

PARKINSON'S DISEASE AND COVID-19

Our goal at Neuro Challenge Foundation is to educate, engage and empower the Parkinson's community. At no time in our history has there been a more important time to provide information and resources in the face of a pandemic that has affected individuals, our state and country, and the globe. The purpose of this Q&A document is to provide information and resources that address COVID-19 and Parkinson's Disease; information that will hopefully optimize your health and safety in our community.

The information comes from a variety of studies and reports and has been reviewed by the Neuro Challenge Medical Advisory Committee. Special thanks to Linda Haller Sloan for conducting the research and compiling this information. **This information does not represent nor substitute for medical advice. Readers should be advocates for their own health and consult with their own health care providers.** Further, this information piece is current as of today's date. COVID-19 is a novel coronavirus and is evolving. Many aspects are unknown, may change, or are yet to be determined.

Some of the information that follows is from other countries because the virus was more prevalent there before it was in the United States, so those areas have more data and were able to study COVID-19 and Parkinson's Disease sooner and longer than we have been able to in the United States.

QUESTIONS AND ANSWERS TO OPTIMIZE HEALTH AND SAFETY

1. Does having Parkinson's Disease make one possibly more susceptible to contracting COVID-19?

The answer is currently unclear.

2. Does having Parkinson's Disease make one more likely to have a worse experience with COVID-19 if one contracts the virus?

Yes, in some cases. It depends on the nature and severity of the Parkinson's Disease in the person, the coronavirus infection, as well as any other existing conditions, and age. Parkinson's does not lower one's immune system per se (a concern regarding other conditions because a weakened immune system can make it harder for the body to defend against COVID-19). Yet, Parkinson's factors can make the COVID-19 experience worse.

One Parkinson's factor that can make COVID-19 worse is breathing and respiratory function.

In March 2020, Dr. Frederick Southwick, University of Florida, Gainesville, cautioned "Issues with the respiratory system muscles can make it difficult for people with Parkinson's Disease to take deep breaths and get enough oxygen into the lungs." <https://www.webmd.com/lung/news/20200325/covid-19-what-people-with-parkinsons-should-know#1>

On June 12, 2020, Dr. Rebecca Gilbert, a medical representative of the American Parkinson Disease Association explained: "people with PD may have *restrictive lung disease* which refers to an inability of the lungs to fully expand with air. Restrictive lung disease can occur in PD because of rigidity of the muscles of the chest wall as well as bradykinesia, or slowness of the muscles responsible for chest wall expansion and contraction. People with PD may also have abnormalities in the posturing of their trunk including head drop, stooped posture, tilting of the trunk and bending at the waist. These postures can restrict the amount that the

lungs can fill up. PD can also predispose a person to [dysfunction of swallow](#) and difficulty clearing secretions from their airway. These issues could contribute to development of complications during a respiratory illness.” <https://www.apdaparkinson.org/article/questions-about-pd-and-covid-19/>

In an April 14, 2020 article published in the Journal of Parkinson’s Disease, Parkinson’s experts from the Netherlands explained: “There are particular concerns around the increased vulnerability of patients living with a chronic disease, and this also includes neurological conditions like Parkinson’s disease (PD). Indeed, PD is more common in the elderly, and PD can compromise the respiratory system, as reflected among others by the increased risk of pneumonia that is present in patients with advanced PD. Although documented reports are thus far lacking, it is conceivable that having a diagnosis of PD is a risk factor for worse respiratory complications or even an unfavorable outcome after a COVID-19 infection.” <https://content.iospress.com/articles/journal-of-parkinsons-disease/jpd202038>

Citing this article, the American Journal of Care Management wrote: “patients with PD (PwP) serve as distinct at-risk populations to COVID-19 as they are typically older and may have compromised respiratory systems due to PD. Although there may not be extensive data on the relationship between PD and the virus, the leading cause of death in PwP is pneumonia, which also serves as a chief symptom of COVID-19.” <https://www.ajmc.com/view/how-are-patients-with-parkinson-disease-faring-amid-the-covid19-pandemic>

Researchers in China published a large study in January 2016 regarding pneumonia being the leading cause of hospitalization, and of death, in people with Parkinson’s. <https://www.dovepress.com/risk-factors-for-pneumonia-among-patients-with-parkinson39s-disease-a-peer-reviewed-fulltext-article-NDT>

