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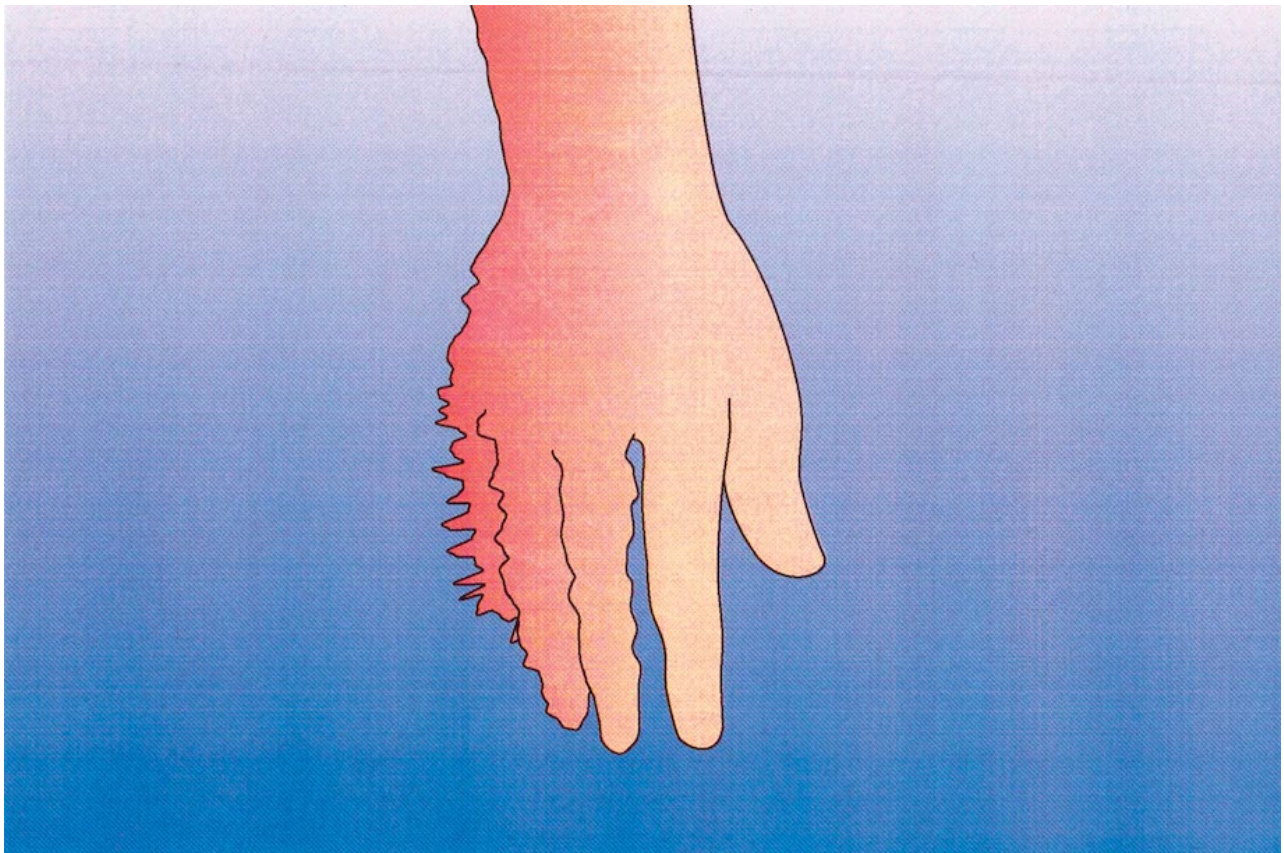
Democracy Dies in Darkness

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She was diagnosed with Parkinson's at 27. These were her warning signs.

People with early-onset Parkinson's disease face challenges different from those with traditional late-onset Parkinson's.



(Illustration by George Wylesol for The Washington Post)



By [Meeri Kim](#)

In her late 20s, [Soania Mathur](#) felt like she was in the prime of her life. She was happily married, pregnant with her first child and had recently completed her residency in family medicine. Soon after starting work at a private practice, she noticed a slight tremor in her right pinkie finger.

“It was intermittent at first, more of a nuisance than anything else,” said Mathur, now 54, a resident of Toronto. “But then as my pregnancy progressed, so did the tremor — so much that it became more constant and concerning.”

Her husband, also a physician, urged her to see a neurologist. After a clinical exam of her symptoms at the leading movement disorder clinic in Toronto, Mathur was diagnosed with Parkinson’s disease at the age of 27. Since there is no cure for Parkinson’s, she did her best to ignore the tremor as it worsened in her right hand, then her right foot and ultimately to the left side of her body over the next decade.

“By then, I had three daughters, a busy family practice, and the symptoms of my Parkinson’s were becoming overwhelming and difficult to manage,” she said. “My doctor at that time said, ‘You can either walk out of your office, or you can crawl out. It’s up to you, but something has to give.’”

Shortly after that visit, Mathur resigned from her medical practice and now dedicates her time to patient education, writing and Parkinson’s advocacy.

Mathur’s quick diagnosis is not the norm. Most younger patients are misdiagnosed, leading to delays in treatment and disease management. They also face challenges that are different from people who are diagnosed later in life.

Mathur and health-care experts said that more awareness of early-onset Parkinson’s is needed, since [some studies suggest](#) that its incidence is increasing, going against the common belief that the rise in Parkinson’s cases is due to an aging population.

Researchers are also trying to understand why some people, such as Mathur, are diagnosed earlier in life, and whether early-onset Parkinson’s may be a distinct disease entity.

