University of Nebraska Medical Center

Parkinson's Post

to educate, inspire and empower individuals affected by Parkinson's

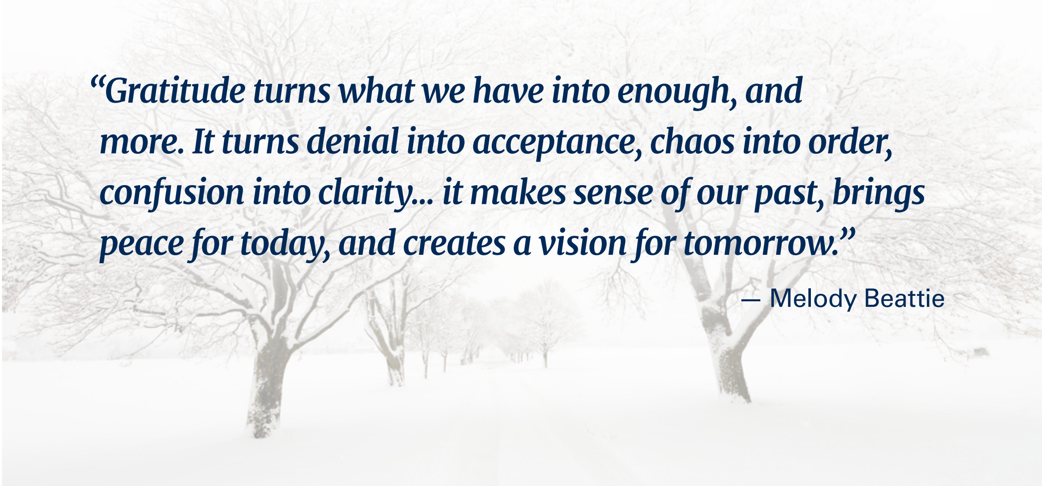
Welcome to the Fall/Winter 2022 edition of Parkinson's Post!

Julie Pavelka, MS, APRN-NP
Co-Director of Lewy Body Dementia Program | Memory Disorders Team
Department of Neurological Sciences | Nebraska Medicine

Autumn has arrived—the leaves are falling and the "fall back" of the clocks has occurred!

Parkinson's Disease in 2022: A Conference for Parkinson's Disease Patients and Their Families/Care Partners took place on Monday, Oct. 10, 2022, at the Scott Conference Center in Omaha and was very successful with offering both an in-person and webinar attendance option. If you were unable to attend and would like to obtain webinar access, please send an email with your request to **unmcneuroconf@unmc.edu**

As many of you know, I am transitioning from the Movement Disorders Team to the Memory Disorders Team at Nebraska Medicine. We have received a grant to develop a Lewy Body Dementia Program at UNMC/Nebraska Medicine and I will be co-director of the program with Dr. Murman, director of behavioral neurology division. I will continue to work closely with our movement disorder specialists to ensure this transition is as seamless as possible and I will continue to see individuals with Parkinson's disease dementia in my new role with the Memory Disorders Clinic. It has been a distinct honor and pleasure to be involved in so many of your Parkinson's journeys and I will forever be grateful for the relationships made over the past ten years.



> *"Gratitude turns what we have into enough, and more. It turns denial into acceptance, chaos into order, confusion into clarity... it makes sense of our past, brings peace for today, and creates a vision for tomorrow."*
>
> — Melody Beattie

Inside this issue

Welcome Dr. Kiel Woodward!

Kiel Woodward, MD, is a new faculty member and Movement Disorder Specialist (MDS) at UNMC/Nebraska Medicine.

Hometown: Omaha

Current position(s):

- Neurologist, Nebraska Medicine
- Assistant professor, UNMC Department of Neurological Sciences, Division of Movement Disorders

Previous position(s), including residencies, fellowships:

- Medical school at UNMC
- Residency in neurology at UNMC/ Nebraska Medicine
- Fellowship in movement disorders at UNMC/Nebraska Medicine

Professional interests: I subspecialize in movement disorders neurology, so I am interested in treating people with Parkinson's disease, tremors, balance problems, dystonia, tardive dyskinesias, restless leg syndrome, tics and any other abnormal movements. I am particularly interested in gait disorders and plan to develop a clinic specifically for people with this problem.

