

# Understanding Parkinson's Disease

## The Ohio State University Parkinson's Disease Quarterly Educational Series

### Q & A Session Follow – Up

Answers prepared by

Dr. Ariane Park, Dr. Aristide Merola, Clarisse Goas, MS, APRN-CNP and Jared Braden, PT, DPT, NCS

#### **What interventions are there for urinary incontinence in males?**

*Consult your urologist about medications you can take, such as Botox, and your physical therapist about bladder exercises that you can do to support this symptom.*

#### **My doctor did “hands-on” diagnostic testing. He rated my movements on a 0 – 4 scale. Is this used by all neurologists? And what is this scale called?**

*This is called the UPDRS (Unified Parkinson's Disease Rating Scale) and is used by most clinicians who care for patients with Parkinson's disease. It's a comprehensive 50-question assessment of both motor and non-motor symptoms associated with Parkinson's. The scores determined by this assessment are used to measure the severity and progression of Parkinson's disease (PD).*

#### **I am 57 and was diagnosed in July 2020. I have been told that because of my age, I am considered early onset. Does this change the progression of the disease? How fast does PD normally progress?**

*Everyone's disease progression is different. The best way to predict your disease progression is to look at the past 6 – 12 months and see what has changed and how fast. Expect this same rate in the future. You can slow down this progression by exercising—specifically riding an exercise bike 20 – 45 minutes a day, most days of the week, alternating fast and slow.*

**Do you have any recommendations concerning the use of over-the-counter sleep aids? We typically recommend melatonin 3 – 10 mg by mouth at bedtime every night to help improve REM sleep disorder. Our patients sometimes say they prefer the extended release formulation as well, but no specific studies have been completed regarding this.**

#### **If a patient is diagnosed with an “essential tremor” (tremor not at rest) or some of the listed pre-motor symptoms, can treatment possibly slow or prevent PD?**

*As we do not know what causes PD, it cannot currently be prevented. Essential tremor does not “turn into” PD, but sometimes people will experience both essential tremor and PD. Essential tremor is familial and mostly causes tremor with action. PD tremor is at rest and may also include postural instability, stiffness and slowness.*

#### **Does insurance (Medicare) pay for genetic testing?**

*Unfortunately, each plan is different. Our genetic counselors typically look into payment before we consider ordering these tests.*

#### **Where can I find more info about participating in a research study?**

*Check [wexnermedical.osu.edu/movement](http://wexnermedical.osu.edu/movement) often. We will have an email address posted on the website soon for inquiries regarding current and upcoming research studies.*

#### **How is Parkinsonism different from Parkinson's disease?**

*Parkinsonism is a more vague term—it can encompass several different variants. Parkinson's disease typically refers to tremor dominant or akinetic rigid disease. These are well known and respond well to medications typically.*

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**My mother was diagnosed with atypical Parkinson's because she exhibits only some of the symptoms related to Parkinson's. Does this disqualify her from research studies and genetic testing?**

*Not necessarily. Atypical Parkinsonism studies are not as common, but there are some available. There is also a local atypical Parkinsonism support group that is helpful. Consult your physician for more information about these opportunities and local support options.*

**Both of my parents currently have Parkinson's. They are in their early 80s. My dad is in a nursing home. My brother has some tremors (no PD diagnosis) in his early 50s. I am 55 with no symptoms, but wondering about genetic testing or a research study for me.**

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**How common is the occurrence of PD in combination with other movement disorders such as essential tremor? Is PD more likely to be genetic if ET (highly genetic) is also present?**

*In general, PD and ET are considered as different disorders. However, it is true that ET patients have a slightly higher probability of developing PD. The reasons are not entirely clear and it is possible that a common genetic background might play a role, but we do not have a definitive answer for that. In any case, we are talking of a rare association. At least 95% of patients with ET will never develop PD.*

**Exposure to chemicals and head injuries were mentioned as risk factors. Are there any indicators that those who served in the military are at higher risk? Is the consumption of dairy products a potential factor in developing PD?**

*People who were exposed to Agent Orange are at higher risk of PD. We also suspect pesticides, head injury, a small genetic component and well water (due to high heavy metal content) as highly likely causes of PD. The evidence that dairy products can cause neurodegenerative disorders is still very slim.*

