis, and breast cancer. Managing these conditions is like herding cats. Pain and numbness from my psoriatic arthritis often wake me up, forced menopause from cancer treatment means I'm low on the hormone estrogen, and these issues can dampen my mood and trigger migraines. Sometimes, it's hard. Really hard.

"But accepting these diseases as a part of me was the first step in letting go of my anger, sadness, and frustration. In a world where moms are made to feel guilty or selfish for taking time to exercise or do something for themselves, having an invisible disease can be a source of freedom, a reason for self-care, a motivating force that empowers us to be present to ourselves and others every day.

"Most days, I can manage all of this because I make my health a priority. Every day, I exercise, pray, meditate, and follow my treatment regimen. I also cope by staying active and doing good works for others, like #BakeItForward projects and Pink Boxes for women with breast cancer. These activities not only keep me physically moving to help me manage psoriatic arthritis but also lift my spirits as I lift the spirits of others.

"My advice to anyone who is newly diagnosed is to let yourself be sad and angry, but don't stay there long. Educate yourself about your treatment options, and be diligent about making your health and happiness a priority every day."

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Kml1

I'm filing for disability for psoriatic arthritis, psoriasis,COPD, anxiety, depression, PTSD,diabetes,cataracts,but I've been denied before, curios how a hearing went for you?

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Carola T DARIO TEAM

Hi Krissy, don´t give up! Do you have an attorney who can overlook your case and can help you with? I heard from other members that this was often the key point when handling disability applications. If you need some suggestions, please feel free to ask in the community. This way many members and experts will read your post and can respond to you. Sending much love and support your way 🧡

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