How I fell in love with neurology and movement disorders: When I started medical school, I thought I was going to pursue a career in surgery, but I became enamored with neurology during a clerkship when I got to work closely with a local neurologist. I was amazed at their ability to diagnose conditions simply by listening and observing, and I feel that movement disorders require the most skilled exam. I love the complexity of the brain and the patients in my clinic. I feel like I learn something new every day.

Memberships:

- American Academy of Neurology
- Movement Disorders Society

Three things people may not know about me:

- My whole family works in medicine. My brother and father are orthopedists, my mother and sisters are registered nurses, my wife is an occupational therapist, and my siblings-in-law are all doctors with Nebraska Medicine.
- My name, Kiel, is pronounced "Kyle."
- Omaha Interclub Men Youth Tennis Doubles Champion, 1997. Now retired.

Clinic location:

- Twin Creek, Bellevue
- Clarkson Doctors North Building, UNMC/Nebraska Medicine main campus

Kiel Woodward, MD

For appointments and referrals: Ask your primary care doctor for a referral or call 402-559-8600 to schedule an appointment.

Upcoming Events

Bellevue Parkinson's Education & Outreach Group

3rd Tuesdays 10 – 11:30 a.m.

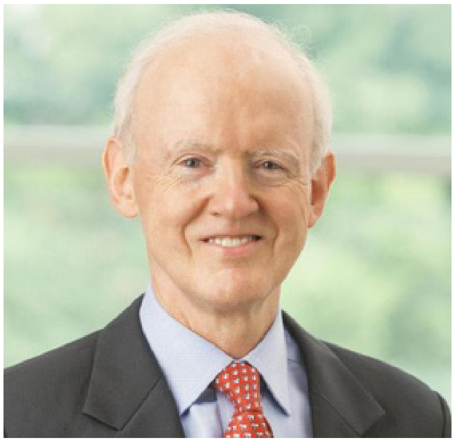
Bellevue Medical Center, Medical Office Bldg, Garden Level, Conference Rooms A & B

No RSVP Necessary. Questions or concerns contact Lauren Kesteloot:
lakesteloot@nebraskamed.com | 402-763-3740

Thoughts on My Retirement

John M. Bertoni, MD, PhD
Professor | Department of Neurological Sciences | UNMC

Life is the most precious gift of all. Life is an adventure. I am thankful to so many people I have met on my journey, and all my encounters with each of them in this incredible universe all around us. We have our many teachers to thank, and we stand on the shoulders of giants. We live and learn, and I hope all reading this will realize the importance of this moment. And of the next moment. Make them count.



John M. Bertoni, MD, PhD

Some say the journey of life is all about the ending or the destination, but we do not know exactly where how or when our journeys will end. This makes each moment even more precious. We cannot know how many moments there will be.

I say it is each precious moment that matters. The past is over and done. If we are wise, we can bring the lessons learned to better live our present moment. The future is unknown, and most of our worries won't happen, and most of what happens we cannot control. We are wise to plan for the future but are wiser to focus on what we do in the present.

I have devoted my working life moments to provide health care for those in need. The study of the brain and spinal cord, and all the nerves that connect us to our muscles, our bones, our skin, and our senses is the final frontier. There will always be more to learn.

I have learned so much from those I have served. I cannot thank my patients enough for all they have taught me.

I learned much from all the textbooks, all my teachers, all my colleagues, and all my experiences, but I learned the most from what my patients taught me. I learned more when I set aside my preconceptions, and really listened. Sometimes they spoke to me in whispers. Whispers tell the innermost secrets of one human being to another. Sometimes it's about how they want to live or why they want to live and sometimes when it's time to accept the end.

