

The New York Times



What It Feels Like to Live With Parkinson's

By Steven Heller and Véronique Vienne. Illustrations by Christoph Niemann. June 23, 2021

Steven Heller, 70, has lived with Parkinson's for more than 10 years. Véronique Vienne, 79, only recently learned that she had the disease. Both have had long careers as art directors, and the two have been friends for more than three decades. Back in March, the pair exchanged a flurry of emails over a 10-day period, where they explored the "before" and "after" of a Parkinson's diagnosis.

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THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

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



This fact can be surprising to anyone unfamiliar with Parkinson's. I often tell people — especially those early in the disease — that your Parkinson's is *your* Parkinson's. Your symptoms, how they change over time and how they impact your life: all unique to you. Some people are bothered mostly by shaking (tremor). Others by walking and balance problems. Still others, by mood or sleep changes.

So, how can you navigate this? Focus on your journey. Find the resources, support systems and other tools to manage *your* Parkinson's. Talking with others about common experiences can be helpful.

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Dear Steve,

It was a year ago, to the day. I noticed how far down the floor had gotten. At the same time, I had lost elbow room — particularly when trying to maneuver a forkful of peas into my mouth. As for folding my underwear, it was frustrating: like trying to catch a fish in a pail.

I had been told that reality is a construction of the mind, and I believed it, but I had never had a chance to test this theory. What I was about to discover is that chemicals in the brain — in my case, absence of dopamine — are acting as interior designers, shaping space this way and that way, shortening some distances, flattening perspectives, raising steps, adding or subtracting a couple of inches here and there to the height of chairs, steps and thresholds. Trying to describe my discomfort to my primary doctor, I told him I felt that “space is closing up on me like a coffin.” He asked me if I was depressed and suggested I speak to a shrink.

Granted, my metaphor was overdramatic. Had my primary doctor been a graphic designer, I would have told him that I felt trapped in a Merzbau — in one of the mazelike installations of Dada artist Kurt Schwitters. No chance he would have understood my reference. To explain the rigid sensation in my legs and arms, I briefly considered mentioning Marcel Duchamp’s famous Nude Descending a Staircase. It would have been gibberish to him.

He sent me to consult specialists: a rheumatologist, an endocrinologist, a cardiologist, a nutritionist, a couple of physical therapists. I was X-rayed, scanned and MRied. No one could figure out what was wrong with me.

We were in lockdown mode. To stay fit, all my girlfriends were taking yoga lessons on Zoom. Joining them was out of the question: the yoga mat on the floor was so far down, I would have had to rappel down a rope from a helicopter to get to it.

Instead, I decided to do some badly needed re-landscaping around the yard. I live in the country in the South of France. I could justify using the furlough to do a little gardening. Being outdoors appealed to me: there, I wouldn’t bump into furniture, fall from a stepladder, or trip on the edge of a rug. For the next three months, I moved enough soil to build a dam across the Yangtze River. I strutted around, pushing heavy wheelbarrows up and down ridges.

In hindsight I realize that, with my hoe, shovel and spade, I was trying to gain control over the spatial dimension that was slowly shrinking my world and, yes, turning me into a prisoner inside my own body. By the time I was done with my earth-moving project, I could hardly walk. The diagnosis: sciatica. The treatment: Advil.

Last week in Paris, it took a neurologist exactly three minutes to diagnose Parkinson’s. She was a pro — like Paula Scher, who took 34 years to learn to draw a logo in a few seconds. The question is: Why did it take so long for me to book an appointment with the right specialist? Was I mentally impaired as well as physically handicapped? What do you think?



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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Dear VV,

I think you were in denial that something could be terribly wrong. We don't really want to know what we don't already know. The first doctor initially told me it was a "nonessential tremor" (look it up, I'm not going near any neurological websites). Then two months later, he said it was PD. I would have been content with the first diagnosis. I remember returning to SVA after that appointment and announcing triumphantly that I had Parkinson's. I don't know what I was thinking. A triumph?

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?



I get it! Too much information can be overwhelming (and sometimes misleading). Some individuals, like journalist and person with Parkinson's Michael Kinsley, prefer a less-is-more approach. Kinsley has said, "I see good doctors, take my pills most of the time, and go about my business. I couldn't tell you some of the most basic things about Parkinson's and how it works."

Not wanting to know much about Parkinson's, especially early on, is understandable. But I'd encourage anyone navigating this disease to know the facts about Parkinson's. It can help you better understand the disease and make informed decisions about your care. Ask your doctor and other people with Parkinson's for credible resources and websites.

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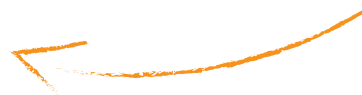
When processing a new Parkinson's diagnosis or as symptoms change over time, it's normal to feel depressed or anxious. These mood changes also can be symptoms of having Parkinson's, just like shaking or slowness. There are many treatment options to support you, such as medication or talk therapy. Exercise,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

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Dear Steve,

Even before I was diagnosed with PD, I had developed a sense of urgency concerning my personal projects. I started writing a novel, even though there is absolutely no evidence that I have the necessary skills to handle fiction writing. It's like my landscaping project: I was trying to move mountains. I felt an urge to reinvent myself. I became a character in a novel of my own making.

Today I have to "reorder my priorities," as the expression goes. What it means is that I am going to have to dedicate more time to exercising every day of the week. The prospect of working out regularly fills me with terror. I find the idea of having to confront my demise on a daily basis totally depressing. With PD, physical exertion is supposed to be a mood upper. Would you say it's true? What's the best way to avoid feeling blue?



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?"



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."

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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.

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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 underscores 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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