

PARKINSON

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Why Expert Care Matters in Parkinson's



When the diagnosis is Parkinson's, does seeing a neurologist for care really make a difference? Yes, according to studies done over the last several years. Yet most people living with Parkinson's disease (PD) don't benefit from the special expertise of a neurologist. Today, some 60 percent of people with PD go to doctors who don't specialize in Parkinson's.

A study led by Allison Willis, MD, University of Pennsylvania, of more than 100,000 people has revealed that regular neurologist visits could help limit the impact of Parkinson's on their lives. People with PD who seek care from specialists are at a lower risk of complications from their Parkinson's: it lessens the risk of injuries from falls, nursing home placement, and hospitalization, and can even increase life expectancy.

Given that the number of people living with PD is projected to double in the next 15 years, the National Parkinson Foundation (NPF) is tackling the crucial question: What should ideal Parkinson's care look like?

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Building a Resilient Life after a Diagnosis of Parkinson's

"Resilience isn't about going it alone, and pulling yourself up by your boot straps..."

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NPF Awards Four Innovative Research Grants

The four grants target key scientific questions about how Parkinson's develops and how to optimize treatment.

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Get Moving this Fall with *Moving Day*®

This fall, NPF is introducing four new walk locations: Boston, Philadelphia, Los Angeles and Phoenix.

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"Currently, there aren't clearly established standards for treating people with Parkinson's in different circumstances. That's why, through our NPF Centers of Excellence network, we're working to identify the factors that are responsible for the best health outcomes associated with expert care. Our aim is to improve the level of Parkinson's care based upon this new knowledge," said Joyce Oberdorf, NPF's President and CEO.

Since 2009, when NPF launched the *Parkinson's Outcome's Project*, the world's leading neurologists have been collecting and analyzing detailed, real-life data on the care and treatment responses of many thousands of patients who receive their care at an NPF Center of Excellence. Piece by piece, this ongoing study is beginning to demonstrate what's working and what's not.

For instance, what's become clear is that adding mental health counseling to Parkinson's care is what makes the difference in patients with depression. This is an important finding, because nearly half of all people living with PD experience depression at some point in their lives and, not surprisingly, their depression typically goes unrecognized or undertreated.

The next important step is to create a protocol for Parkinson's care. Our goal is to discover how to empower neurologists to provide a care strategy for the 85 percent of patients who can be helped by a model for basic care and directly intervene for the 15 percent who need extra help, said Peter N. Schmidt, PhD, NPF's CIO and Vice President, Research and Professional Programs.

A basic set of guidelines like this would help address the current treatment gaps, informing doctors how to proceed under certain circumstances in order to improve health outcomes.

A recent analysis of Parkinson's data shows that adopting a protocol for Parkinson's care could save as many as 7,000 lives a year. A protocol would help ensure, for instance, that patients who seek care from a primary doctor would be referred to a neurologist for the treatment of their PD. "Some statistics suggest that the benefit of seeing a movement disorders neurologist could be double that of a general neurologist," Dr. Schmidt said.

Part of the value of neurologists, especially those who have pursued advanced training in movement disorders, is the

network surrounding them. "What we now know is that patients need a team of experienced and reliable advisors who they can reach out to when they need them as much as brilliant and compassionate neurologists who they can see at regular office visits," Dr. Schmidt said.

The ongoing benefits of expert care on how people feel in day-to-day life—from helping to delay the loss of independence to alleviating the psychological stress on caregivers—is undeniable. But the majority of people living with PD and their caregivers aren't informed about what Parkinson's experts consider to be good care, and, consequently, never seek that level of care. That's why NPF has made education and outreach top priorities.

As technology continues to create new possibilities, NPF wants to ensure that every advance in Parkinson's care reaches every patient who needs it, Dr. Schmidt said. "Today we have the knowledge to improve outcomes by 20 percent. It's time to harness that knowledge for everyone living with Parkinson's."

For more information about NPF's network of care, visit www.parkinson.org/search.

Download the Parkinson's Central App Today!



Parkinson's Central is a free app for people with Parkinson's and their caregivers.
www.parkinson.org/parkinsonscentral