Atul Gawande says it very well in his book *Being Mortal*. We physicians and all of us health care providers often think our job is to ensure health and survival, but it is really to enable well-being. Well-being is about the reasons one enjoys life and wishes to be alive and for whom they want to be alive. When we and our patients and colleagues approach burnout with the pandemics and the sorrows we share together, we find these reasons the best we can. Sometimes, it is about the well-being of just living well and dying well, if for no other reason than to show others around us an example. The inspiring examples of so many of my patients have given me reasons to live and to give them all I can.

I love what I do. On my watch, I strive to give every patient the best care possible, so they may enjoy each of their precious moments for as long as possible. I also love the teaching of the next generations, as they climb higher and stand on our shoulders. I love sharing whatever skills I have to help those who need my help. I love the challenge of the research to find a way to cure and to alleviate the suffering. I love the challenge of thinking outside the box and finding the solution and returning our patients to a better life with many more precious moments on their own journeys. It is because I tell my patients to exercise and take care of themselves and be in the driver's seat of their own lives that has made me practice what I preach and has given me more precious moments to serve them!

I'm retiring from what I do now in early 2023 to give others their opportunity to come to the front of the line and stand on our shoulders. It's time for them to reach even greater heights. They have been taught the latest and best truths and have learned more ways to help in this ever more complicated final frontier. They will serve you well in your many precious moments to come, and learn much from what challenges and inspirational life stories you present to them.

I am not done yet, however. I will continue in my precious moments to find ways of serving this final frontier and all of you as long as possible.

Reflection on Past and Future of PD Care in Nebraska

Diego R. Torres-Russotto, MD, FAAN (he/him/él)
Professor & Vice-Chair for Education | Department of Neurological Sciences
Chief, Division Program & Fellowship Director | Movement Disorders | Students Clinical Neurology Education University of Nebraska Medical Center
Adjunct Professor of Kinematics | University of Nebraska at Omaha

As I get ready for my departure from UNMC, I would like to share some thoughts on what has been accomplished, and what we must do in the future.

Diego R. Torres-Russotto, MD, FAAN

Physicians, advance practice providers and nurses are under attack by insurers, health care administrators and executives, other payers and sadly sometimes even by patients. We are being asked to do more with less, to see more patients in a shorter amount of time. This is causing medical errors and a growing lack of satisfaction from physicians and -more importantly- from patients and their families. Medicine is currently the profession with the highest rate of suicide in the U.S. With this prospect, less and fewer young people are interested in joining the medical profession.

Medical training is an arduous process. For example, for a general neurologist to be board-certified, we need to do four years of college, four years of medical school and four years of neurology residency training. About 50% of Nebraskans suffer from one of the many hundreds of neurological conditions. Therefore, if we wanted all neurological care provided by specialists, we would need about 500 neurologists. We don't have a fifth of that in Nebraska. And with the advent of hundreds of treatment options, Neurology has become so complex that most neurologists now must undergo one to three years of additional subspecialty training in order to focus their practice. New knowledge and new skills are needed every day. For example, movement disorders experts need to learn about more than a thousand conditions, obtain additional skills like brain mapping, deep brain stimulation, botulinum toxin injections, skin biopsies, electrophysiological assessments, use of personalized devices to measure disease (like Parkinson's kinetograph), use of CALA-trio and similar devices to treat tremors, DUOPA pump treatment, and many more. It would be impossible for a general neurologist to be able to learn during residency all of this, and therefore subspecialists in movement disorders spend at least two years of additional training after residency. That's 14 years after high school.

One of the many movement disorders is Parkinson disease (PD). There are more than 20,000 patients with PD in Nebraska. This would require about 80 movement disorders experts to be able to care for them and for the other disorders of the subspecialty. We must also consider that, beyond clinical care, we must attend to three other missions: Research (to find the cures and treatments that our patients need), Education (to train the new generation of specialists that our patients need), and community outreach. So, it should be clear that these estimates of physicians needed in the state are a gross underestimation.