**What is the relationship found between PD and exposure to mold?**

*There have been reports of certain types of mold (i.e., 1-octen-3-ol) associated with PD, but not just mold in general. Also, the number of cases of PD due to mold are very few. Mold can be dangerous or unhealthy for many other reasons and any exposure should be avoided as much as possible.*

**Can long usage of the medication alprazolam contribute to developing PD?**

*Alprazolam is not typically thought to lead to PD.*

**Can PD be stopped? Or is our best option only slowing of the disease?**

*Currently, our best option is slowing the disease. However, we are working interventions such as gene therapy, which is very exciting. We continue to look for a cure.*

**Are there any studies going on about a possible link between artificial sweeteners in diet soda and PD?**

*At this time, we are unaware of any studies looking at this relationship.*

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### **Are there research trials for family members who are concerned about developing PD?**

Check [wexnermedical.osu.edu/movement](http://wexnermedical.osu.edu/movement) often. We will have an email address posted on the website soon for inquiries regarding current and upcoming research studies. You may also want to look at information from the Michael J. Fox Foundation and [ClinicalTrials.gov](http://ClinicalTrials.gov).

**Why is exercise so important? Does it help slow the rigidity?** Exercise is so important because it's the only treatment that's been shown to slow the progression of disease and symptom progression.

### **Is Xanax OK to use for anxiety with PD?**

We don't typically recommend Xanax, as it can be addicting. Consult your physician to determine the best course of medications to treat anxiety.

### **Will carbidopa-levodopa help someone with tremors if they haven't been told that they have Parkinson's?**

Rarely. There is something called "dystonic tremor," which is rare and may respond to carbidopa-levodopa.

### **Does the progression tend to be straight line or variable?**

Variable. Often patients tell us they have good days and bad days. Good hours and bad hours. Good seasons and bad seasons.

### **Is there a benefit to starting meds at diagnosis rather than waiting on starting meds? I am mostly tremor based and not on meds yet because tremors don't yet affect function in my life.**

The benefit to starting medications at diagnosis is if your tremor is accompanied by bothersome rigidity or slowness. If your tremor is non-bothersome, and it is more bothersome to take medications, waiting will not impact the future of your disease.

### **What is vascular Parkinson's disorder?**

In vascular Parkinsonism, small strokes in brain areas that control movement cause Parkinson's-like symptoms. (In PD, cells in the same area are damaged or die due to other causes.) Vascular Parkinsonism typically affects the legs much more than the arms, often leading to significant walking and balance problems. Because strokes happen suddenly, the symptoms may come on without warning. But because the strokes in vascular Parkinsonism are small, the symptoms also could come on gradually over weeks or months. As in PD, vascular Parkinsonism symptoms can worsen over time, particularly if more strokes happen.

### **What therapies are you finding provide real help to the PWP?**

Typically LSVT-BIG or PD-specific therapies.

### **I struggle with rigidity and slowed movement in my right leg. When should I start physical therapy?**

Today! Physical therapy is always helpful in PD.

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**In regard to PD research, how much cross-national study is being undertaken? My PD was initially diagnosed in Japan, where treatment is quite nicely developed, but the Japanese would not have the genetic characteristics (or a number of others, including environmental) outlined in the presentation. The domestic counterpart to this issue is, of course, testing/experimentation that crosses racial and ethnic heritages.**

*Some large clinical trials are conducted in multiple countries. For instance, we recently participated in a clinical trial conducted in 37 centers across seven countries. This is generally limited to phase III studies (investigational products in a very advanced phase of development, with imminent commercialization). Usually, phase I and phase II studies are limited to 1 – 5 centers within the same country.*

**My wife has been on levodopa now for two years, but at times it doesn't seem that the full effect of it gets to her brain. I understand that as an oral medication, the body consumes a lot of it before it can be effective.**

**What can we do to help it be effective for her as she progresses in her disease?**

*This medication can be less and less effective as the disease progresses. Sometimes Rytary, Duopa or deep brain stimulation (DBS) can help. Consult your physician for further recommendations on what medications should be incorporated for your wife's specific needs.*