In the U.K., the guidance for people with Parkinson’s, updated on July 30, 2020 says: “Parkinson’s can cause respiratory issues for some people. If you have advanced Parkinson’s or have lived with the condition for a long time, you are more likely to have breathing and respiratory difficulties. Coronavirus affects your lungs and airways. Therefore people with Parkinson’s are described as being at greater risk of severe illness if they get coronavirus.” <https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

Some people with Parkinson’s and COVID-19 have died. Some of the deaths of people with Parkinson’s and COVID-19 are attributed to COVID-19 pneumonia. In a study published April 29, 2020 of 10 patients from Padua, Italy and London, England, with Parkinson’s and COVID-19, four patients died. Of these, one died from respiratory problems and three died from COVID-19 pneumonia. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28104>

There have been other more positive outcomes. In a study published May 25, 2020 regarding 12 people from Lombardy, Italy, with Parkinson’s and COVID-19, three had mild cases of COVID-19, eight had moderate cases, and one was hospitalized with pneumonia. No one died. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28170>

Age also creates higher risk of more serious COVID-19 illness because of the older a person is, the weaker the immune system is, and therefore, the less able the body is to combat the virus. So, the older a person with Parkinson’s is, the more at risk the person is to difficulty with COVID-19 based on age. And the older a person is with Parkinson’s, the longer the person probably has had Parkinson’s, or the more advanced the condition, so these aspects add risk as well. Further, the older a person with Parkinson’s is, the more likely the person is to have other health issues like heart, lung or kidney disease that also compromise a body against COVID-19. Excluding age, a person of any age with Parkinson’s and with any of these conditions, could have a more difficult COVID-19 experience.

A study of people with Parkinson’s and COVID-19 in Padua, Italy and London, England published April 29, 2020 found that (footnotes omitted): “Older advanced PD patients may represent a particularly vulnerable population, as respiratory muscle rigidity as well as impairment of cough reflex alongside preexisting dyspnea may lead to increased severity of COVID-19. In addition, there are indirect possible effects, such as the impact of stress, self-isolation, and anxiety, as well as the consequences of prolonged immobility because of the lockdown.” <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28104>. People who have had deep brain

stimulation or are on levodopa infusion therapy, appear to have a higher death rate. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28104>

3. For a person with Parkinson's who has COVID-19, does COVID-19 negatively affect a person's Parkinson's?

Yes. In general, any infection can make existing Parkinson's symptoms worse. Specifically, COVID-19 worsens Parkinson's symptoms - physical and mental.

COVID-19 has been found to rapidly worsen Parkinson's symptoms. <https://parkinsonsnewstoday.com/2020/05/26/covid-19-infection-may-appear-as-rapid-worsening-parkinsons-motor-symptoms/>

Knowing this can occur is very important for being able to identify COVID-19 early - and to see the warning signs and not mistake them for Parkinson's.

Researchers from the Netherlands published an article in the Parkinson's Research Journal on April 3, 2020 stating that: "the pathophysiology of PD puts patients at increased risk of chronic stress, and a further worsening of this may well be one of various hidden sorrows of the COVID-19 pandemic. Importantly, increased levels of stress during the COVID-19 pandemic may have several short-term as well as long-term adverse consequences for individuals with PD." The authors also stated (footnotes omitted) that "increased stress may unmask a latent hypokinetic rigid syndrome, possibly by depleting compensatory mechanisms. This could lead to an increase in numbers of new PD diagnoses during the pandemic. In a year from now, it might be worthwhile to investigate incidence levels of PD during this time of crisis, as compared to the period before." <https://content.iospress.com/articles/journal-of-parkinsons-disease/jpd202038>

The April 29, 2020 study from Italy and England included eight people in London with COVID-19 and Parkinson's Disease with severe motor dysfunction and found that those people experienced worse fatigue, orthostatic hypotension, cognitive impairment and psychosis during coronavirus infection. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28104>

In a study in the Lombardy Region of Italy first published May 25, 2020, researchers identified 12 people with COVID-19 among 141 people with Parkinson's Disease. Both nonmotor and motor aspects of Parkinson's were affected by COVID-19. There were more "off periods" leading to greater need for more medication. Urinary issues also were reported, as well as diarrhea, and increased fatigue, which was attributed to the virus. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28170>. See also <https://parkinsonsnewstoday.com/2020/06/02/covid-19-exacerbates-some-parkinsons-symptoms-study-finds/>

