

Dr. Rebecca Gilbert,  
APDA Chief Scientific Officer,  
**ANSWERS YOUR  
QUESTIONS ABOUT  
PARKINSON'S DISEASE  
AND COVID-19**



*People with Parkinson's disease (PD) have been asking a lot of questions about COVID-19 since the pandemic began and APDA is here with the answers you need.*

**Q: Could the COVID-19 vaccine negatively affect someone with PD and dementia?**

A: The side effects of the COVID-19 vaccine tend to be sore arm, fatigue, headache, and the like for 1-2 days. If someone has dementia, they may act or respond differently because they might not feel well. However, this does not mean that there is a worsening of the person's underlying neurologic condition. Side effects should get better and the person should return to his/her baseline in 1-2 days.

**Q: Are there any reasons why a person with PD should not get a COVID-19 vaccine?**

A: There are no substantiated scientific concerns to suggest that the vaccines have a different safety profile in people with PD as compared to the general population, so what we know about the vaccines for all-comers would hold true for those with PD. Having PD might lead to a more complicated infection should you contract

COVID-19, plus people with PD also tend to be older which further increases risk for complicated COVID-19 infection. Because of these issues, vaccination for COVID-19 for people with PD is a good idea. Discuss with your doctor any concerns you have about the COVID-19 vaccine, and to find out when and where you can receive the vaccine.

**Q: I have heard that people can have side effects from the COVID-19 vaccine. I am concerned that I may have worsening of my PD symptoms after receiving the vaccine. What should I do?**

A: While there have been some varied reactions, the COVID-19 vaccines are approved by the FDA and considered safe. Some people may simply experience a mildly sore arm and that is it. There are some who may have a more noticeable reaction and feel chills, body aches, headaches and/or fatigue for 1-2 days, but these generally clear up quickly. I have heard an occasional person state that his/her PD symptoms were worse after the vaccine. My prediction is that if this were to happen, the worsening of PD symptoms would be short-lived and fully reversible. Remember, it is clear that PD symptoms tend to worsen in the short term when someone contracts COVID-19. Weighing the risks of someone with PD getting COVID-19, as well as the significant downsides of all the pandemic-related restrictions on social and physical activities to someone with PD vs. the potential for side effects from the vaccine, I would favor getting the vaccine. As always, discuss all your medical concerns with your neurologist and primary care physician.

[continued on next page]

**Q: Once I am vaccinated, can I go back to doing things as I was doing them before the pandemic?**

A: You are not adequately protected from COVID-19 until about 2-3 weeks after your second vaccine dose. At that point, protection from COVID-19 infection is about 95% for both the Pfizer and Moderna vaccines for the original strain of COVID-19. This number may be lower for some of the new variants of COVID-19 that are emerging. What we don't yet know is whether a vaccinated person would still be able to transmit the disease to someone else. For that reason, and because of the concern of emerging COVID variants, masks and social distancing will remain in place for everyone for the foreseeable future (please follow your local health authority guidelines). However, you can feel comfortable that your chance of getting the virus decreases significantly after you are fully vaccinated. In addition, even those who do get the virus after vaccination tend to have a milder course, which is another reason to seek vaccination.

**Q: I am not vaccinated against COVID-19 yet. I have a new rash and would like to see my doctor. Is it safe?**

A: Hopefully, you will be vaccinated soon, but until then, you should seek medical care if you need it. The pandemic has been in progress for close to a year now, so at this point you should no longer be delaying the in-person doctor's visits or medical procedures that you need. You should discuss with your doctor how to proceed. Doctor's offices and hospitals are taking many precautions to keep patients safe. In addition, if you have not already, consider telemedicine as a way to see your physician for routine care without being there in person.

**Q: My husband has PD with moderate symptoms. Normally, he is independent with all his activities, although he walks slowly. One day, his symptoms worsened dramatically, and he was not able to walk. I took him to the ER where he tested positive for COVID-19. His recovery has been very slow and he is now in rehab. Is this normal? Will he recover?**

A: In general, people with PD and other brain illnesses often have 1) worsening of their PD symptoms in the face of inter-current illnesses such as COVID-19, and 2) have a slower recovery



to their baseline once they have recovered from the inter-current illness. It sounds like both have happened to your husband. However, with proper rehab and some perseverance, there is hope that he will slowly return to his baseline.

