

- Sometimes I can do stuff: sometimes I can't. This changes moment by moment. I never know which plans or activities I can keep. If you are frustrated by this, imagine how I feel
- It's not just like...(fill in the blank). When people seek to identify with someone, they can minimize that person's struggle. Parkinson's is not like a cold, a leg falling asleep, losing your balance, or being really tired. It is unlike anything I have ever experienced.
- I am not the only one suffering. I have a family. Yes, I may be the poster child because I am fighting this battle, but they are hurting and battling this disease just as much as I am, and must watch me suffer and decline. Just like me, they have to deal with so much.
- Sometimes, it can be very lonely. Battling this disease at 44, my family and I can feel very alone. We know very few in this fight. Sometimes, you do feel like no one understands, and that can be very isolating.

Parkinson's is so much more than just shaking, and even good days are hard...there is so much many never see.

These are just some of the things that make this disease challenging. Day to day, you never know what you are going to face, which is why we must take this disease one day at a time. Fighting this disease is hard, but it helps to have people around us who work to understand our struggle and help us along the way. I am thankful to have many of these people in my life.

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Mine's Parkinson's

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HOW DO YOU EXPLAIN...

...something to a person who has never experienced it" It is hard for any of us to understand the depth of another's struggle if we have not walked that path ourselves. Still, when we begin to see just a small part of what another is dealing with, it can help us as we work to help them.

I was asked what it was like to have Parkinson's and what I wish others knew and understood about this disease. I realized it was harder to describe than I thought. I hope this helps others understand a little of the battle many are facing.

It can be hard to understand a battle we have not walked.

10 THINGS I WISH PEOPLE KNEW:

Parkinson's is more than shaking. So many things are affected that are never seen. Anxiety/depression, pain, fatigue, difficulty sleeping, slow movement, spasms, speech changes, issues swallowing, cognitive problems, and so much more. Even when you can't see the "shakes," there is a battle raging.

- **Every person's battle is different. My experience is different than other patients I know. Some symptoms are severe, some do not show up. Some progress slow, while others progress fast - , and no two of us are alike.**

- **Parkinson's is always there. I never get a break. There are dozens of constant reminders each moment, and there is nothing I can do to change it.**
- **Even good days are hard, because there is so much you can't see. Even when I am doing "good," everything is still a struggle and takes more effort. Very few things are simple,**
- **There is always constant pain. There is never a time when I am pain-free. I might have less pain that day, but there is still the "white noise" of constant pain.**
- **I am never getting better, and there is no cure. All we can do is slow it down and strengthen my body with exercise and control the symptoms with medicines. It will never get better - and that is a hard thought to deal with.**