**What are the distinctive benefits of amantadine at various doses?**

*Amantadine can be helpful at any dose. Dosages are typically 100 mg 2 – 3 times per day with the last dosage before 6 p.m. to avoid insomnia. This is often given early in disease for tremor or dystonia (muscle stiffness). Later, it is often used for dyskinesia. Unfortunately, not everyone can tolerate amantadine as time goes on due to side effects including confusion and hallucinations.*

**Do antidepressant meds affect the efficacy of Sinemet?**

*Not as far as we know. In fact, we often recommend that our patients take antidepressants as decreased dopamine caused by PD can contribute to depression or anxiety.*

**Is the Duopa pump better than deep brain stimulation (DBS)?**

*They can be equally "good" depending on what you would like to improve. For tremor, Duopa is not ideal if your tremor does not improve with oral medications. For wearing off, both Duopa and DBS can be helpful.*

**Is there any drug that can be used that would just be on an "as needed" basis? I.e., you are going to a dinner party and just want to control your tremor for that evening?**

*Unfortunately, for PD tremor, we really do not have an "as needed" medication. Propranolol is sometimes tried, but typically only helps with essential tremor, not Parkinson's disease tremor.*

**As there is minimal correlation between COVID-19 and PD, are PD patients moved up in the COVID-19 vaccine queue or does PD as a pre-existing condition have no influence on when you might be eligible for the vaccine?**

*Unfortunately, no, PD is likely not a factor into moving up on the list for the COVID-19 vaccines. Vaccine eligibility is determined by the state and local health departments.*

**Can amantadine help with dyskinesia that remains even after DBS?**

*It can. However, folks often become intolerant of amantadine due to side effects the longer they have the disease.*

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#### **What's the meaning of COMT?**

*COMT: catechol-O-methyltransferase inhibitor. COMT inhibitors are a class of medications that are used along with carbidopa-levodopa therapy in the treatment of symptoms of Parkinson's disease (PD). Carbidopa-levodopa therapy is the most effective medication for alleviating the motor symptoms of PD; however, over time people experience less effect from the medication. COMT inhibitors can extend the effectiveness of carbidopa-levodopa therapy, and allow for lower doses of carbidopa-levodopa.*

#### **If taking a probiotic, should one consider the timing of taking that with Parkinson's meds? Does it affect medication absorption?**

*There's quite a bit of research regarding PD and probiotics. At this time, we don't know of any interactions with the timing of medications. Probiotics do seem to be helpful in the PD population.*

#### **What is rivastigmine used for?**

*Rivastigmine is a medication used for the treatment of cognitive impairment and memory deficits. This medication proved to be effective both in Alzheimer's disease and in Parkinson's disease and we generally use it in our patients. Alternative medications with the similar scope include donepezil and memantine.*

#### **What are treatment options for patients with Parkinson's psychosis?**

*Nuplazid works well to control Parkinson's psychosis. We have found that treatment options for movement/pain are limited since the majority of the Parkinson's medications cause hallucinations.*

#### **What are the dietary restrictions associated with carbidopa-levodopa?**

*Taking Sinemet with foods high in protein can decrease its effectiveness. Also, taking Sinemet with a high-fat meal will cause a delay in its transit through the stomach. We recommend Sinemet be taken 30 minutes prior to or 1 hour after a high-protein or high-fat meal.*

#### **Is the Ohio State Wexner Medical Center going to be participating in stem cell research for Parkinson's disease?**

*There are some new and exciting gene therapy trials going on here at Ohio State. Check [wexnermedical.osu.edu/movement](http://wexnermedical.osu.edu/movement) for the latest updates.*

#### **Can medications a patient takes to treat diabetes, inflammation, high blood pressure or high cholesterol negatively impact/counteract with their medication taken to treat Parkinson's?**

*Typically, these medications do not interact with the drug Sinemet. Consult your physician for further recommendations on what medications should be taken for your specific needs.*

#### **Are there medications that will counteract each other if taken together to treat Tardive dyskinesia?**

*Yes, one medication that's typically used to treat Tardive dyskinesia increases dopamine and a second that is typically used to treat the same condition works to decrease dopamine. Consult your physician for recommendations on what medications should be used to treat your specific needs.*

#### **What are the benefits of gabapentin being used along with carbidopa-levodopa?**

*Gabapentin is not typically a PD medication. It's often used for restless legs syndrome (RLS) or essential tremor. Consult your physician for further recommendations on what medications should be incorporated for specific needs.*