**Q: I have multiple home health aides who come into my home to help in the care of my husband with very advanced PD. Should I eliminate this care because of the concern that these aides will inadvertently infect him?**

A: Healthcare workers are likely to be vaccinated soon, you should inquire as to whether your home health aides have already been or plan to be vaccinated. Until then, there are no easy answers. It does not seem realistic to make you the sole caretaker of your husband who typically needs multiple people to help him over the course of the week. Of course, every time someone comes into your house, they could be bringing the virus in, even if they are asymptomatic. On the other hand, without help, he has an increased risk of falling, for example. So, there are risks in both directions. In this case, it is likely that the benefits of aides outweigh the risks, and you should continue to have at least some of the aides come to your house.

I would make sure the aides are scrupulous about their hand hygiene throughout the day and remind them to avoid touching their face, nose, and eyes. Frequently touched surfaces should be cleaned often and disinfected. Of course, if any of the aides are not feeling well, they should NOT come to the house.

**Q: Can the stress of the COVID-19 situation make Parkinson's symptoms worse?**

A: Stress can increase PD symptoms. I have discussed the relationship between stress, anxiety

and PD in general before, and COVID-19 has certainly created a very stressful environment for everyone right now. It is being felt much more acutely by older adults and those with chronic medical issues, members of the population who have an increased risk of complications from COVID-19 infection. Many people with PD experience anxiety as a non-motor feature of their PD, and many are reporting that anxiety has increased during this tense time. To help minimize stress and normalize the current situation, be sure to establish daily routines, continue to exercise at home, and stay connected with family and friends online or on the phone.

In addition to a potential worsening of PD symptoms from the overall stress of the COVID-19 situation, people with PD should also be aware that PD symptoms would also be expected to worsen if they were to contract the COVID-19 virus. In general, it is very common for PD symptoms to get worse when there is any inter-current illness. In the pre-COVID era, if PD symptoms worsened suddenly, a clinician would be suspicious that an infection was brewing such as a UTI, the flu or bacterial pneumonia. PD symptom worsening can also occur with a COVID-19 infection as well.

## TIPS AND TAKEAWAYS

- The first COVID-19 vaccine has been approved in the US. Distribution of the vaccine is underway, but logistically complicated, and you will need to contact your health care provider to learn how and when you will be able to receive it.
- Most people who are infected with COVID-19 will recover completely. However, older adults and those with underlying medical issues are at an increased risk of developing serious outcomes from COVID-19 as compared to those who are younger and healthier.
- It is incredibly important for everyone, especially the PD community, to follow all recommended risk-reduction guidelines and adhere to local regulations.
- PD symptoms such as balance problems/falls, swallowing difficulties, urinary dysfunction and weight loss contribute to general frailty and increased risk of complications from COVID-19 infection.
- Talk with your doctor about any concerns you have about COVID-19.



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# VIRTUAL MIDWEST PARKINSON CONGRESS

April 8th - 9th



The 4th Annual Midwest Parkinson Congress presented by the APDA-Greater St. Louis, Midwest, and Oklahoma Chapters will take place virtually on April 8th and 9th from 10:00am – 1:00pm CST. Participants will have the opportunity to hear from an esteemed panel of industry leading professionals discussing the latest in Parkinson's research, mental health, caregiving, speech, financial planning, and patient empowerment. This year, *The Elliot and Mary Ann Stein Keynote Address* will be presented by Heather Kennedy. Heather is the founder of *Kathleen Kiddo*, an advocacy site offering PD resources and

connections through social media. She is a motivational speaker, writer, blogger, visual artist, and mother of two. Diagnosed with PD in 2012, after many years of misdiagnosis, she works to raise awareness about the disease, and especially the challenges that living with Parkinson's presents. Since her diagnosis, she has collaborated with organizations such as the Davis Phinney Foundation, The Cure Parkinson's Trust, and The World Parkinson's Congress.

Registration for this event is required and is available online. Visit [www.apdaparkinson.org/greaterstlouis](http://www.apdaparkinson.org/greaterstlouis) to complete the online registration.

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*Did You Miss*

## THE COVID-19 VACCINE & PD PRESENTATION

by Dr. Joel Perlmutter?

The approval of the COVID-19 vaccine was good news to wrap up 2020, but for people with Parkinson's, questions and concerns regarding the shots' safety, efficacy, and logistics abound. **Visit <http://bit.ly/VACCINEPD>** to watch Dr. Perlmutter answer questions related to the COVID-19 vaccine and PD.



