

THE IMPORTANCE OF TACKLING PD WITH A TEAM APPROACH

A Parkinson's disease (PD) diagnosis can be challenging — especially when trying to navigate it on your own. For most, symptoms change over time, and having multiple people on your team with different areas of expertise will help you make informed decisions and feel supported along the way.

How to Build the Best Parkinson's Care Team

The first member of your team will most likely be your primary care physician who made your original PD diagnosis and/or the person who provides your current treatment.

It is best for people with PD to be treated by a neurologist as they have unique training in brain diseases and can understand your diagnosis on a deeper level. If possible, a neurologist who specializes in PD and other related disorders — referred to as a Movement Disorders Specialist — will be a great addition to your team. Their training allows them to have a greater level of expertise in managing complex symptoms and treatments of this disease. They are also more likely to be familiar with available clinical trials for PD if you are interested in participating.

Who Else Should be on My Care Team?

It's important to remember that everyone's needs with PD are different, and the members of your team may change over time. With help from your

neurologist or Movement Disorders Specialist, you can select members of your support system based on your current symptoms and treatment goals.

For example, building strength, walking, and improving balance are common goals for people with PD, therefore a physical therapist might be a great addition to your team.

Even if you do not experience motor challenges now, it is wise to be evaluated by a physical therapist periodically to address any issues before they become worse. Your neurologist can help connect you to physical therapy services, or contact the **APDA National Rehabilitation Resource Center at 888-606-1688**.

Depending on your needs, you might also consider an occupational therapist who can help you better manage the tasks of daily living, a speech and language pathologist who can help you strengthen your voice, a registered dietician who can help you build a diet that works for your particular health and medication needs, a social worker who can help you navigate the health care system and provide support, and others.



Having multiple people on your team with different areas of expertise will help you make informed decisions and feel supported along the way.

To learn more about building a care team that's right for you, visit
apdaparkinson.org/CareTeam

A MESSAGE FROM OUR PRESIDENT & CEO



Dear Friend,

As we begin a new year, I wanted to tell you just how thankful I am for your steadfast support. Because of your loyal friendship, we can provide hope and strength to those impacted by PD.

In this issue of *Insights*, we talk about the importance of building a strong care team. This may seem like an overwhelming task, especially if you or a loved one was recently diagnosed, so we have included some basic guidelines on how to begin building the best care team with knowledgeable doctors and specialists.

I am so proud of the work we are doing to provide life-changing support to the PD community — and I am excited to maintain this positive momentum in the year to come. Thank you, from the bottom of my heart, for your generosity.

Wishing you a happy and healthy year ahead,

A handwritten signature in black ink that reads "Leslie A. Chambers". The signature is written in a cursive, flowing style.

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

ARE YOU WORRIED ABOUT COGNITIVE CHANGES?

Changes in cognition can unfortunately be a common non-motor symptom of Parkinson's disease (PD). Mild cognitive impairment (MCI) is an early stage of cognitive difficulty that does not interfere with independent living, yet the symptoms can still have an impact of your life – affecting your confidence and abilities to perform complex cognitive activities. People with PD and MCI may be aware that their thinking is not what it once was or notice they cannot multi-task like they once did. They may notice that math problems that they once were able to solve in their head, now require pen and paper, or that they forget names or words more easily.



During a recent episode of Dr. Gilbert Hosts we spoke with Dr. Jasdeep S. Hundal who is an expert in MCI. Dr. Hundal explained the basics of MCI and talked about restorative and compensatory cognitive rehabilitation, diet, and exercise as ways to manage and improve MCI, as well as clinical trials for MCI, and much more. *We encourage you to visit APDA's YouTube channel and view the Dr. Gilbert Hosts playlist to watch the episode. You can also read our MCI factsheet at apdaparkinson.org/publications for more in-depth information on this topic.*

There are no medications currently approved for MCI in PD, but as Dr. Hundal explained, exercise can improve brain functioning and overall cognition, pointing out that the duration (30-45 minutes or more), intensity (break a sweat), and frequency of exercise (three to four days per week) make a difference. There are also simple lifestyle modifications that can help minimize effects of MCI on your activities:

- ▶ Make sure that you are doing only one cognitive task at a time
- ▶ Do not attempt complicated tasks when you are tired or not performing at your best
- ▶ Keep to-do lists
- ▶ Keep written instructions for tasks that require multiple steps
- ▶ Keep household items in the same place every day

Cognitive rehabilitation, often performed by an occupational therapist, can introduce you to strategies that address your specific needs.

It is important to remember that some cognitive changes are just a part of normal aging that we all are likely to experience at some point, but if you are concerned about MCI in conjunction with PD, be sure to talk to your neurologist about your concerns.

WHAT'S HAPPENING AT APDA



Save the date!