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**My husband has early onset Parkinson's and ankylosing spondylitis and it has been hard for his neurologist and rheumatologist to decide which disease causes the intense stiffness and pain he experiences. If it is Parkinson's, what are the best treatments?**

*This is a challenging situation. In general, Parkinson's disease should not cause pain. Stiffness (rigidity) that is experienced can be treated with all of the typical PD medications, including Sinemet. Continue working with your physicians to determine the best course of treatment for your specific needs.*

**Given recent studies linking the use of anticholinergic drugs and the development of Alzheimer's, it seems counterintuitive to use such drugs in connection with Parkinson's treatment, from an overall brain health standpoint. What is the risk/benefit considerations of the use of these drugs?**

*This is very true. We tend to avoid as much as possible anticholinergic medications as they may cause cognitive deficits. Some centers still use these medications for the treatment of severe tremor disorders or dystonia. It's best to consult your physician to discuss the best course of medications for your specific needs.*

**What role do exosomes play in the brain and why are some Parkinson's research studies targeting exosomes in drug development?**

*Exosomes are little vesicles that can contain important genetic material or protein and serve the function to vesiculate within one cell or between cells information (in other words, it is a way that cells use to talk to each other) or to dispose of proteins that do not serve anymore to the cell. These vesicles can also be used to deliver medications. In other words, the medication can be stored into exosomes and delivered directly into the cells.*

**Do you find that the drug Nuplazid, used to treat Parkinson's psychosis, may also help to treat dementia?**

*Nuplazid is a medication used to treat hallucinations in Parkinson's disease. It will not improve the condition of dementia, but it may improve the hallucinations that are experienced by a person with PD or dementia.*

**I have been told by my ortho surgeon who did my spinal fusion surgery in 2019, that there are questions being raised about the benefits of deep brain stimulation for the resolution of PJK (proximal junctional kyphosis) in people with Parkinson's. Do you have any info on this?**

*The effect of DBS on trunk posture abnormalities and spinal deformities is very limited. We did a study showing that posture improves after DBS. However, the magnitude of the effect is minimal (5 – 10%). In general, the presence of severe spine problems represent a red flag for possible DBS failure and should be discussed carefully during the evaluation process for this advanced therapeutic option.*

**Can slowness be reversed with exercise?**

*It cannot be reversed unfortunately, but it can be significantly slowed. Exercise can also improve mood and cognition (thinking).*

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**There have been some recent some suggestions there is a gut-brain connection involved with Parkinson's. I know there are some therapies for gut problems involving inserting feces into the intestine to correct problems. Have there been any studies on if treating the intestine in this manner would have any improvement in Parkinson's?**

*This is a very important topic and an active area of research. The intestinal microbiome of patients with Parkinson's (basically, the composition of the intestinal bacteria resident in the bowel of each one of us) is different from the one of healthy subjects. Many groups are working on this to understand whether this represents the cause of PD or rather a consequence of PD (for example, PD causes constipation and this can lead to changes in the intestinal microbiome). Some groups are studying fecal transplantation, which consists of replacing the intestinal microbiome of patients with PD with "healthy" intestinal bacteria to see whether this helps. We still do not have any definitive results, but are following the literature with interest.*

**What do you recommend as methods to work on de-stressing? Such as meditation, etc.**

*Excellent question! Decreasing stress is important in PD. Typically, we recommend meditation, exercise and other relaxing activities.*

**I recently saw an article indicating that light and sound projected at a 40 Hz rate provided some improvement in Alzheimer's patients. Have there been any studies suggesting this might provide positive results for Parkinson's patients?**

*Light therapy is indeed an innovative research approach to PD. If interested in participating in this type of research, please contact us and we will provide additional information on one available trial at Ohio State.*

**I have been practicing martial arts for 51 years. I have the impression that has been more helpful than simply the exercise component. Is there any research evidence to suggest this is true?**

*There is some evidence of this regarding tai-chi. Yoga, qigong and boxing are also good options that help you practice breath work, controlled movements, mind/body connection, strength building and balance. All of these things are key factors in exercise that may slow down PD.*

