

MASK THE DOCTOR"

with Dr. Rebecca Gilbert

Q. My husband was diagnosed with Parkinson's disease (PD) and mild cognitive impairment and his neurologist prescribed donepezil (brand name Aricept), but it says on the package insert that this medication is for Alzheimer's disease. Should he be taking it?

A. While it is true that donepezil is approved for Alzheimer's disease, it is sometimes used by neurologists off-label to treat cognitive issues of all types. (It is legal and fairly common for doctors to prescribe a medication off-label.) It is likely that his neurologist felt there was a strong enough chance that donepezil could help your husband and therefore prescribed it for him.

If you still have concerns or questions about him taking it, you should talk directly to his doctor. It is always wise to understand the medications you're taking and why you are taking them.

Q. Is lower back pain a symptom of PD?

A. Lower back pain is extremely common in the general population, so it is hard to tease out whether it is even

more common among people with PD. It probably is, since rigidity, or stiffness of the muscles — which is a common symptom among people with PD — can exacerbate pain.

As always, make sure any new or worsening symptom, including lower back pain, is evaluated by your physician to make sure that any serious medical condition is ruled out first. The focus can then turn to reducing pain and improving quality of life. There are multiple strategies to manage lower back pain in the context of PD. Exercise and physical therapy are usually the first lines of treatment to try and often can result in a noticeable improvement.

If the pain is exacerbated by the rigidity of PD, it could potentially fluctuate with medication timing and therefore may be able to be treated by adjusting the timing and dosage of medications, so be sure to talk with your doctor about this possibility.

Q. My wife has had PD for many years. She is currently not able to swallow her medications and often spits them out. What can we do?

A. The first step would be a swallow study performed by a speech pathologist to see what her swallowing function looks like. Since she may also be having trouble swallowing certain foods, a swallow study will help determine what consistencies of foods your wife can safely eat.

Also, you should be aware that depending on which medications she is supposed to take, her doctors can prescribe formulations that are easier to swallow or can be crushed. Regular carbidopa/levodopa (brand name Sinemet) can be crushed and mixed with food. Carbidopa/levodopa also comes in a formulation called Parcopa that dissolves under the tongue. The extended-release formulation Rytary is designed as different sized beads inside a capsule. The capsule can be opened, and the beads can be mixed with food such as apple sauce, and they retain their long-acting status.

Dr. Rebecca Gilbert is the Chief Mission 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.



Published quarterly by the American Parkinson Disease Association, P.O. Box 750, Merrifield, VA 22116 (800) 223-2732 Chairman of the Board of Directors: Bernard F. Battista; Chairman of the Scientific Advisory Board: David G. Standaert, MD, PhD; President & CEO: Leslie A. Chambers

American Parkinson Disease Association is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. apda@apdaparkinson.org | apdaparkinson.org

AMERICAN PARKINSON DISEASE ASSOCIATION

INSIGHTS

MAKING HOPE POSSIBLE: APDA FUNDS INNOVATIVE RESEARCH

From genetic causes of PD to the neurobiology of cognitive dysfunction, APDA-funded researchers begin new work.

The American Parkinson Disease
Association (APDA) recently awarded \$2.6
million to support innovative Parkinson's
disease (PD) research for the 2024-2025
funding year. Exciting projects will tackle
a wide range of key areas of PD research
including new genetic causes of PD, the
neurobiology of cognitive dysfunction in
PD, and the regulation of alpha-synuclein
production in the nerve cell. Projects will
also tackle the underpinnings of walking
dysfunction in PD, the biology behind deep
brain stimulation, and more.

Each year, APDA's Scientific
Advisory Board diligently and
methodically reviews grant proposals
to determine the most promising
and cutting-edge research to fund. It
is a challenging process, approached
with the utmost care.

66 We have an incredible responsibility to the Parkinson's community to choose the research that shows the most promise for real progress. ?? "Additionally, we have a responsibility to our donors to use their generous support wisely, making sure every dollar counts in the search for answers," states Leslie A. Chambers, President & CEO, APDA.

Twenty-six grants have been awarded including five Post-Doctoral Fellowships, three Diversity in PD Research grants, eight Research grants, nine Centers for Advanced Research, and one George C. Cotzias Memorial Fellowship (APDA's most prestigious award).

To learn more about these new grants, visit apdaparkinson.org/What-We-Fund.







Mark your calendars for GI WINGTUESDAY DECEMBER 3!

Join APDA during this global generosity movement and show the PD community you care.

Visit apdaparkinson.org/GivingTuesday to learn more!