The presence of movement disorders experts in the state has lacked consistency and strength in numbers over the years. We are so thankful to Dr. Ron Pfeiffer who in the 1980's, and then Dr. Bertoni in the 1990's, worked tirelessly to care for our PD patients. The invaluable work of our general neurologists has been critical as well, but we have always been overwhelmed by the growing need. The only way to improve our healthcare situation was through creating our own neurologists. In the early 2000's we finally started to move forward at a faster pace, when Dr. Pierre Fayad became the chair of the UNMC Department of Neurology, while Dr. Bertoni took the reins at Creighton University. With two growing educational programs, we were finally going to be able to train the physicians that Nebraskans deserved. We have seen growth and stability since then.

When I was recruited in 2008, my plan was to create the first approved, comprehensive Movement Disorders Fellowship Program to train the subspecialists we needed. With the help of UNMC, the support of my department chairs (Drs. Fayad, Murman and Rizzo), and donations from the community (from the Hawks Foundation), we achieved our dream. Over the years, we have trained 15 subspecialists in movement disorders, and many have stayed in Nebraska to

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care for our patients. We have been able to create many comprehensive multidisciplinary clinics including PD, Huntington disease, PD-PLUS syndromes, dystonia and spasticity and ataxia, to provide best possible care and organize research.

I am extremely proud of the work that we, together, have done. Upon my departure, I know that I will miss my patients and my co-workers the most. I have accepted the position of inaugural chair of neurology at the Miami Neuroscience Institute/Baptist Health/Florida International University. It has been an amazing privilege to have met you, be your physician, and count with your friendship. Dr. Amy Hellman will become our interim division chief, and Dr. Erin Smith will become the director for our Movement Disorders Fellowship Program.

However, the work is not done yet. About 20% of people in Nebraska suffer from a movement disorder. From Tourette syndrome, restless legs syndrome and tremors to PD and dystonia, there are still a lot of people suffering from these diseases. I am humbly asking that you step up and support our center to ensure a bright future for Nebraska patients. All four missions are critical to the state: clinical care, research, medical education and community education and outreach.

I know our growth will continue in the steady hands of Dr. Hellman. Please keep me in your prayers as I embark in this new challenge. I am doing the same for all of you, for our team at UNMC and our students and trainees.

Vision Deficits with Parkinson's Disease

Anne Mahnke, OT
Occupational Therapist | Nebraska Medicine

When thinking about a movement disorder such as Parkinson's disease (PD), most thought of problems are with big movements like walking, going up and down stairs, or tremors in the hands.

Less common, but still very prevalent, are deficits with some of the smallest movements we make such as moving our eyes. There are many typical age-related changes that occur with vision, however, some may be exacerbated or related to PD.

According to the Parkinson's Foundation, some of the changes that can occur include double vision, convergence insufficiency or difficulty focusing at near, dry eyes, and a low rate of blinking. Smaller and slower eye movements needed for tracking objects and looking from point to point can also occur. In the day-to-day routine, these issues translate into difficulty with reading, trouble keeping up with moving cars or people around you and can even contribute to balance and coordination problems when walking, going from sitting to standing, and completing basic self-care tasks.

So, what do you do if you have PD and notice changes in your vision? One of most important things is to keep regular visits with your optometrist. Routine visits will monitor changes in your vision and catch issues that may be related to PD. Speaking with your neurologist or PD provider should also be a priority, so they are aware of visual changes and can make an appropriate referral to an ophthalmologist or therapist as needed. The ophthalmologist can complete a more in-depth assessment of visual skills and make recommendations for medications and lenses based on their assessments.

An occupational therapist can also help to address vision deficits and their impacts on someone's daily routine. The occupational therapist should be someone who specializes in vision or neurological disorders. During occupational therapy, the focus can be both on exercises to maintain functional movements of the eyes, as well as adaptations to assist with maintaining independence during daily tasks. As we know with PD, exercise is a form of medicine, and this includes the eyes. Programs such as LSVT-BIG and PWR! that are taught by a certified therapist, as well as specific eye movement exercises using the same principles, can improve and help maintain eye movements for better function. When using adaptations for visual deficits, some examples of items provided could include environmental modifications like lighting and contrast, glasses for glare, filters, or magnifiers. Occupational therapists specializing in PD and visual deficits would be most appropriate to see for this kind of care.

