

I WAS JUST DIAGNOSED WITH PARKINSON'S DISEASE ... NOW WHAT?

Confusion. Anger. Fear. If you or someone you love has been diagnosed with Parkinson's disease (PD), you may be overwhelmed by emotions. The American Parkinson Disease Association (APDA) is here to help.

With a nationwide network dedicated to fighting PD, APDA can help connect you and your loved ones to resources, education, and experts like Dr. Stephanie Bissonnette, a Movement Disorders Specialist at Boston Medical Center. In the wake of a PD diagnosis, Dr. Bissonnette shares the top six things you need to know.

1 Take a deep breath.

"Try to relax as best as you can," explains Dr. Bissonnette. "PD is definitely a new challenge and something that is going to change the way you live your life." But Dr. Bissonnette says that a concrete diagnosis is the first step towards the right medical support and education that can ensure you live well with this disease.

2 Educate yourself.

Social media is a great way to find people who understand what you're going through — but when you're looking for real facts about PD, use reputable websites like [apdaparkinson.org](https://www.apdaparkinson.org).

3 See a Movement Disorder Specialist.

Movement Disorder Specialists like Dr. Bissonnette have had years of training to learn how to best recognize and treat

PD. They also stay up to date on the latest treatments and trials. Contact APDA if you need help finding a specialist.

4 Get moving.

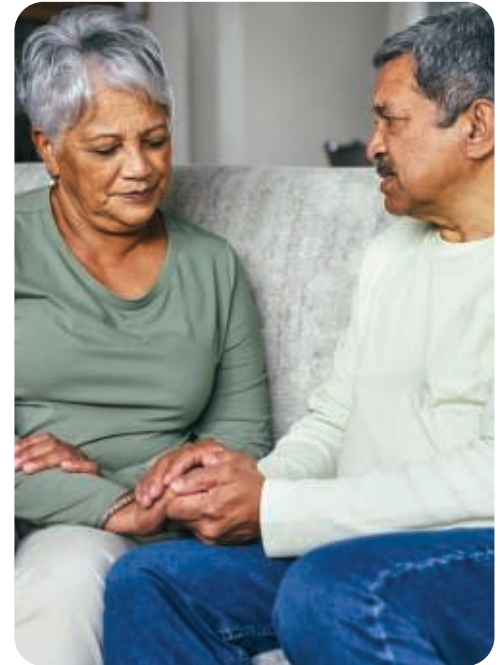
"By far the most important thing you can do from this point forward is to start moving," says Dr. Bissonnette. Exercise not only helps control PD symptoms, but it may also slow down the disease progression. Dr. Bissonnette recommends a combination of endurance, strength, and balance training as well as stretching. Wondering how to get started? Talk to your doctor, start small, and do something you enjoy. APDA's *Be Active & Beyond* booklet is a helpful resource. Learn more at [apdaparkinson.org/beactive](https://www.apdaparkinson.org/beactive).

5 Consider your diet.

Dr. Bissonnette explains that a healthy, Mediterranean diet is the best diet for the brain and is likely the best diet for PD. The Mediterranean diet features lots of vegetables, fruits, whole grains, legumes, low-fat proteins, and olive oil.

6 It takes a team.

Most importantly, if you or a loved one is diagnosed with PD, you don't have to go at it alone. "Over time, you're going to actually put together a healthcare team," says Dr. Bissonnette. This team may include a Movement Disorder Specialist, rehabilitation services, psychosocial support, exercise instructors, and a primary care doctor, among others.



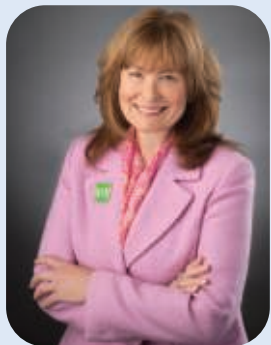
Need support for yourself or someone you know with PD?

Find the help you need at [apdaparkinson.org](https://www.apdaparkinson.org) or call us at **800-223-2732**.