## LEGACY GIVING

Because of generous supporters like you, APDA Greater St. Louis Chapter has been able to provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest. You can also be an integral part of our future by including a charitable gift within your will, overall estate, and financial plans. Truly an easy and effective way to leave a legacy. With a little planning, you can help us improve and expand support groups, exercise classes, educational programs, wellness courses, and research support for years to come. For more information please call 636.778.3377.





## CONSTIPATION AND PARKINSON'S DISEASE

Constipation affects many people with Parkinson's disease (PD). PD slows the muscle movements of the gut, directly increasing risk for constipation. In addition, lack of physical activity, poor dietary habits, decreased fluid intake, and some medications can also contribute. The best treatment approach is to prevent constipation using diet and lifestyle changes.

### Diet and Lifestyle

Changes in diet and lifestyle may take some time before they restore regularity, so be patient. Here are some suggestions:

- Eat meals at the same time each day
- Add more fiber to your diet
- Exercise and remain as active as possible
- Drink warm liquids with breakfast
- Establish a fixed time every day for bowel movements
- Never put off the urge to move your bowels

**Exercise and Physical Activity:** Increasing your activity level is good for general health and for reducing constipation. A physical therapist can recommend appropriate exercises. Consult with both your doctor and physical therapist before

beginning any new exercise program.

**Dietary Habits:** It is important to eat the proper number of servings of each food group daily, with an emphasis on balanced nutrition and high fiber intake. A general guide is that half your plate should be fruits and vegetables. Whole grains are a good source of fiber. Drinking enough water is important to prevent constipation, especially when taking fiber supplements. Six to eight 8-ounce glasses of water daily are recommended. Some foods increase constipation, including dairy, fried foods, meats, bananas, sugary foods, and white flour.

**Fiber Content:** Fiber is an essential component of a healthy diet and the lack of fiber is the most common cause of constipation. Some fiber sources include fresh and dried fruits, vegetables, beans, whole-wheat and whole-grain products, bran, oatmeal, and brown rice.

### Helpful Foods

Certain foods may be helpful in relieving constipation. A natural recipe involves combining 2 parts of unprocessed wheat bran, 1 part applesauce, 1 part prune juice (for example 1 cup,



½ cup, and ½ cup, respectively) and refrigerating the mixture. Make a new mixture every week. You can take 1–2 tablespoons daily for one week. If needed, you can increase by 1 tablespoon a week. Stool frequency and gas may increase the first few weeks, but will usually adjust after one month of using this mixture. Yogurt that is fortified with probiotics may improve constipation as well.

### Medication

Certain medications can cause constipation. The best way to know if a medication is the cause of your constipation is if the symptoms start when you start the new medication. Do not stop these medications, but ask your doctor if they could be the cause of your constipation.

### Medication Management

**Over the Counter (OTC) Medications:** There are various medications used to treat constipation. If you have questions about ingredients or if the product is safe to use, ask your doctor or pharmacist.

If after two weeks of dietary/lifestyle changes there is no improvement in constipation, bulk-forming laxatives may be used. It is important to continue your healthy eating habits while taking these laxatives. Stool softeners may also be added if the bulk-forming laxatives do not provide relief soon enough, and to help relieve straining during bowel movements. Both items are generally safe when used as directed. Stimulant laxatives and hyperosmotic laxatives may not always be safe and **SHOULD NOT** be used without the advice of a doctor or pharmacist. Don't take laxatives within two hours of taking other medications. **If, after dietary/lifestyle changes and using a laxative fails, a more serious underlying condition may be responsible for the constipation.**

**Bulk-forming Laxatives:** Bulk-forming laxatives or fiber supplements are the safest and most naturally-acting type of laxative provided they are taken as directed. These products are not habit-forming and can be used daily to help prevent and treat constipation. Not drinking enough water can result in an obstruction of the gastrointestinal tract. Make sure to take these with an 8-ounce glass of water. Increasing fiber intake too quickly may result in gas, bloating, and upset stomach.

These products usually take between 12 to 72 hours to work.

**Stool Softeners:** Stool softeners, also called emollients, are oral products containing the ingredient docusate and are generally only useful in preventing constipation. Stool softeners do not cause a bowel movement, but help to allow one without straining. They are not habit forming and usually work in one to two days, but can take up to five days. If bulk-forming laxatives and stool softeners don't work, talk with your doctor or nutritionist about other options.

