

## How to Use This Guide

Follow this path to get the most from this guide:



### **Start with symptoms**

Go to *The Symptom Iceberg* to identify symptoms that affect daily life. This helps you recognize what may be getting in the way.



### **Identify your supports**

Go to *Build Your Support Team* to see who can help and how. Support may include your care team, family, friends and others.



### **Focus on daily activities**

Go to the sections on everyday activities. Start with what matters most right now, or read through them all.

Each section includes:

- Self-check
- Practical tips
- Tools and supports
- Care partner tips

The tips and tools in this guide come from the lived experience of people with Parkinson's and care partners, along with input from specialists. Not everything will fit your needs. For some changes, it may help to check in with your care team for individualized guidance, especially if something feels unsafe or involves added cost.

## The Symptom Iceberg

Parkinson's can cause many different symptoms. Some — such as tremor, stiffness or slowed movement — are easier to see and are often described as the tip of the iceberg. Others may be less visible but can still affect daily activities and quality of life. As Parkinson's progresses, symptoms may change or new symptoms may appear.

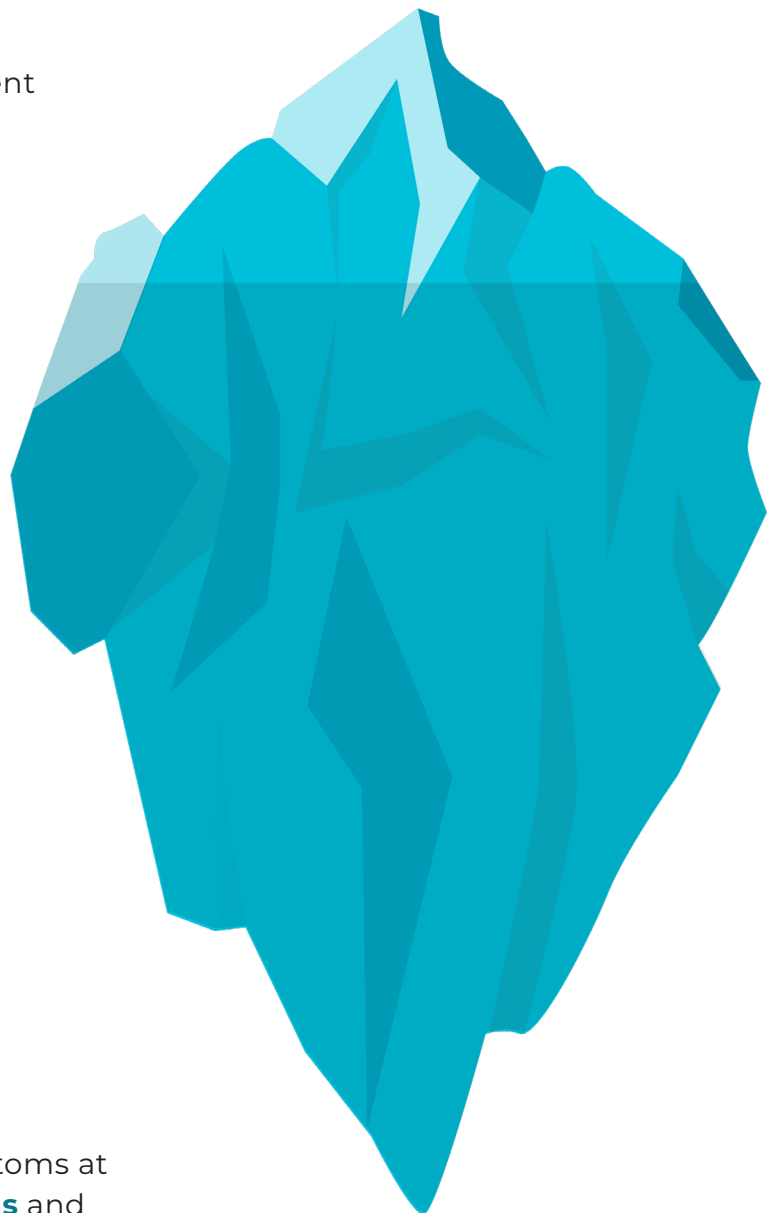
Learn about these symptoms to help you notice changes and identify topics to discuss with your care team.

### More visible symptoms

- Tremor, stiffness, slower movement
- Balance issues
- Walking changes

### Less visible symptoms

- Fatigue or low energy
- Sleep problems
- Anxiety, depression and apathy (low motivation)
- Changes in thinking or focus
- Constipation
- Bladder issues
- Pain or discomfort
- Swallowing changes
- Low blood pressure (dizziness when standing)
- Breathing issues



Learn more about Parkinson's symptoms at [Parkinson.org/MovementSymptoms](https://www.parkinson.org/MovementSymptoms) and [Parkinson.org/NonMovementSymptoms](https://www.parkinson.org/NonMovementSymptoms).

## Build Your Support Team

Building a strong support team is important at every stage of Parkinson's and can become even more essential as daily tasks become harder to manage on your own.

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### Work with your care team

Regular appointments with your Parkinson's care team can help monitor symptom changes, address daily challenges and explore treatment options.

#### Key actions

- Notice and track changes in symptoms. This is easier to do when you write things down as they happen or keep a daily log.
- Write down your top questions, concerns and goals before appointments.
- Share examples of how symptoms or other concerns affect daily activities. Some symptoms may not come up unless you mention them.
- Ask what options may help, including medication adjustment or referrals to specialists.

#### Medication reminder

Missing or delaying doses can affect how you feel, move and function during the day. Let your care team know if you miss doses or have trouble following your medication schedule.

Download the Steps to Prepare for a Parkinson's Appointment worksheet at [Parkinson.org/OptimizingCare](https://www.parkinson.org/OptimizingCare).

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### Include rehabilitation therapists

Physical, occupational and speech therapists are an important part of Parkinson's care. They can help improve daily function, support safety and adapt routines as needs change. They can also teach care partners safe ways to help.

#### Physical Therapists

Focus on improving movement and mobility. They may help with:

- Walking, balance and fall prevention
- Exercises to maintain strength and flexibility
- Strategies for freezing and turning
- Safe movement when getting in and out chairs, bed or car

### **Occupational Therapists**

Focus on everyday activities. They may help with:

- Daily activities such as bathing, dressing, and eating
- Simplifying routines and managing fatigue
- Cognitive skills such as attention, planning and completing tasks
- Identifying and using adaptive equipment, such as special utensils
- Making home modifications to improve safety and independence

### **Speech Therapists**

Focus on communication, swallowing and thinking changes. They may help with:

- Making speech clearer and easier to hear
- Ways to communicate more effectively
- Checking swallowing and suggesting safer ways to eat or drink
- Managing changes in memory and finding words

Ask your Parkinson's care team about referrals to physical, occupational or speech therapists with Parkinson's experience. For help finding specialists or local resources, contact the Parkinson's Foundation Helpline at **1-800-4PD-INFO (1-800-473-4636)** or **Helpline@Parkinson.org**.

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### **Expand your support circle**

Managing daily activities with Parkinson's often works best as a shared effort. Looking beyond your immediate household can help with transportation, daily tasks, emotional support and hands-on care as needs change. You are not alone.

Support may come from many places, including:

- Family members or care partners
- Friends, neighbors or community groups
- Support groups, including virtual options
- Personal care aides who provide paid, hands-on help with daily activities

See the Resources section at the end of this guide to explore more ways to build support.