A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friend,

Over the last six decades, we've invested in research to help unlock the mysteries of PD. While there are still many challenges to solve, we know one thing for sure: your generosity makes this important work possible.



As a supporter, you play an integral role in our mission to help people with PD live life to the fullest in the face of this chronic, neurological disorder. Not only are we making advances in research, we're also helping to raise awareness and provide outstanding patient services.

Thanks to you, there are people with PD across the United States who are looking toward the future with optimism. As you read this issue of *APDA Insights*, you will see the impact of your support. With you by our side, the PD community is stronger than ever.

With sincerest gratitude,



Leslie A. Chambers
President & CEO
American Parkinson Disease Association

MAKE IT A SUMMER TO REMEMBER

Two years ago, our world was turned upside down by COVID-19. This summer, we're settling into a new normal, but it still can be difficult to navigate social situations — and while some are embracing fewer restrictions, some are still hesitant or confused about how to proceed. Should you sit inside a restaurant or eat



outside on the patio? Attend a group fitness class or go for a swim in the lake?

For people with PD and other health issues, knowing the “right” answer can be tricky. That's why it's important to talk to your doctor about your concerns. Ultimately, it's essential to see the people you love and do the things you enjoy even if you may need to take additional precautions such as wearing a mask or gathering outdoors.

Socialize to thrive.

Even before COVID-19, fatigue, speech difficulties, and other symptoms often impacted the social lives of people with PD. But continuing to socialize despite these challenges can help boost your mental health and decrease feelings of depression and isolation. We know that human interaction is one of the essential components of well-being. So beyond maintaining your current friendships, consider expanding your network by participating in an APDA event or reaching out to your local Chapter or Information & Referral (I&R) Center.

Get out there and get creative.

Summertime goes by quickly, so we must make the most of it. When you're planning activities, think about:

- ▶ **Making your socializing “active”.** From meeting a friend for a walk to doing an aqua aerobics class, there are so many ways to stay active (and social).
- ▶ **Taking in the scenery.** Whether you like birdwatching or seeing an outdoor performance, expand your mind by exploring new horizons.
- ▶ **Eating the rainbow.** Summertime means fresh, colorful fruits and vegetables. Get your friends together for strawberry picking or just enjoy some delicious fruit salad.
- ▶ **Resting easy.** For people with PD, staying hydrated and resting when necessary are also incredibly important. So when you're on the go, bring extra water along — and if you start feeling tired, take a break or head back home.

Need more ideas about how to make it a summer to remember? Find your local APDA Chapter by visiting apdaparkinson.org/community for resources and support.

THE BENEFITS OF WORKING WITH A PHYSICAL THERAPIST

Exercise and movement are so important for people with PD — but for those who have never exercised before, or have limited mobility or balance issues, they might not know how to get started.

No matter your situation, a great way to begin is to make an appointment with a Physical Therapist (PT), ideally one who is knowledgeable about PD. Physical therapy experts from the APDA National Rehabilitation Resource Center at Boston University share their thoughts about the benefits of working with a PT:

Q: How can someone with PD benefit from physical therapy?

A: A person with PD may experience changes in their walking and/or balance, or feel they are moving slower or feel more stiffness. A Physical Therapist evaluates a person's walking, balance, posture, strength, slowness, and stiffness and develops an exercise program that will support each person's specific needs.

Q: When should someone with PD seek help from a PT?

A: After someone is diagnosed with Parkinson's, it is very helpful to be seen by a PT right away for an evaluation. The PT will design an exercise program with the goal of preventing or slowing the progression of symptoms. We recommend visiting a PT at least once a year for a "check-up" to make modifications to the exercise program to optimize mobility and to adjust for any changes in their walking, balance, or general mobility.

Q: How can I find a PT in my area who knows how to work with people with PD?

A: Contact your neurologist's office or local hospital outpatient Physical Therapy department to see if they have PTs who specialize in treating people with PD or who are board certified in Neurologic Physical Therapy.