**Prescription Medication:** If other products fail, discuss with your doctor or pharmacist about a prescription medication that may be available to treat chronic constipation in people with PD

Always make certain all of your doctors and your pharmacist are aware of all the medications (OTC and prescription), vitamins, supplements, and herbal products you are taking so they can check for drug interactions or side effects.



## LIVE STREAM EXERCISE CLASS SCHEDULE

Please visit: [bit.ly/APDAYoutube](https://bit.ly/APDAYoutube) for exercise classes.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
MONDAY	10:00am	Strength & Cardio	Level 2	Marina Clements
MONDAY	1:00pm	Interval Training	Level 2	Jen Berger
TUESDAY	1:00pm	Seated Exercise	Level 1	Michelle Valenti
TUESDAY	posted weekly	Yoga & Meditation	All Levels	Ulrikke Malik
WEDNESDAY	1:00pm	Interval Training	Level 2	Michelle Valenti
THURSDAY	1:00pm	Seated Exercise	Level 1	Jen Berger
FRIDAY	10:00am	Tai Chi	Level 1	Craig Miller
FRIDAY	11:15am	Tai Chi	Level 2	Craig Miller

## ZOOM EXERCISE CLASS SCHEDULE

For more information, please contact Angela Weaver at [aweaver@apdaparkinson.org](mailto:aweaver@apdaparkinson.org).

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
TUESDAY	9:00am	Seated Exercise	Level 1	Jen Berger
TUESDAY	10:00am	Strength & Cardio	Level 2	Jen Berger
THURSDAY	10:00am	Strength & Cardio	Level 2	Rachel Lehman
FRIDAY	11:00am	Seated Exercise	Level 1	Rachel Lehman
FRIDAY	10:00am	Strength & Cardio	Level 2	Michelle Valenti
FRIDAY	11:00am	Seated Exercise	Level 1	Michelle Valenti

## VIRTUAL SUPPORT GROUP SCHEDULE

For more information, please contact Angela Weaver at [aweaver@apdaparkinson.org](mailto:aweaver@apdaparkinson.org)

### MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER
Chesterfield	First & Third Tuesday	11:00am	Carrie Burgraff
Chesterfield Caregivers	Second Monday	11:00am	Lynda Wiens & Jay Bender
Carthage	First Friday	2:00pm	Tericia Mixon
Kirkwood	Fourth Tuesday	6:00pm	Terri Hosto
South County	Fourth Wednesday	10:30am	Caitlin Jones
St. Peters	First Tuesday	1:00pm	Jodi Peterson
St. Louis Caregivers	Third Monday	1:00pm	Kathy Schroeder
Webster Groves	Fourth Thursday	1:00pm	Laurel Willis
YOPD	Every Wednesday	6:00pm	Karen Frank & Mike Mylenbusch

### ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER
Carbondale	First Wednesday	1:00pm	Gala Lockwood
Charleston	Fourth Tuesday	1:00pm	Jean Shobe & Jean Penrod
Edwardsville	First Tuesday	2:00pm	Pam Pinegar
Highland	Fourth Tuesday	2:00pm	Kayla Deerhake
Quincy	Saturdays	10:00am	Dave & Terri May





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## SAVE THE DATE!

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**Monday, June 21, 2021**

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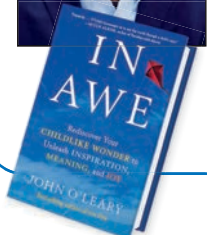
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GREATER ST. LOUIS CHAPTER



In the fall of 2020, the APDA Greater St. Louis Chapter established the Optimism Society to honor those who provide annual support of \$1,000 or more. Optimism Society members are a vital component of the Greater St. Louis Chapter, and each year we extend our gratitude to those who support us with a special Optimism Society celebration.

**To join the Optimism Society**, contact Director of Development, Melissa Skrivan at [mskrivan@apdaparkinson.org](mailto:mskrivan@apdaparkinson.org) or 636-778-3377.



### Sunday, August 1st

The Elliot and Mary Ann Stein Speaker Series featuring JOHN O'LEARY, author of *On Fire*, who will celebrate and share his new book *IN AWE: Rediscover Your Childlike Wonder to Unleash Inspiration, Meaning, and Joy.*

### APDA Community Resource Center

1415 Elbridge Payne Rd, Ste 150 | Chesterfield, MO 63017  
Hours: 8:00 a.m. - 4:00 p.m. M-F  
636.778.3377

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