The complexity of PD is vast and ever changing for everyone. Make sure to mention any visual changes to your providers to get you set up with the resources you need in a timely manner. And remember, keep moving! Your muscles both big and small will benefit from any exercise you do!

Research in Parkinson's Disease: Where It's Headed and How You Can Be Involved

Erin L. Smith, MD
Movement Disorder Specialist & Co-Director | Comprehensive Multidisciplinary Parkinson's Disease Clinic
Assistant Professor | Department of Neurological Sciences | Nebraska Medicine Movement Disorders Center

As a Parkinson's disease (PD) specialist, one of the most frequent questions I get from my patients is "When are we going to find a cure?" We have come a long way since James Parkinson first described the disease in his 1817 essay "The Shaking Palsy," but we are still a long way from where we'd like to be. The advent of levodopa (branded as "Sinemet" or Carbidopa/Levodopa) has helped sufferers from PD live longer, but to this day we still do not have a cure.

Research in PD has focused on many areas and is headed in many directions. We still need to fully understand what is happening in the brain and why, much less how we prevent it, treat it, or cure it. A lot of current research also aims to refine the tools and treatments that we already have, investigating more effective ways to deliver medications or different ways we can utilize deep brain stimulation (DBS) and other advanced therapies. Some areas of research shift their focus to how we can simply improve quality of life and prevent complications for those suffering from the disease.

Causes of Parkinson's Disease

We have some limited understanding of what exactly is happening in the brain in PD, having known for a long time that it is related to deposits of a protein called alpha-synuclein in the brain. However, as it turns out those brain changes can vary widely between each person with PD and do not seem to explain the entire picture. It's difficult to find the "cause" of PD because now we know that it's likely a "multi-hit" disease process, where a combination of many factors is at play for each individual person. We still do not completely understand why some people develop PD at a certain age and others do not, with current research investigating factors such as environmental exposures (like pesticides), diet, and even genetic changes that can modify brain aging.

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Genetics and Parkinson's

Genetics in PD is a rapidly growing area of research, with hundreds of genes identified and more being found every day. Though 90% of patients with PD have no direct genetic link that they will pass on to their children, we have learned that genetic changes can impact disease progression, response to treatment, likelihood to develop medication side effects, and more. Gene modifying therapy is also emerging to develop tailored treatment options for patients with specific genetic changes.

Free genetic testing is available through the PD GENEration study, just visit **parkinson.org/pdgeneration** to learn more and see how you can participate. This study not only provides testing to identify any genetic changes you have that we know are related to PD, but it includes a consultation with a genetic counselor so you can have a better understanding of what the results mean for you and your family. Your information will then be stored in a database to be used for future research about genetics and PD.

UNMC is a participating site for the PD GENEration study but currently does not offer in-person enrollment, but does offer online enrollment options. There are in-person options available in neighboring states if prefered. All the sites are listed on their website.

Clinical Trials

When most people think of becoming involved in research, they are likely referring to clinical trials. These are the studies that include multiple medical institutions where new therapies are developed and tested on willing research participants across the country to see if they're safe and effective.

We have used recent clinical trials to find different ways to make levodopa better, with some of the latest delivery methods including a subcutaneous pump and on-demand treatments that do not need to be swallowed. Other current clinical trials are investigating medications that can help prevent complications of PD such as falls or bone fractures.

The currently enrolling clinical trials at UNMC involve patients who have undergone or are considering DBS surgery. One study is looking at how to use DBS to improve quality of sleep in PD, and another is investigating new and improved batteries that can collect data on symptoms and predict what programming settings are the best for you. Ask your neurosurgery team to see if you qualify, or visit the UNMC clinical trials website at **unmc.edu/research/clinical-trials**.

How You Can Get Involved

You can always start by asking your neurologist about any clinical trials or other research that they or their colleagues are currently involved in. The best way to learn about currently enrolling clinical trials and your eligibility to participate is by contacting the UNMC Research Advocate Office at **402-559-6941**, emailing **unmcrsa@unmc.edu** or visiting **unmc.edu/research/clinical-trials**.

