

## **Powerful Lessons About Living with a Chronic Illness.**

(from the book *Shake, Rattle & Roll With It* by Vikki Claflin)

**1. It can happen to you.** No one is immune from illness. You say you've never been sick? You do all the right things? You never smoke, you eat kale, and drink acai juice every day, and you only use organic cleaning products? Good for you, but don't be smug. Sometimes it just happens.

**2. You may never know why.** True of many chronic illnesses, but particularly with Parkinson's. Since medical science has not yet determine the actual cause, you will probably never actually know why you got it. "Why me?" is the great unanswerable question. Let it go.

**3. Don't lay everything at the feet of Parkinson's.** Every stumble isn't necessarily a sign of Parkinson's progression. Sometimes it's just a stumble.

**4. If you find you can't do something you used to enjoy, find a way to modify it or find something else.** Yes, if you have a tremor, there will be things you either can't do as well or possibly shouldn't do at all. But if you can do what you love without needing to be good at it, for instance playing the piano, do it anyway. If it requires an ability you no longer have, such as target practice with a shotgun, find another hobby. Who knows? You might discover a new passion.

**5. Don't look back.** Endless wailing about "what used to be" is self-pitying and guaranteed to send friends and family scurrying in the opposite direction after the first 12 hours.

**6. Give it so much attention and energy, then stop.** You need to be aware of what you can and cannot do, and stay on top of your medications, but other than that, go live your life. You are not Parkinson's. You *have* Parkinson's. There's a difference.

**7. Stay off the internet.** Nothing will make you want to bungee jump without a rope faster than an hour on WebMD, looking up every horrific, worst case scenario of your illness. If you want to educate yourself about Parkinson's, talk to your doctor or get information from recognized Parkinson's research foundations.

**8. The world will not stop.** When potentially devastating events happen in our lives, we somehow expect that the world will stop and take notice. It won't. People will go on about their lives no matter what's happening to you. Don't take it personally. Before you were diagnosed, you did it, too.

**9. You have to be your strongest advocate.** No one will care as much as you do. If your medications aren't working or you don't like the side effects, ask your doctor for a different prescription. If you don't understand something, ask questions. And keep asking until you do understand. If a new symptom scares you, get into your doctor, even if it's not time yet. This is not the time in your life to let other people drive the bus.

**10. People will treat you differently.** Chronic illness makes people uncomfortable. They often don't know what to say, and it can remind them of their own vulnerability. Again, don't take this personally.

**11. "What ifs" are exhausting and completely unproductive.** Stop it.

**12. You are not to blame.** You didn't cause this by drinking diet coke or not eating kale. Don't heap self-blame onto the laundry pile of emotions you'll experience. The fact is no one knows what causes Parkinson's.

**13. Your life will change.** The good news is that Parkinson's won't kill you. The bad news is that you'll be stuck with it for 20 plus years, so you better learn to live with it. For some it's about finding and sharing the humor in it. Other people get involved in fundraising and awareness efforts. Whatever gets you out of bed and living a joyful life is a good thing.

**14. It's okay to be angry or sad.** But it's not okay to stay that way. Everyone has days where we shout "SERIOUSLY?" to the cosmos, or spend the day in our footie pajamas, eating Ben & Jerry's chunky monkey ice cream by the quart while watching the entire series of *Little House on the Prairie*. But a day is different than a life. You get 24 hours, then you're done.

**15. Even without a cure in your lifetime, you can fight a good fight.** There will be countless frustrations, epic falls, and a wealth of embarrassing stories to delight your offspring around the dinner table. If you can laugh, you will own that moment. And ultimately, a life made up of joyful moments means you've won.