*For more information and to get help finding physical therapy resources near you, contact the APDA National Rehabilitation Resource Center at rehab@bu.edu or at 888-606-1688. You can also view our webinar series *Let's Keep Moving With APDA* presented by PT experts from Boston University (visit the APDA YouTube channel and look for the *Let's Keep Moving* playlist.)*

WHAT'S HAPPENING AT APDA



Resources in Simplified Chinese.

We are excited to announce that we have translated our *Parkinson's Disease Handbook* and our *Medical ID card* into Simplified Chinese. You can download the *Handbook* and *Medical ID card* for free (along with any of our other publications in English and Spanish) at apdaparkinson.org/publications.



Getting Social.

Follow APDA on social media for the latest PD information and inspiration! Get the scoop on upcoming programs, get access to the latest PD information and announcements, and see the #UnshakeableSpirit of the PD community through the personal stories we share. Look for *APDA Parkinsons* on Facebook, Instagram, and Twitter!



Walk With Us!

Exercise is important for the PD community, so come on out and join us at an APDA Optimism Walk! The events kicked off this spring and don't wrap up until the end of October, so check out the schedule at apdaparkinson.org/optimism-walks and see if there's a Walk near you!

Thank you to our Optimism Walk National Sponsors, Amneal and Avion Pharmaceuticals.





“ASK THE DOCTOR”

with Dr. Rebecca Gilbert



Q. My husband has PD and he is on carbidopa/levodopa 10/100 taken three times a day. The medication makes him very nauseous. Is there anything that we can do?

A. Carbidopa is contained in the pill with levodopa primarily to control the nausea side effect of levodopa. There are different formulations of carbidopa/levodopa. The 10/100 formulation contains 10mg of carbidopa and 100mg of levodopa. The 25/100 formulation contains 25mg of carbidopa and 100mg of levodopa.

If your husband's doctor would consider changing the formulation from 10/100 to 25/100, that would increase the amount of carbidopa in the pill and could potentially help to decrease the nausea that the levodopa causes. Make sure the doctor is aware of the nausea issue so he/she can make any necessary adjustments.

In addition, I would recommend taking the carbidopa/levodopa (even the 25/100 formulation) with food such as crackers. Ginger ale can help as well. If these tricks are not enough, an anti-nausea medication such as Zofran may help (be careful, because there are anti-nausea medications that are contraindicated in PD and should not be used for this purpose).

Q. I'm 61 years old and I've had Parkinson's for 15 years. Every day around the same time I get very depressed. Why is that, and what can I do?

A. This sounds like a non-motor OFF issue. After several years of living with Parkinson's, it is common that a dose of carbidopa/levodopa does not last as long as it used to. In between doses, there is a dip in the levels of dopamine in the brain and symptoms of PD can return. For most people, the dip in dopamine leads to motor symptoms — slowness, stiffness, and balance problems. For other people however, the symptoms that occur are non-motor — depression, anxiety, pain. For you, it sounds like at a particular time of day, your dopamine levels are low and you get depressed.

There are a number of ways to deal with this. The simplest is to talk with your doctor about adjusting the timing of your doses to better cover the time of day that you feel depressed. You can read more about ways to deal with non-motor OFF episodes in our *Communicating About OFF Episodes & Dyskinesias With Your Doctor* booklet by visiting apdaparkinson.org/publications.

Q. I am a care partner for a wonderful lady who has been diagnosed with PD. She has been having a lot of urinary problems lately in which she feels like she constantly has to go to the bathroom, even if she's just gone. Is there anything she can do to alleviate this problem?

A. Urinary problems are very common in Parkinson's and many experience what you are describing — an urgency to go to the bathroom even if it seems like the bladder was just emptied. The first step would be to visit the urologist who can perform an ultrasound to determine if there is urine left in the bladder after the person with PD urinates. It could be that she is only sensing that there is urine left, but she actually empties her bladder completely. There are medications to decrease this annoying sensation if this is warranted. You may also want to check out our *Understanding Bladder Symptoms* in PD fact sheet at apdaparkinson.org/publications.

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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apda@apdaparkinson.org | apdaparkinson.org

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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.