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My Health Story

Illness on a personal level



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Six Words That Changed My Life: 'I Think You Have Parkinson's Disease'

By [Everyday Health Guest Contributor](#)

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YOUR REACTION?

I LIKE IT

SO SO

INSPIRING

INTRIGUING

IMPORTANT



By Soania Mathur, MD, Special to Everyday Health

I always wanted to be a doctor. For as long as I could remember, being a doctor was always my goal and what motivated my academic career. At the age of 26, my dream became a reality. I finished my residency in family practice, started my first job as a physician in a clinic, and was expecting my first child. It was a busy time, but I thrived in the hectic

pace of it all.

My excitement was soon interrupted by an [annoying intermittent tremor](#) in my right pinkie finger. It was hardly noticeable at first, but as my pregnancy progressed, so did the tremor — so much so that I decided to consult a neurologist and colleague of mine.

Reluctantly, I booked a few minutes off between seeing patients for what I believed to be an unimportant assessment. It didn't take long for our casual banter to take a more serious tone. Following a series of clinical testing he said the six words that would change my life: "I think you [have Parkinson's disease](#)."

After second and third opinions from two movement disorder specialists (neurologists specializing in Parkinson's disease), what I had originally dismissed as an annoying tremor in my pinkie became a diagnosis of young onset Parkinson's disease. I was 27.

The Relentless Pace of Parkinson's

There was no escaping the inexorable progression of the disease: The tremor spread into my right arm, then my left, soon followed by my right foot, then my left. I woke up stiff and experienced severe cramping in my feet that made walking difficult; my tremor amplified, and my nights filled with restless exhaustion. Relentlessly, Parkinson's followed me into all aspects of my life — from caring for my young children to taking care of my home, and keeping up cherished relationships with friends and family.

Worst of all, Parkinson's was robbing me of the career that had been my lifelong dream. The career that I had worked so hard to achieve. I mourned the day I had to stop assisting in the operating room, then suturing in urgent care. I resented having to time my medications so my hands wouldn't shake when I gave immunizations. Infuriatingly, the tremor gave me an air of nervousness, even though I was certain of my knowledge and skills. It was extremely difficult to do what was best for my patients, to help them through their medical issues, while trying to hide and manage my own symptoms.

What Parkinson's Takes Away – and What I Regained

The [emotional struggle](#) lasted a number of years. I focused on the difficulties I faced every day, and all that I felt I was giving up. I was consumed by thoughts of disability.

But eventually I stood at a crossroads. Until a cure was found, my future would always include Parkinson's. The diagnosis itself was not within my control. But how I faced this challenge, and my resulting life experience, was mine to determine. The disease that had stolen so much was now teaching me a powerful life lesson: I held the ability to choose my response to any challenge, including a diagnosis of this disease. I realized I had the power to choose optimism over despair.



After 12 years of practicing family medicine, my symptoms and medication side effects made the pace of my career impossible to maintain, and I gave up clinical practice. But even this loss opened up a new world of [patient education](#) and advocacy — writing, speaking and working with incredible organizations devoted to advancing Parkinson's research, and fostering community among Parkinson's patients and caregivers.

Be a Part of the Solution: Finding a Cure

Today, I educate people on how to live well with a Parkinson's diagnosis. However, I cannot provide the simple, yet unbelievably complicated answer that the millions of us affected by this progressive disease need — a cure. While it may be tempting to think of the search for that elusive endpoint as something patients are far removed from, it's not. We are an integral part of the process.



Drug development is a lengthy and expensive affair, especially when it comes to the brain. Successfully shepherding a new treatment for a neurological disease from “bench to bedside” — that is, from the research lab to the pharmacy shelf — routinely takes decades and well over a billion dollars. A majority of that time and money is spent in clinical trials — the portion of drug testing conducted in human beings, to make sure that potential new treatments are both safe and effective. Most drugs fail well before they ever make it into clinical testing. Even if they do make it that far, the supremely frustrating reality is the

majority of clinical trials are delayed because of a lack of volunteers to participate in the testing. A staggering number of trials fail to recruit even a single volunteer.

Despite my status as a physician, I was shocked by these statistics. Any delay a study faces leads to a huge loss of resources, money and most importantly time — time that we, as patients, truly can't afford to waste.

Why Join a Clinical Trial?

From talking to patients over the years, I know there are a number of reasons we don't sufficiently participate in research; a lack of interest is not one of them. Part of the problem is logistics — who can afford more time away from family and household responsibilities? Not to mention the hassle of securing transportation, time off from work, and so forth.

Those aren't the only issues. Most patients and caregivers have trouble finding studies in their own community. I faced the same issue, which led me to talk to my Parkinson's doctor about studies he knew of. Then I discovered several tools that can help connect willing volunteers with the studies that need them. One of these is [Fox Trial Finder](#), where patients and those without the disease can get matched to local trials seeking someone specifically like them.

My husband and I have both registered on Fox Trial Finder and have participated in clinical trials we found — a deeply satisfying experience. Every person I know who has taken part in a trial echoes the same sense of empowerment that stems from contributing to a greater cause.

As a physician, I know the overall effect that comes from [participating in science toward improved therapies](#). I have immense gratitude for the thousands of volunteers who have come before me, whose contributions have led to treatments for a number of chronic diseases and everyday ailments. It is with the same gratitude that I look to the thousands of future volunteers who will continue the science through trial participation, fundraising, or advocacy, knowing that eventually their dedication, too, will result in better treatments and cures for the diseases that continue to impact countless lives.

Dr. Soania Mathur is a family physician outside of Toronto, Ontario. She serves on the Patient Council of [The Michael J. Fox Foundation for Parkinson's Research](#) and is the Parkinson's expert on [About.com](#). She also is the founder of [Designing A Cure Inc.](#), a platform to educate and inspire people with Parkinson's to take charge and live well with the disease. She has written two children's books about Parkinson's: [My Grandpa's Shaky Hands](#) and [Shaky Hands: A Kid's Guide to Parkinson's Disease](#) (publication forthcoming). She and her husband, Arun, a urologic surgeon, have three daughters (pictured above). You can follow Soania on [Twitter](#) and [Facebook](#).