A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friend,

As President and CEO at the American Parkinson Disease Association (APDA), I know how complex and challenging living



with Parkinson's disease (PD) can be. However, I know that we as a community are stronger than PD — and that every day, with your support, we're helping those facing this disease live life to the fullest.

I am deeply inspired by the incredible advancements being made by APDA researchers.
Thanks to partnerships like yours, findings from these studies have the potential to change countless lives. Your generosity also allows us to continue offering resources to help the PD community and their care partners maintain their mental health, find connection, and stay strong and positive.

When we work together, there's nothing we can't do. Thank you for your dedication as we fund groundbreaking research and empower our community members across the nation.

Sincerely,

Lexu J. Clambers

Leslie A. Chambers President & CEO

FROM STIGMA TO SUPPORT:

RETHINKING MENTAL HEALTH IN THE PD COMMUNITY

Tremors, rigidity, and mobility issues are commonly associated with Parkinson's disease (PD). However, beneath the visible symptoms are many non-motor symptoms that are not always outwardly noticeable. One of these quieter yet equally important aspects of this disease are the mental health challenges that can accompany PD. For many navigating PD, the shifts in mental health can often overshadow their physical symptoms.

Mental health difficulties including anxiety, depression, hallucinations, and delusions can occur for some people living with this disease. In a recent episode of *Dr. Gilbert Hosts*, Dr. Gilbert spoke with Dr. Mark Groves — a psychiatrist with a

particular interest in the mental health challenges of those living with PD — about the importance of mental well-being. He says that treatments such as cognitive behavioral therapy or medications can help in coping with mental health complications and are essential to improving quality of life.



Dr. Mark Groves

If you feel as if your mental health has declined because of PD, it's critical to talk with your healthcare team to come up with a plan that's right for you. When talking with your healthcare provider, it's important to be proactive. Because there are so many different symptoms that can manifest in PD, your doctor may be focused elsewhere such as your tremors, blood pressure, or sleep. If your doctor does not bring up cognitive impairment, depression, anxiety, or psychosis — take action and bring it up yourself!

To hear the full conversation between Dr. Gilbert and Dr. Groves — and to get advice on how to handle mental health challenges in PD — visit apdaparkinson.org/MentalHealth.



TRACK YOUR SYMPTOMS WITH EASE

New and improved with expanded features and updates, the APDA Symptom Tracker app version 3.0 is ready to help you easily and accurately track your Parkinson's disease (PD) symptoms and medications, and relay that important information to members of your medical team — with the ultimate goal of receiving better, more personalized care.

Since everyone experiences PD differently and symptoms can vary greatly day by day, the more specific someone can be with their health care team about the types of symptoms they're experiencing, and the timing of their medication, the better the doctor(s) can tailor a treatment plan specifically for each person. But it can be hard to remember how certain symptoms have or have not affected you since the last time you connected with your health care team, or if you missed a medication dose, which is precisely why the APDA Symptom Tracker App was created!

And now, this highly specialized mobile application features enhanced functionality, including:

- ► An expanded list of 16 PD symptoms
- ► "My Medication List" a list of your medications, dosages, and dosing times that can be saved or printed to share with your care team
- "My Notes" a helpful section to add your notes during doctor appointments or when at home to reference during your next appointment
- Updated resources and medications referenced with the app
- Enhanced home screen design for improved user experience
- ► And more!

It includes an in-app Spanish language option, which enables a much larger audience to take advantage of this technology and builds upon APDA's commitment to better serve and support under-represented PD communities.





The APDA Symptom Tracker App is available for free in the Apple App Store and on Google Play — download it today!

WHAT'S HAPPENING AT APDA

Falls prevention

Did you know that September was Falls Prevention Awareness Month? Throughout the month, we raised awareness through social media, emails, and conversations with the PD community. Some common causes of falls in PD are postural instability, freezing of gait, festinating gait, orthostatic hypotension, and more. Physical therapy and medication adjustments are two ways to help, but search "falls prevention" on our website to learn more ways to reduce your risk of falls and stay safe. In honor of Falls Prevention Awareness Day on September 22, many donors made a \$22 monthly gift — it's not too late to join them. Visit apdaparkinson.org/Monthly to learn more today.

Save the date

Our third annual APDA
Virtual Education Conference
will be held on February 19 and
20, 2025. Get ready for two great
days of hot topics, energizing
movement, and inspiring stories
as our community comes together
once again! To view presentations
from last year's program, visit
APDAparkinsons on YouTube
and look for the 2024 Virtual
Education Conference playlist.