

# How to Talk with Your Family About Parkinson's

## Family members want to understand and help. How do you begin to explain Parkinson's disease to them?

First, you must understand the disease yourself. The Parkinson's Foundation offers several options to help you and your family learn all about Parkinson's disease (PD), including warning signs, diagnosis, symptoms, treatment, living well and much more.

- » Explore **Parkinson.org** for information on any PD topic.
- » Call our **toll-free Helpline at 1-800-4PD-INFO (473-4636)**. Our PD Information Specialists can answer your questions, provide resources and offer referrals and support.
- » Order your free copy of our publication ***What You and Your Family Should Know***. Get it online (Parkinson.org/books) or by calling the Parkinson's Helpline.

Your family may have questions or fears about Parkinson's and genetics. For the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible precursors – not necessarily causes – to disease development.

People unfamiliar with Parkinson's often think of it only as a disorder of movement. It is important to help family understand that there are other facets of the disease, and these can have an even greater impact on quality of life than the motor symptoms. Emphasize that Parkinson's is an ongoing journey, one in which we need to face realities little by little, make adaptations, stay connected to the people and things that are important to us and live each day in the best way possible.

### **Engage your family to help them understand.**

- » **Include your family in care planning discussions.** Ask for their observations about how the person with Parkinson's is doing.
- » **Make specific, concrete requests** to your family members about how they can help you or the person with PD.
- » **If your family members live out of town,** refer them to the Parkinson's Foundation website and Helpline for information, referrals and answers to any questions.