Challenges of early-onset Parkinson’s disease



Soania Mathur, her husband, Arun Mathur, and their three daughters. (Arun Mathur)

Parkinson's disease is often thought of as an illness afflicting older people, typically those in their [early to mid-60s](#) or older. But [5 to 10 percent](#) of patients, like Mathur, develop the motor symptoms that are a hallmark of Parkinson's decades earlier.

People with early-onset [Parkinson's disease](#) — defined as an age of onset between 21 and 50 — are often misdiagnosed, leading to delays in appropriate treatment and management of the condition. One [study](#) found that patients under 45 had a much longer latency from disease onset to diagnosis — over two years compared with nine months for late-onset patients. Younger patients also required significantly more neurologist visits and clinical exams to receive the correct diagnosis.

"Doctors don't think about early-onset Parkinson's, and even neurologists who are experienced in movement disorders sometimes don't think about it," said [Bart Post](#), a movement disorder neurologist at the Radboud University Medical Center in the Netherlands. "A lot of patients will go to a physiotherapist or orthopedic surgeon, get surgery on their shoulder, hip or knee, and then later on it comes out that it was all Parkinson's."

Younger patients experience similar symptoms as their older counterparts — tremor, slowness of movement, limb stiffness — but with some notable differences. [Dystonia](#), a movement disorder characterized by sustained or intermittent muscle contractions, is more often seen in

early-onset Parkinson's disease, particularly after exercise. However, dementia, gait disturbances, gastrointestinal issues and loss of sense of smell are less frequent, less severe or delayed in [younger individuals](#).

Perhaps most intriguing is that the progression of the disease is much slower in early-onset patients.

Age is probably a factor for the stark clinical differences, with younger patients having better overall health. But the discrepancies have led to [speculation](#) that early-onset Parkinson's may be a distinct disease entity altogether.

"We typically tell our patients with late-onset Parkinson's disease that they'll be functional — as in, not confined to a wheelchair — for 15 years," said [Raja Mehanna](#), associate professor of neurology at McGovern Medical School at UTHealth Houston. "But if you are diagnosed at age 45, I don't expect you to be in a wheelchair at age 60. We're talking two to three more decades of being up and running."

For instance, Mathur was able to continue working as a family physician for 12 years following her diagnosis — without her colleagues and patients being any the wiser. Because of the stigma surrounding Parkinson's, she kept it a secret from everyone but family and close friends for fear of being judged as incompetent.

"I know plenty of people who have been let go from their positions once they've disclosed in the workplace, or been labeled as drunk or on drugs because of the symptoms that they have," she said.

Genetic susceptibility and environmental exposures



Soania Mathur, now 54, was diagnosed with Parkinson's disease at age 27. (Arun Mathur)

Why some people are diagnosed at such a young age is still being studied. Genetics plays a role, with early-onset patients being more likely to have a [mutation](#) associated with Parkinson's disease. Compared with the relatives of controls, the parents and siblings of early-onset patients possess an nearly [eightfold higher likelihood](#) of having Parkinson's. But still, about [80 percent](#) of early-onset cases — and 93 percent of late-onset cases — have no known cause.

Many experts suspect that Parkinson's disease arises from an interaction between genetic susceptibility and environmental exposures. For example, trichloroethylene (TCE), a chemical widely used to degrease metal, has been strongly linked to Parkinson's disease and was [banned by the Environmental Protection Agency](#) in December. A 2021 [study](#) in rats showed that exposure of rats to TCE induced the activation of LRRK2, an enzyme that when mutated is a genetic risk factor for Parkinson's disease.

One possibility is that people who develop early-onset Parkinson's have a genetic predisposition that, after being triggered by an environmental exposure, causes symptoms to manifest more quickly. In late-onset patients, the disease is thought to begin [up to 20 years](#) before the first motor symptoms.

"Say I have mutation type A, which makes me evolve full-blown symptoms within five years, versus mutation type B, which takes 20 years. Then, here I am having Parkinson's at 45 versus 60," Mehanna said. "But if this early-onset mutation is more aggressive, in a sense, then why is the evolution of the disease slower, not faster, afterward? We're still trying to figure it all out."

Certain lifestyle changes can reduce the risk of Parkinson's — in one [study](#), greater adherence to the [MIND diet](#) was associated with a higher age at disease onset, by up to 17 years — but more research is needed, particularly for early-onset disease.

"Definitely something we do not emphasize enough is how much you can do for your brain with your diet. And there are great studies that have shown people who engage in midlife exercise can reduce their risk of Parkinson's," said [Rebecca Gilbert](#), chief mission officer at the American Parkinson Disease Association. "There's no magic pill, and it's something you have to sustain over time."

Advocacy for Parkinson's patients



Soania Mathur has written two children's books, both meant to help kids understand the Parkinson's disease. (Arun Mathur)

After retiring from medicine, Mathur co-founded [PD Avengers](#), a patient-led global organization with a mission of ending Parkinson's disease, in 2021. Her symptoms have gotten worse, especially after going through menopause, she said.

But her three daughters give her strength, and her marriage has only gotten stronger post-diagnosis, Mathur said. Taking control of her physical and mental health with a nutritious diet and exercise, frequent medical visits and a strong social network have helped her thrive.

"You have to be an active participant in order to live well with this disease," Mathur said. "We don't have control over the diagnosis, but we can control how we face the diagnosis."

Do you have a question about human behavior or neuroscience?

Email BrainMatters@washpost.com and we may answer it in a future column.

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