

Revealing the faces and voices of Parkinson's disease

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Parkinson's is currently the second most common neurodegenerative disease in the United States—1 million people have it; 90,000 more are diagnosed every year. And it's working its way to No. 1. Yet few know

Parkinson's is a disease any of us—any person of any gender, race, ethnicity, or age—can get.

And many who have Parkinson's already keep its existence to themselves. Stigma, shame, and embarrassment add to the burden of other symptoms.

"I keep hearing the story over and over, how they're in hiding," says neurologist Hiral Shah, MD, of patients and other people she meets as medical director of the Parkinson Foundation's Center of Excellence at Columbia University.

She mentions young men and women afraid to talk about it at work because they don't want to lose their jobs. Athletes and professionals who don't want to lose their status among peers, clients, or patients. People who don't yet know what impact Parkinson's will have on their well-being and do not wish to encumber other members of their family.

Due to lack of awareness, it can take years for patients to get a diagnosis, especially if they are not white. In most cases, Parkinson's has by then already progressed to loss of movement control.

Parkinson's looks like all of us

The face of Parkinson's can be hard to see. It's as diverse as the population itself, something Shah realized everyone could benefit from understanding.

In addition to prolonged delay in diagnosis, Black and brown people are less likely to be seen by a neurologist or specialist, started on medication at diagnosis, referred to rehabilitation services, or get advanced treatment, research shows.

Shah, motivated by the absence of Black and brown people in neurology waiting rooms in Washington Heights, joined a local church outreach director on a journey to educate and empower people to get the health care they need.

Small-group sessions grew to large health fairs. Shah looked for a published guide to use as a handout. Her ideal was something that put the faces and voices of patients and their families and care partners at the center, using personal stories to educate and connect. She hoped to find a way to prepare people and address misconceptions—that Parkinson's disease is a death sentence or only white or old people can get it. Preconceived notions increase the challenge of timely and proper diagnosis.

Nothing of the kind existed.

A Parkinson's book is born

Determined to provide as much help as possible to as many as possible, she invited local African American and Black people who had Parkinson's disease and their care partners to a virtual meeting to create a pamphlet.

"The group's first meeting was an a-ha moment," recalls Shah. "It was the first time so many people living with Parkinson's were in a room with so many people who looked like them."

The camaraderie and comfort motivated everyone. Over nine months the pamphlet evolved into a complete, vibrant, illustrated book full of true stories of people connected to disease.

A paradigm shift in patient education

["PD Movers"](#) is already in its second printing (people in the Parkinson's community refer to the disease as PD). The book will be featured at this year's [World Parkinson Congress](#) and shared with participants in upcoming studies. Individuals and groups in California, Florida, and other states are reaching out for copies. Requests for presentations and speakers are also coming in. All are signs to Shah that people are more and more open to learning about and discussing Parkinson's.

Her enthusiasm and commitment are moving.

"This is a paradigm shift in terms of medical education: patient and care partner's voices front and center, as experts and teachers, with medical education layered on," says Shah. "The patients really are the experts. It can be hard to explain things in a sensitive way if you do not appreciate the sensitivities and the challenges. No one understands better than someone who has Parkinson's themselves."

And people love it. "We keep hearing that people are reading the book cover to cover because the stories pull them in," says Shah, with joy and some amazement. "Regardless of race or gender or ethnicity, this book speaks to everyone we share it with."

The impact in the community

Each community has its own challenges, but secrecy and hiding are common threads.

The book has inspired people to share their diagnosis with family and co-workers. A social worker in northern Manhattan says it helps patients and families feel encouraged. Black patients say it's the first time they've ever seen something for them, by them.

"This book allows people to not feel so alone and have hope and

purpose. It shows them it's OK to talk about what's going on for them," says Shah.

She hopes it will be a model for [health care](#) workers to effectively engage with their own community: "If we allow the patient and care partners to dictate the priorities and issues to address, we can do amazing work together and make truly meaningful impacts for their health."

Provided by Columbia University Irving Medical Center

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