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, children, and my retirement. 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.

The Parkinson’s Foundation is a trusted source of information and support when you need it. As Chair of the Parkinson’s Foundation People with Parkinson’s Advisory Council, I’m here to tell you there is a tremendous community to support you, and that life goes on after a diagnosis with Parkinson’s disease. The most important thing to know is that YOU ARE NOT ALONE.

With the guidance of people with Parkinson’s, including myself, the Parkinson’s Foundation created this Newly Diagnosed kit to ensure you have the information you need now and know where to turn for more.

This kit includes:

• Steps you can take to live well with this disease
• Important facts about Parkinson’s disease
• Key questions to bring up with your doctor
• How to connect with a trained information specialist via our Helpline and with others living with Parkinson’s through our online community

I also highly recommend the book, Living Your Best Life with Parkinson’s, when you are ready for even more information. Visit our website at Parkinson.org/NewlyDiagnosed or call our Helpline at 1.800.4PD.INFO (473.4636) to order your free book. Remember, you are not alone.

Sincerely,
Kelly Sweeney, Chair, People with Parkinson’s Advisory Council

We hope to hear from you. Whether you are a person newly diagnosed with Parkinson’s, a care partner, or a family member, the Parkinson’s Foundation is here for you.

John Lehr, CEO, Parkinson’s Foundation
Newly diagnosed with Parkinson's disease?

You are not alone.

1.800.4PD.INFO (473.4636)
When you are first diagnosed with Parkinson’s, it can be overwhelming. We are here to help.

Find newly diagnosed resources and connections through the Parkinson’s Foundation:

Talk with a PD information specialist by calling 1.800.4PD.INFO (473.4636). In English and Español. Open M-F from 9 am to 8 pm ET.

Connect with others living with Parkinson’s through our online community.

Access resources tailored to those newly diagnosed at Parkinson.org/NewlyDiagnosed.

Get your Parkinson’s questions answered today. Our Helpline information specialists are here to talk in English and Español.

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

– Lonni, newly diagnosed Helpline caller

Who will I be talking to when I call?
Compassionate, trained Parkinson’s disease (PD) information specialists.

The Helpline is a toll-free number for people with Parkinson’s, their families and friends to call after a diagnosis and through their Parkinson’s journey.

You can also email us at Helpline@parkinson.org.

You are not alone.
You have control in how you handle and manage Parkinson's. The Parkinson's Foundation is here for you, every step of the way.

Questions? Call our Helpline: 1.800.4PD.INFO (473.4636)

Staffed by Parkinson’s disease information specialists speaking both English and Spanish, the Helpline is free and here to support you — and your loved ones — in any way possible, including:

- Current information about Parkinson’s
- Referrals to healthcare professionals
- A wide variety of free publications
- Emotional support
- Community resources

Parkinson.org/NewlyDiagnosed
When you are first diagnosed with Parkinson’s, it can be overwhelming. Take time to understand how the disease can impact you physically and how it can impact your mood and emotions.

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

Based on what’s important to you, determine your personal goals and priorities. This will help you create an action plan to continue doing the things you love and care about most.

   “The mind is not separate from the body. It directly affects the quality of life for people with PD and their care partners.”

   – Gretchen, person with Parkinson’s diagnosed 2017

2. Find someone you can talk to

   “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, care partner, husband diagnosed 2002

3. Create healthy habits

   Choosing healthy foods may help your medications work better and improve your energy. Getting enough sleep can help your body and brain recharge. Small changes can make a big difference and creating a healthy routine may help you feel better. Learn from others through our online community, Parkinson.org/NewlyDiagnosed.

4. Be active in whatever way works best for you


   – Dave, person with Parkinson’s diagnosed 2004

5. Find a doctor who is an expert in Parkinson’s disease

   Call our Helpline to find expert care in your area. Look for a neurologist who treats people with Parkinson’s, and when possible, a movement disorder specialist.

   “Go to the best specialist you can find. Talk with others for recommendations. Don’t settle.”

   – Andréé, person with Parkinson’s diagnosed 2007

What’s one step you can take NOW that will help you the most?
When you are first diagnosed with Parkinson’s, it can be overwhelming. **Take time to understand** how the disease can impact you physically and how it can impact your mood and emotions.

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**
   Based on what’s important to you, determine your personal goals and priorities. This will help you create an action plan to continue doing the things you love and care about most.
   