Mark your calendar for February 15-16 for the **APDA Virtual Parkinson's Conference: Educate, Empower, Engage**. It will be a fantastic two days, chock full of topics that matter most to you and your loved ones. We're excited to showcase great info, presenters, and more! **Check apdaparkinson.org for details!**



Recursos en Español

APDA is adding more Spanish-language programming and resources. You can watch all of our Spanish webinars and broadcasts by checking out the Spanish playlist on our YouTube channel. **Keep an eye on our Virtual Events Calendar to catch new Spanish programs live (apdaparkinson.org/events).**



A New APDA Information & Referral (I&R) Center

The APDA I&R Center at Grady/Morehouse School of Medicine is the latest addition to APDA's nationwide network of resources. The Center will serve the greater Atlanta area (and beyond) with a special focus on reaching and supporting the African American community. For assistance and information, please contact 470-791-4332 or BGadson@msm.edu.

YEAR-ROUND SUPPORT WITH A MONTHLY GIFT

PD doesn't quit. It doesn't take a break on weekends, after hours, or during the holidays. But neither does APDA.

And with your help as a monthly supporter, we can be there wherever and whenever individuals and families facing this chronic disease need us. You can make a difference every day and all year long when you join our dedicated circle of monthly donors. Together, we can provide the support, education, and research to help everyone impacted by PD live with hope.

Best of all, its quick and easy to sign up.

Visit apdaparkinson.org/sustainer today to start making an impact each month.



QUESTIONS TO ASK YOUR DOCTOR ABOUT PARKINSON'S DISEASE

Your doctor just told you that you have Parkinson's disease (PD). No matter what emotions you're experiencing, there is a very good chance you have no idea what to do next. APDA has compiled a list of questions to help guide those first conversations with your doctor.

Q What caused my Parkinson's disease?

A For most people, there is not one specific cause that can be identified. This can be frustrating, but your energy is better spent looking forward and learning how to best navigate your new diagnosis.

Q Am I going to be prescribed PD medications?

A There are many medications available to treat the motor and non-motor symptoms of PD. Your medication dosage and/or the types of medications you take will likely change over time.

Q Is diet important? If so, what should I eat or avoid eating?

A Yes! In addition to exercise, diet is a major influence on your health that is under your control. Vegetables, whole grains, legumes, olive oil, and low-fat proteins like fish and poultry are among the recommended foods.

To see the full list of questions APDA has compiled to ask your doctor, visit apdaparkinson.org/PDQuestions.



ASK THE DOCTOR

with Dr. Rebecca Gilbert



Q. My friend was recently diagnosed with Parkinson's, but I am not convinced that she has it. She was prescribed carbidopa/levodopa. Is there any harm in taking this medication if you do not have PD?

It is not harmful to take carbidopa/levodopa if you do not have PD. Having said that, levodopa is given to treat symptoms. Sometimes it is not clear if the symptoms are due to PD or not, so on occasion, it may be given to someone who ends up not having Parkinson's. If it is given for symptoms and does not help to improve symptoms, talk with the prescribing doctor about potentially stopping it.

Q: No matter how much I exercise my legs, they don't get any stronger. They seem to just get weaker. What am I doing wrong?

It can be frustrating when you hear about how important exercise is and how much good it can do you – but then you don't seem to be reaping the benefits. You may need to alter the frequency and/or types of exercise you are doing in order to

build muscle strength. I would ask your neurologist for a referral to a physical therapist. You can explain your issue to the physical therapist and he/she can come up with an exercise regimen that meets your needs and goals. Please note, Parkinson's disease should not cause actual weakness in your legs, but rather slowness and stiffness of movement. If your legs are truly weak, which your neurologist can assess, he/she may want to order other tests to rule out causes of weak legs.

Q: My dad has PD and had COVID about three weeks ago. Since then, he has been extremely fatigued. Is this related to COVID? To PD? Will he recover?

Fatigue is a common symptom of COVID and can linger longer than other COVID symptoms. Fatigue is also a common non-motor symptom of Parkinson's. Additionally, people with Parkinson's are often less medically resilient when they experience a health problem, like an infection with COVID. So, the combination of COVID and PD may be

conspiring to make your dad's course more complicated and drawn out. I would expect him to slowly recover to his baseline, although I don't know the time course. I would talk with his neurologist about this setback and if any changes in his PD medications may be helpful for him as he recovers.

Q: I was just diagnosed with mild PD and was told that I do not need to take a medicine. Is there any disadvantage to me if I am not taking medicine now?

In general, there is no downside to postponing PD medications if your PD symptoms are not affecting function. However, you want to maximize your ability to exercise, which research suggests may be neuroprotective. So please discuss with your neurologist if he/she thinks that you are able to exercise effectively and up to your maximal capabilities while unmedicated. If you are, then delaying the start of medication makes sense.

Dr. Rebecca Gilbert is the Chief Scientific Officer at APDA. She oversees APDA's research portfolio in conjunction with APDA's Scientific Advisory Board. She also provides medical and clinical expertise to support APDA programming as well as print and web content.



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For more information, or to learn about the many ways you can support APDA, please call (800) 223-2732 or visit [apdaparkinson.org/Renew](https://www.apdaparkinson.org/Renew).