The Michael J. Fox Foundation conducted a survey and released findings as of July 14, 2020. The survey included 51 people with Parkinson's who reported a COVID-19 diagnosis. Of these, 55% reported worsening of an existing Parkinson's motor system (i.e., tremor, slowness, imbalance). More than 50% reported the worsening of non-motor symptoms (i.e., mood issues, digestive problems, pain and fatigue). <https://www.michaeljfox.org/publication/michael-j-fox-foundation-releases-first-and-largest-data-set-self-reported-outcomes>

4. If a person with or without Parkinson's Disease gets COVID-19, what are the possible neurological effects of COVID-19?

a. Short-term:

COVID-19 can have neurological effects. The neurological effects can have different causes, or sources. Neurological effects can be caused by the virus affecting nerves that go to the brain from the nose, or from possible infection in the brain, or from inflammatory response in the brain.

In some cases, the part of the brain that controls breathing may cause breathing issues.

An April 9, 2020 article published in Psychology Today regarding COVID-19 and neurological effects stated: “Virologists are alerting doctors to a possibility that could help explain two of the most puzzling aspects of COVID-19—why the severity of the disease varies so widely, and how the infection can be so deadly. In severe cases the virus may enter the brain through the olfactory nerve in the nasal cavity and damage neurons that control breathing. ‘Doctors should be aware of this possibility,’ warns Pierre Talbot, Professor of Virology at the Institute Armand-Frappier, Université du Québec, Laval, Québec. ‘It may not be only pneumonia [killing patients]—the virus could be infecting the brain,’ he says. This is the conclusion reached in a [new paper](#) by Yan-Chao Li, Wan-Zhu Bai, and Tsutomu Kashikawa from the Jilinan University of China and RIKEN Brain Science. According to the authors, patients suffering from COVID-19 who were admitted to intensive care in China could not breathe on their own, and many showed neurological signs, such as headache, nausea, and vomiting. Nearly all of the patients in ICU (89%) could not breathe spontaneously, and about half of the patients in intensive care worsened in a short period of time and died from respiratory failure.” <https://www.psychologytoday.com/us/blog/the-new-brain/202004/neurological-implications-covid-19-raise-concerns>

According to a study in the U.K. published June 25, 2020, effects of COVID-19 can include stroke, hemorrhage, central nervous system vasculitis, unspecified encephalopathy, encephalitis, and altered mental status. <https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366%2820%2930287-X/fulltext>

An earlier study in Lombardy, Italy speculated that subacute clinical changes in people with Parkinson’s from non-severe cases of COVID-19 likely are caused by systemic inflammatory response, rather than a direct invasion of the central nervous system, but further study in larger groups is necessary to clarify the cause and effect relationship among clinical changes and the severity of COVID-19 illness, cytokine levels, and virus detection in the cerebrospinal fluid. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28170>

Linkages between coronavirus in general and Parkinson’s has been seen for decades. Citing a 1992 study, a report released in April 2020 noted that antibodies against coronavirus were found in the cerebrospinal fluid of people with Parkinson’s and that this suggests that infections may play a role in neurodegeneration.

Linkages between the novel coronavirus COVID-19 and neurological conditions are illustrated by the common olfactory condition of the loss of sense of smell. Loss of smell can be both Parkinson’s symptom, and/or a COVID-19 symptom. Thus, loss of smell is a two-way street of precaution: if a person with or without Parkinson’s loses the sense of smell - it could be a sign of Parkinson’s Disease, or a sign of COVID-19, or both.

On July 24, 2020, a new Harvard study was published addressing the cause of loss of smell in COVID-19, finding that the virus affects the function of supporting cells, rather than directly infecting neurons. <https://hms.harvard.edu/news/how-covid-19-causes-loss-smell> <https://advances.sciencemag.org/content/6/31/eabc5801>

The findings suggest that COVID-19 is not likely to permanently damage olfactory neural circuits and thus not cause permanent loss of smell. Yet the researchers noted that more data and better understanding of the underlying mechanisms is necessary to confirm this conclusion. At least one non-Parkinson’s COVID-19 patient is known to have lost the sense of smell while symptomatic, later regained it, then lost it again.

b. Possible Longer-Term Effects

There are emerging indicators that in some cases, the COVID-19 virus, like other viruses, can lead to neurological issues like Parkinson’s Disease after the acute COVID-19 experience. For example, following the 1918 influenza outbreak, there was an increase in neurological conditions in the public, including Parkinson’s.