   “The mind is not separate from the body. It directly affects the quality of life for people with PD and their care partners.”
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2. **Find someone you can talk to**
   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, care partner, husband diagnosed 2002

3. **Create healthy habits**
   Choosing healthy foods may help your medications work better and improve your energy. Getting enough sleep can help your body and brain recharge. Small changes can make a big difference and creating a healthy routine may help you feel better. Learn from others through our online community, Parkinson.org/NewlyDiagnosed.

4. **Be active in whatever way works best for you**
   It’s a fact: exercise can improve your quality of life. Visit our website, Parkinson.org/NewlyDiagnosed, to learn about the importance of exercise and find a Moving Day event near you. Get up, get out there, get active.
   
   – Dave, person with Parkinson’s diagnosed 2004

5. **Find a doctor who is an expert in Parkinson’s disease**
   Call our Helpline to find expert care in your area. Look for a neurologist who treats people with Parkinson’s, and when possible, a movement disorder specialist.
   
   “Go to the best specialist you can find. Talk with others for recommendations. Don’t settle.”
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- Emotional support
- Community resources

Parkinson.org/NewlyDiagnosed
Key Questions For Your Doctor’s Visit

Below is a list of recommended questions to help you prepare for your upcoming doctor’s visit. Based on your personal priorities, think ahead of time about what questions you want to discuss with your doctor.

1. How quickly does Parkinson's disease usually progress and what will change over time?
2. How is Parkinson’s treated? Are there ways I can slow the progression of my Parkinson’s?
3. What test(s) or tools did you use to determine my diagnosis?
4. How often should I make appointments, and should I expect to see you or another staff member at each visit?
5. What other specialists or healthcare professionals should help me manage my care?
6. What symptoms or side effects should I report immediately?
7. How and when should I take my medication? Should I take the medicine before, with, or between meals?
8. What are the potential side effects of medication? Is there anything I can do to avoid or manage the side effects that I might experience?
9. Besides taking medications, what else can I do to manage my Parkinson’s disease? Are there specific therapies, exercises, or lifestyle changes that can help?
10. Are there any clinical trials I could participate in?

Get more of your questions answered today:

Parkinson.org/NewlyDiagnosed
Helpline 1-800-4PD-INFO (473-4636)
About Parkinson’s Disease

**What is Parkinson’s disease?**
Parkinson’s disease (PD) is a neurodegenerative, progressive disorder that affects predominately dopamine-producing neurons in a specific area of the brain called substantia nigra.

**How common is PD?**
Nearly one million Americans and 10 million people worldwide live with PD, with approximately 60,000 people in the U.S. diagnosed with PD each year. It is the second most common neurodegenerative condition after Alzheimer’s. The number of people with PD will increase substantially in the next 20 years due to the aging of the population.

**What are the symptoms of PD?**
Symptoms generally develop slowly over years. The progression is often different from one person to another. People with PD may experience:
- Tremor, mainly at rest and described as pill rolling tremor in hands
- Slowness of movements (bradykinesia)
- Limb rigidity
- Gait and balance problems

In addition to movement-related (“motor”) symptoms, Parkinson’s symptoms may be unrelated to movement (“non-motor”), such as apathy, depression, constipation, sleep behavior disorders, loss of sense of smell and cognitive impairment.

**Who does PD affect?**
Getting older is the biggest factor for PD with most people diagnosed in their 60s. In rare cases, some people will develop PD before age 50, known as young-onset PD. Men are 1.5 times more likely to have PD than women. Directly inheriting the disease is quite rare. Only about 10 to 15 percent of all cases of Parkinson’s are thought to be genetic forms of the disease. In the other 85 to 90 percent of cases, the cause is unknown.

**How is PD diagnosed?**
There is no diagnostic test for PD. Physicians rely on a combination of clinical exams and tests evaluating symptoms. Often, a Parkinson’s diagnosis is first made by a primary care physician. Many people seek an additional opinion from a movement disorder specialist, a neurologist with experience and specific training in the assessment and treatment of PD.

**How is Parkinson’s treated?**
It is possible to have a good to great quality of life with PD. Treatment for each person with Parkinson’s is based on his or her symptoms, and may include medication and, later, surgical therapy. Other treatments include lifestyle modifications, like getting more rest and exercise. There are many medications available to treat Parkinson’s symptoms, although none yet that reverse the effects of the disease.

**About the Parkinson’s Foundation**
The Parkinson’s Foundation makes 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.