




**NEWLY
DIAGNOSED**

**Building a Better Life
with Parkinson's**



**Newly
Diagnosed
Guide**



 **Parkinson's
Foundation**



Hello —

When I was diagnosed with Parkinson's disease, my world changed. I experienced many emotions, had lots of questions, and found myself concerned with thoughts about work, my family, and my future. In those first weeks, what was most important to me wasn't having all the answers but knowing that there was somewhere to go when I was ready to ask questions.

I found support through the Parkinson's Foundation website and Helpline. The Parkinson's Foundation is a trusted source of information and support when you need it. I want you to know that there is a tremendous community to support you, and that life goes on after a diagnosis. The most important thing to remember is that **YOU ARE NOT ALONE**.

The Parkinson's Foundation created this Newly Diagnosed Guide with direction from people with Parkinson's to ensure you and your family have the information you need now and that you know where to turn for more, when you are ready.

Sincerely,



Gregg Hummer,
Living with Parkinson's
Member of People with Parkinson's Advisory Council



We hope to hear from you.

Whether you are a person newly diagnosed with Parkinson's disease (PD) or your loved one was recently diagnosed, the Parkinson's Foundation is here for you when you are ready.

- **Visit** us online at Parkinson.org/NewlyDiagnosed.
- **Call** our Helpline at **1.800.4PD.INFO (1.800.473.4636)** for answers to your PD questions. In English and Español.
- **Connect** with your local Parkinson's Foundation chapter to find community events near you at Parkinson.org/Chapters.

About Parkinson's Disease

When you are first diagnosed with Parkinson's disease (PD), it can be overwhelming. Take time to understand how the disease can impact you and your family. Remember it is possible to live well with PD.

What is Parkinson's disease?

Parkinson's is a progressive neurological disorder that causes a gradual loss of brain cells that produce dopamine. In the U.S., nearly one million people live with PD and about 90,000 people are diagnosed each year. Parkinson's is typically diagnosed after 60, but people under 50 can also have PD, known as young-onset PD (YOPD).

What are early signs of Parkinson's?

- Tremor
- Small Handwriting
- Loss of Smell
- Trouble Sleeping
- Trouble Moving or Walking
- Constipation
- Soft or Low Voice
- Masked Face (less expressive)
- Dizziness or Fainting
- Stooping or Hunching Over

Do Parkinson's symptoms change over time?

Every person's experience with PD is unique, as is the rate of its progression. Symptoms progress over time and can be both movement-related or non-movement related. Many people with PD experience depression, anxiety and/or apathy. We encourage you to talk to your doctor about any symptoms that interfere with every day life.

What causes Parkinson's?

PD is caused by a combination of genes, environment and lifestyle influences. Genetics cause about 10 to 15% of all PD. In the other 85 to 90% of cases, the specific cause is unknown.

How is Parkinson's treated?

Individuals should work with their doctor, ideally a neurologist with experience treating PD, to tailor treatment to their symptoms and goals. Treatment options include medication, lifestyle adjustments and possibly surgery. **Exercise is essential to managing PD and can slow the progression of many PD symptoms.**



5 Steps to Live Better Today with Parkinson's Disease

These 5 steps — in any order that works for you — will help get you started on your journey to living well with Parkinson's.

1 Think about what is most important to you

Reflect on what brings you meaning and joy, then set goals to build those activities into your routine. Consider these examples:

- Spending time with family
- Planning trips with friends
- Spending time outdoors
- Pursuing hobbies

“Continue to do the things you love and know that you have amazing resources available to help you on this new journey.”

– **Diana**, spouse of person with Parkinson's

“We now have a whole network of people who understand. It may be hard at first, but connect with other people who are living with PD. You'll be glad you did.”

– **Karen**, spouse of person with Parkinson's

2 Find someone you can talk to

When you're ready, talk to someone. Consider reaching out to:

- Our Helpline to ask questions
- A family member or friend
- Another person with Parkinson's
- A counselor or spiritual advisor

Do not isolate yourself; you are not alone.

