

A Parkinson's diagnosis can come with some hope, experts say

December 31 2023, by Carole Tanzer Miller



Patients with Parkinson's disease call it "D-Day," the date they were told they had the incurable movement disorder.

Now, a new study suggests they might be getting the wrong message

when they get the news.

"A lot of people say 'I'm sorry, you have Parkinson's,'" said lead author Dr. Indu Subramanian, a movement disorders neurologist at UCLA Health in Los Angeles. "In fact, I think it's a very treatable disorder. Giving hope, giving the patient agency, is a critical part of the message."

So, she offered some advice to primary care doctors or community neurologists who face this sensitive task in the face of limited patient access to movement disorder specialists.

"The doctor should say, 'You have Parkinson's and these are the things that you can do to live better and here are some people who can support you and I'm part of your team,'" she advised in a UCLA news release.

About 1 million people in the United States live with Parkinson's, and the Parkinson's Foundation forecasts that number to reach 1.2 million by 2030. What's causing that rise is unknown. About 90,000 Americans a year are diagnosed with Parkinson's.

For the new study, published Dec. 21 in the journal [Parkinsonism & Related Disorders](#), researchers drew on [patients'](#) experiences to create a guidebook to help health care providers avoid pitfalls.

They noted that the words used in delivering a Parkinson's [diagnosis](#) can affect a patient long after, with some falling into hopelessness. As with dementia, suicide risk rises within six months of a Parkinson's diagnosis.

"I have a number [of] patients who have told me about things that have adversely affected them and it became clear that the way that the diagnosis of Parkinson's is given is something that is not done well," Subramanian said. "A lot of patients have especially hung their hat on 'Diagnosis Day—some refer to [it] as D Day—they remember it very

clearly."

Others reveal another concerning issue.

"I think there is a growing body of people—women, [young people](#) with Parkinson's, minoritized populations—who talk about how sometimes their diagnosis was missed and they didn't get the care that an older white man would get," she said.

The report urges doctors to deliver the diagnosis in person and to avoid euphemisms such as "honeymoon phase" to describe the early stages.

It also lists recommendations from co-authors who live with Parkinson's disease and from past patient surveys. These include having doctors provide patients tips on [self-care](#); new treatment options; and coping strategies and lifestyle choices.

The study said doctors may want to give the news over two appointments. Patients who came alone to the first can be urged to bring a relative or trusted friend to their second appointment.

"I hope this paper starts to create a dialogue and some much-needed change," Subramanian said.

More information: The National Institute on Aging has more about the causes, symptoms and treatments of [Parkinson's disease](#).

Indu Subramanian et al, Delivering the diagnosis of Parkinson's disease—setting the stage with hope and compassion, *Parkinsonism & Related Disorders* (2023). [DOI: 10.1016/j.parkreldis.2023.105926](https://doi.org/10.1016/j.parkreldis.2023.105926)

Copyright © 2023 [HealthDay](#). All rights reserved.

Citation: A Parkinson's diagnosis can come with some hope, experts say (2023, December 31)
retrieved 28 April 2024 from

<https://medicalxpress.com/news/2023-12-parkinson-diagnosis-experts.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.