An email exchange between two friends who live with Parkinson's — published in The New York Times — gives a closer look at the thoughts and feelings the disease brings. Here, the Foundation answers common questions and shares more information on living with Parkinson's.

**COMMENTARY BY:**

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Dear VV,

Now both of us are members of a club I’d rather not belong to. What are the odds of two collaborators, like us, getting the same neurological disease?

You know, over 10 years ago I learned that I had Parkinson’s disease. Whatever the cause, it was not welcome news. “There is an upside,” my first doctor smilingly told me, as he informed so many before me, “you won’t die from it. Something else will do that.” Well, that was comforting.

I decided to seek a second opinion.

My new doctor said more or less the same but added: “Don’t try to self-diagnose from the internet.” Wise advice: There are just too many nuances, and every PDer has their own peculiar symptoms.

I’ve learned to live, albeit with a modicum of trepidation, with the disease. After all, everybody has something wrong with them, even if the worst is acne – and some things are worse than others. My life has not radically altered. Still, I am aware that things can change. What’s more a combination of PD and getting older has cut into my productivity. But at least I am productive.

What about you? When did you learn that you became a club member? And what are the dues you now pay?

Illustrations by Christoph Niemann
In Parkinson’s, there’s no blood test or brain scan that can tell if you have the disease. To diagnose it, doctors examine your movements and ask about your medical history. That’s why it can sometimes take a while to get the correct diagnosis. And why it’s important to see a “pro,” if possible. Parkinson’s “pros” are called movement disorder specialists, and they are experts in diagnosing and treating the disease.

These experts can be hard to find in some places around the world. And they can have long waiting lists. For these reasons, MJFF created a program that supports the training of new Parkinson’s doctors around the world.

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When processing a new Parkinson's diagnosis or as symptoms change over time, it's normal to feel depressed or anxious. These mood changes also can be symptoms of having Parkinson's, just like shaking or slowness. There are many treatment options to support you, such as medication or talk therapy. Exercise, too, can boost mood and ease worry.

But it is something that requires jiggling of the mental wiring. The worst part is when I shake uncontrollably. People I meet either try to ignore it, or they ask: “Do you have PD?” When I don't shake, they say: “You must be doing better, you’re not shaking.” I figure at least I can get a job ringing a bell as a Christmas Santa. Do you have any plans, now that you know?
In my conversations with Parkinson’s families, I often hear, “Is there reason for hope?” Absolutely. Parkinson’s drug development is bursting with possibilities. Many people find (and keep) hope by joining research studies. Curing the disease requires us to understand its biology much better, and you can help make that happen — whether you have Parkinson’s or love someone who does.

You can also find hope in other actions: exercising, building a care team and connecting with others. And you might try to focus on the positive, however small. Michael J. Fox has said, “Gratitude makes optimism sustainable.”

Many people worry about sharing their diagnosis. They don’t want to be treated differently. Or have people feel sorry for them. But, most say they feel relief after they share. And they wish they’d done it sooner. Keeping a secret can be a burden. (And this stress can increase your Parkinson’s symptoms, which can make it harder to hide.)

It’s your story. You decide whom to tell, what to tell and when to tell. You will likely tell loved ones, children, friends and colleagues in very different ways and at different times.

Dear Steve,

I haven’t experienced self-pity yet. I am still in phase one: trying to process the reality of my situation. No sooner was I diagnosed with PD, and even before I got the wherewithal to walk into a pharmacy to fill my prescription for dopamine, I had to decide whom to tell and what to tell. I knew that the minute I would announce that I had an incurable disease, people’s perception of who I am would change. It’s only human. Healthy folks are spooked by friends’ illnesses.

Suddenly, I had to decide how to frame my narrative to — let’s be honest — get maximum sympathy without making family members and friends feel condolences are expected. Sounds trivial, doesn’t it, but we live by and for the opinion of others. Anyway, I do. My whole life, I have flaunted my good health as if I deserved it. Now I realize that I used to feel secretly superior to people who were less resilient than I was.

It’s as if I had to rewrite my “brand story.” The temptation for me is to be self-deprecating. Banter and flippant remarks come easily to me when I am under stress, with adrenaline coursing through my veins instead of dopamine. But when I told friends over the phone that I was “relieved to find out that I had Parkinson’s instead of Alzheimer’s,” I could hear the question mark in their silent response. They knew I was faking it. But what else am I supposed to do? I don’t have the skills of a crisis communication specialist.

The toughest thing was to share the information with my daughter. As a parent, you feel that your job is to be available no matter what. Role reversal is the next thing I should teach my ego.

Steve, do you talk to your son, Nick, about the stress of PD, or are you trying to shield him from this “narrative?”

Dear VV,

What a story! Were there people around? I’m impressed (and amazed) that you held it together. I cannot even imagine how I would react. I would have had to rely on so much adrenaline.

I don’t see you as deluded, but age is certainly a very real psychological burden. I don’t “feel” old. I feel mixed up. Technically I’m “senior,” which used to be called “elderly.” I will not accept “elderly.” But I am disturbed that there are fewer years ahead than behind. OK, Parkinson’s won’t kill me, but it contributes to an overall state of tenuous being (mortality?). I continue to convince myself that I’m younger. My friends are mostly in their 70s, 80s and 90s (and all are extremely productive). This is a shock to the system. Yet I work with much younger people, which both mediates and undermines the shock.

When I cannot complete as much work as I did just a few years ago, that’s when I feel despair. I am not an aging wine, but I’m at whining age. That is not a good state of mind. I have to recognize the process but my denial/survival quotient is higher than my recognition capacity.

Your mom was elderly, do you relate more to her now? Or is there some internal mind-set that allows you some sense of hope or optimism? Can you, Veronique, still be you?
Dear VV,

It has been a gift to correspond with you. But it’s also opened up wounds I’ve been letting scab over.

I am kind of shocked that all France expects to alter life at 65. It has a sci-fi tinge to it, like Saul Bass’s convoluted feature sci-fi movie, Quest, about a civilization of individuals that each lives for only 24 hours. Every week someone is selected to run an obstacle course as fast as possible over difficult terrain to reach a huge fortresslike door. The goal is to open it and free the civilization from its 24-hour fate. (I said it was convoluted.) The film is about (spoiler alert) the one individual who succeeds. Hope reigns happily ever after, I suppose.

You and I can work forever, if we choose to. But then all these obstacles are thrown in our paths. My best friend, Seymour Chwast, is going to be 90 this summer. He just sold four children’s books. He just published a book of his 100 plus posters. And we are working on a book together about HELL. He’s also losing sight in one eye and has other normal malfunctions of a man his age. He survived Covid-19. I don’t have half his talent, energy or willpower to make art. Should I berate myself, or should I give myself a break? We all meet the same fate eventually, anyway. What is the answer? Is there an answer? Should there be an answer? You don’t have to answer . . .

In sharing their frank correspondence, Steven and Véronique gave us a gift. They gave us a closer look at the feelings, worries and questions that Parkinson’s brings for so many. And they showed us the power of connection in finding answers and building a path forward.

When Parkinson’s is part of your life, making connections is key. Parkinson’s can feel lonely. But I want every person and family living with the disease to know you aren’t alone. Whether you want to talk (or email!) with a friend, meet others in a support group, or just exercise together, the community is here for you. For every step of your journey.

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