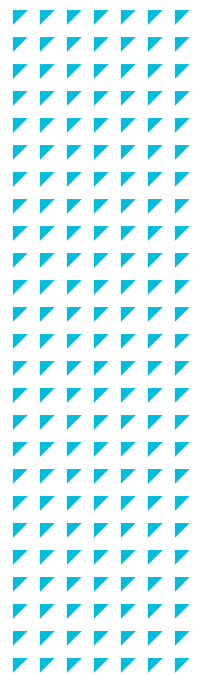
3 Create healthy habits

Even small changes can make a big difference.

- Choosing healthy foods may help medications work better and improve energy.
- Getting enough sleep can help your body and brain recharge.
- A self-care routine can help maintain your emotional health.

“I call diet, exercise and rest the 'Holy Trinity' of Parkinson's self-care. Most people do not realize how critical rest is for a person with PD.”

– **Mark**, person with Parkinson's



4 Be active in whatever way works best for you

Parkinson's Foundation research shows that exercise can improve many PD symptoms. Consider including stretching, aerobic and strength activities in your routine. Establishing early exercise habits is essential to overall disease management. Visit [Parkinson.org/Exercise](https://www.parkinson.org/Exercise) to learn more and find an exercise class near you. Get up, get out there, get active.

“Take a walk. Climb those stairs. Keep moving. Find activity everywhere you go.”
– **Dave**, person with Parkinson's

5 Find a doctor experienced in treating Parkinson's disease

“Go to the best specialist you can find. Talk with others for recommendations. Don't settle.”
– **André**, person with Parkinson's

Call our Helpline to find a neurologist in your area who is experienced in caring for people with Parkinson's. If possible, see a movement disorders specialist.

Was your loved one recently diagnosed with PD?
These 5 steps can help you get started, too. Remember, you are not alone.



Parkinson's Care Appointments

Making the most of your time with your doctors can help you live well with PD.

Your Care Team

Parkinson's is often best treated through a team approach, with you at the center of your team. Try to build a support team of loved ones, your PD doctor and any healthcare providers who treat specific symptoms of Parkinson's.

How to Prepare for an Appointment

Your care team will be able to provide better care and tailor treatment when you come prepared for appointments.

- Track your PD symptoms for one week leading up to your appointment.
- Think about which symptoms currently have the greatest impact on your daily life and at what time of day you experience these symptoms.
- Answer the question: "What do I most want my doctor to know about me?" Your answer does not have to focus only on PD and can include things like the relationships and activities that are most important to you.



What to Bring to an Appointment

The more information you can bring, the more meaningful the visit can be.

- List of current medications
- Notes about current symptoms
- List of questions for your doctor



Try to bring someone with you to every doctor's appointment to help take notes and ask questions.

Questions for Your Doctor

Based on your goals and priorities, think about what you want to discuss at your next doctor's visit. Ahead of your appointment, **write down your top questions**. Below are a few examples.

- How and when should I take my medication (before or with meals)? What are the potential side effects and what can I do to manage them?
- Besides taking medications, what specific therapies, exercises or lifestyle changes can help manage my PD?
- How can a physical therapist, occupational therapist, speech-language pathologist, and/or mental health counselor help me? Can you provide a referral?
- How often should I make appointments, and can I expect to see you at each visit?
- What is the best way to contact you between appointments? What symptoms or side effects should I report immediately?



At the end of your appointment, ask for any printed notes or instructions. If any information is unclear, ask for clarification.



Reach out to the Parkinson's Foundation Helpline for answers to your PD questions.

Call **1.800.4PD.INFO (1.800.473.4636)** or email **Helpline@Parkinson.org**





You are not alone.

You have control in how you handle and manage your Parkinson's. The Parkinson's Foundation is here for you, every step of the way.

Questions?

Call: [1.800.4PD.INFO \(1.800.473.4636\)](tel:18004PD.INFO)

Email: Helpline@parkinson.org

The **Parkinson's Foundation Helpline** is staffed by nurses, social workers and health educators. We welcome calls from people with Parkinson's, care partners, loved ones and healthcare professionals, in English and Spanish.

We answer thousands of calls and emails each year. **We are ready to help** and can provide:

- Current information about Parkinson's
- Referrals to healthcare professionals
- Educational and community resources, including local support groups and exercise classes

“ I was diagnosed 5 weeks ago and I was really scared. Then I called the Helpline. I'm so thankful there is a place I can call to get my questions answered. **”**

– **Lonni**, newly diagnosed, Helpline caller



About the Parkinson's Foundation

We make life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.