5. Is the COVID-19 pandemic negatively impacting health conditions and services of people with Parkinson’s Disease?

In April 2020, researchers from the Netherlands identified loss of isolation and physical activity as a COVID-19 threat to people with Parkinson’s and emphasizing the value of on-line offerings. <https://content.iospress.com/articles/journal-of-parkinsons-disease/jpd202038>

The Michael J. Fox Foundation conducted a survey of people with Parkinson's Disease between April 23 and May 23, 2020. It found wide-ranging impacts of the COVID-19 pandemic negatively impacting health conditions and services of people with Parkinson's, especially people of color or of lower income, including: canceled healthcare appointments, involuntary reductions in needed in-home care, or difficulty in obtaining medications. In addition, some people with Parkinson's had issues with at least one essential daily activity such as obtaining food. Many survey participants reported the need to cancel exercise or social activities. Some people used on-line classes to continue activities, though people with Parkinson's with lower income were less likely to do so. These various changes, as well as the need to self-isolate, were associated with worsening of Parkinson's symptoms.

6. What can people with Parkinson's Disease do to optimize COVID-19 safety?

- Comply at minimum with all applicable COVID-19 safety government rules and ordinances, as well as rules and protocols in place in community residential settings, including condominium buildings and apartments.
- Follow at minimum the Guidelines from the CDC <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>; <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/shared-housing/index.html>
- For people in Florida, follow at minimum the Guidelines from the Florida Department of Health. <https://floridahealthcovid19.gov/>
- Stay home as much as possible.
- Wear a face covering if leave home.
- Maintain at least six feet distance from all others, except co-residents of one's household who are not sick.
- Wash hands often or use hand sanitizer.
- Avoid or limit close physical contact with others outside one's household
- Avoid crowds.
- If you are to have person-to-person contact, do it outside if possible.
- Require anyone coming into the home to wear a face covering, other than people who reside in the home (unless the co-resident has been exposed to the virus or is sick - in which case, the co-resident should isolate and wear a mask and keep at least six feet distance from the person with Parkinson's).
- Eat healthy.
- Get plenty of sleep.

7. What can people with Parkinson's Disease do to optimize Parkinson's health and well-being during the COVID-19 pandemic?

- Physically move your body and exercise, exercise, exercise.
- Get fresh air outside when possible.
- Engage with others. Stay connected with family and friends. Call or email us to talk at: NeuroChallenge.org. Participate in talk, recreational, and support group sessions offered on-line, including the Neuro Challenge monthly/weekly/daily sessions.
- Mental Health tips: <https://www.apdaparkinson.org/article/maintaining-mental-health-during-covid-19/>
- Educate yourself and those around you. Participate in education sessions offered on-line, including the Neuro Challenge monthly/weekly/daily sessions at NeuroChallenge.org. Here's additional information from the Michael J. Fox Foundation: <https://www.michaeljfox.org/news/michael-j-fox-foundation-covid-19-resource-hub> and the Parkinson's Foundation: <https://www.parkinson.org/search/node?keys=Covid-19&op=>
- Empower yourself. You are NOT alone. The whole world is grappling with the coronavirus. Medical, physical and mental health effects. Economic and financial effects. This literally is a first in a century pandemic with wide effects. It is normal for the uncertainty and the limitations to make one feel sad, depressed or anxious. Everyone has better days than some days.
- The best we each can do is to focus on today - rather than the days of uncertainty - doing what is safe and healthy and enjoyable today. And to find comfort and joy in the public information that vaccine are being earnestly worked on, and should be available in 2021. Our country, and individuals, have endured great hardships in history including wars, economic crises, and the 1918 influenza.
- There is hope. Every day brings us closer to COVID-19 therapies and a vaccine.

And in the meantime, Neuro Challenge is here for you.

Here are some other PD and COVID-19 resources:

<https://www.michaeljfox.org/news/michael-j-fox-foundation-covid-19-resource-hub>

<https://www.parkinson.org/blog/tips/Coronavirus>

<https://www.apdaparkinson.org/article/questions-about-pd-and-covid-19/>

<https://www.ajmc.com/focus-of-the-week/how-are-patients-with-parkinson-disease-faring-amid-the-covid19-pandemic>

Exercise: <https://www.apdaparkinson.org/article/online-exercise-classes-and-resources/>

Mental Health: <https://www.apdaparkinson.org/article/maintaining-mental-health-during-covid-19/>