**Are there any posture exercises that can help with severe leaning to one side while sitting?**

*Yes. The treatment of Pisa syndrome is challenging and requires a lot of hard work with specialized physical therapists. In certain cases, we also use Botox injections to improve the outcomes. If you suffer from Pisa syndrome associated with Parkinson's, we recommend getting in touch with our team of physical therapists.*

**What is brain plasticity?**

*The brain has the ability to change both in structure and in function, depending on its environment. If you have PD, you can improve how your brain works through specific activities to help your brain relearn some mobility and movement tasks.*

**What do you mean by "forced" exercise?**

*This is a term used to describe that patients are forced to exert their maximal effort during the exercise, similarly to what is done during a professional training. Forcing the body to its maximal capacity is critical to improve strength and resistance.*

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**Is exercise still beneficial when there is minimal feedback for movement and posture? What are some recommendations for exercise options during the pandemic?**

*Yes. Exercise is always beneficial! You will get some feedback through the encouragement of voice and participating in online exercise opportunities. Flexibility, strength, balance, aerobic and functional activities are all beneficial to people with PD. We recommend a DVD called "LSVT BIG Exercises" that is a great option. If you have a loved one that wants to help, they can provide feedback that the instructor is providing. Keep active and exercising—all movement is beneficial!*

**Any thoughts on a treadmill, exercise bike or rower if someone can purchase only one piece of equipment? Which offers the best whole body workout?**

*Typically, we recommend an exercise bike as these have been the most studied and are the safest for most patients.*

**What percentage of PD patients need the DBS? Is DBS only used for the severe motor symptoms of PD?**

*No, DBS is used to help with wearing off and bothersome tremor, as well. Consult your physician to discuss the treatments that are best for your medical needs.*

**Does insurance usually pay for the DBS?**

*Insurance varies, but typically, it is covered by most insurance plans. DBS has been around for more than 30 years and is an appropriate treatment method. Contact your insurance provider for your plan details.*

**What does battery replacement entail?**

*This is typically an outpatient procedure but does involve a preoperative screening, anesthesia or visit. The battery in the chest is removed and replaced with a new battery.*

**How long do implants last?**

*Some implants are rechargeable and may last up to 15 years. Others (depending on settings) may last around 2 – 4 years.*

**Is focused ultrasound ablation (FUA) performed on young patients diagnosed with Parkinson's or is it used in older patients?**

*It can be used on either as long as they would like to improve tremor.*

**Can focused ultrasound be used in advanced disease?**

*Yes, to treat tremor only.*

**Does DBS help to improve gait and balance issues?**

*It typically does not, and can potentially worsen them. The best improvement for gait and balance is physical therapy—specifically LSVT-BIG.*

**Is DBS surgery an option for patients with Parkinson's psychosis?**

*Unfortunately, it is not. It can worsen instead of improve symptoms in these cases.*

**Can you have an ablation, and later be included in a gene therapy study currently in progress?**

*Although it is hard to predict the future, this is unlikely.*

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**Are the effects of focused ultrasound ablation permanent and, if not, can the procedure be repeated?**

*The effects of focused ultrasound ablation are permanent. If necessary, the procedure can be repeated, but this is not typical.*

**Does stress cause Parkinson's?**

*Stress does not cause Parkinson's disease, but it can temporarily worsen symptoms. It is helpful to see a movement disorders specialist to discuss possible treatment options.*

**How would you know if you qualify for deep brain stimulation?**

*Typically, you would see a movement disorders neurologist. If they felt you were a potential candidate you would then see a neuropsychologist for cognitive testing. A neurosurgeon and the nurse practitioner would also do a "levodopa challenge" (assess you on and off PD medications). Then, the entire medical team would discuss your case to determine if you were an appropriate candidate and if the surgery would have more positive outcome than negative outcome.*

**What is the website for exercises that can be done at home with a caregiver?**

Visit [hrs.osu.edu/research/research-labs/mend-laboratory](https://hrs.osu.edu/research/research-labs/mend-laboratory) for these exercises.

**Are you familiar with David Zid and Jackie Russell and "Delay the Disease"?**

*We are familiar with this well-respected program. Here at Ohio State, we have our own program for PD patients called "Moving with Purpose." You can learn more about Parkinson's disease fitness classes, including "Moving with Purpose," [here](#).*