Willing to travel? You can find the participating locations for any clinical trial in the U.S. listed at **clinicaltrials.gov**. The American Parkinson's Disease Association (APDA) also funds eight Centers for Advanced Research across the county where more clinical trials are taking place. For more information visit **adaparkinson.org** to learn more.

The only way to understand PD better and finally find a cure is with your help. We appreciate all of you who have already participated in research through UNMC or a neighboring institution. You can make a difference not only for you but for others suffering from PD in the future.

Helpful Contact Info & Website Links:

UNMC Research Advocate Office:
☎ 402-559-6941
✉ unmcrsa@unmc.edu
🖥 unmc.edu/research/clinical-trials

Current Clinical Trials in the U.S.:
🖥 ClinicalTrials.gov

Parkinson Foundation:
🖥 parkinson.org
Under "Advancing Research"

Michael J. Fox Foundation:
🖥 michaeljfox.org
Under "Take Action" --> "Participate in Research"

National Institutes of Health (NIH):
🖥 ninds.nih.gov
Search "Parkinson's Disease: Hope Through Research"

American Parkinson Disease Association (APDA):
🖥 apdaparkinson.org/

PD GENEration Study:
🖥 parkinson.org/pdgeneration

Imaging and Parkinson's Disease

Kiel Woodward, MD
Movement Disorder Specialist | Assistant Professor | Department of Neurological Sciences | Nebraska Medicine Movement Disorders Center

A common question that arises during clinic visits for Parkinson's disease (PD) patients is whether to obtain imaging studies of the brain, such as a CT scan or an MRI scan.

There are several different imaging techniques that can be performed, and each has their place in the care of patients who present with possible PD. At some point during your disease course, you will likely have brain imaging obtained for one reason or another, although not everybody with PD needs to have imaging. There are a few key times and reasons why your doctor may want you to have a brain scan.

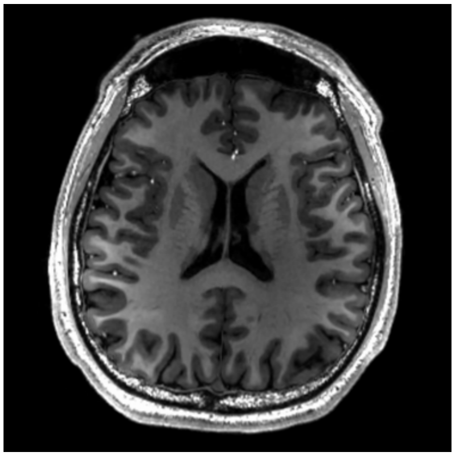
1. **After your first visit or two to aid with diagnosis**
   If your doctor thinks that your history and examination are consistent with classic PD, then they may not think that imaging studies are necessary. Some neurologists obtain brain imaging on every PD patient. However, if there are any atypical findings then they will most likely decide to get imaging to look for other causes of PD symptoms such as the atypical Parkinsonism syndromes, stroke, tumor, or other brain abnormalities. Contrary to what you might expect, CT and MRI imaging is usually normal in PD, so any abnormalities may suggest another diagnosis. Your doctor may also decide to get imaging of your spine for the same reasons.
2. **If there is a significant change in your symptoms**
   PD tends to progress steadily and gradually. If there are rapid changes to your symptoms that are unexpected, imaging can help assess for other contributors aside from the PD that could potentially be treated.
3. **After a fall with head trauma**
   Head imaging is often performed in the emergency department after a significant fall, this is to assess for bleeding in the brain that can often go undetected for several days or weeks if imaging is not performed. You will also likely have imaging performed of other involved areas of your body to assess for other bleeds and/or bone fractures.
4. **Prior to consideration of brain surgery, such as deep brain stimulation (DBS) or focused ultrasound**
   Even if you have classic PD symptoms without question of the diagnosis, imaging will be required prior to consideration of DBS or other brain surgery. This helps the surgeon target the exact area of your brain where the stimulator will be placed.

Obtaining imaging in any other situation will be up to you and your neurologist. If you have PD, then there is no need to perform serial imaging without a reason. There are three main types of brain scans that are performed in the above situations:

CT (Computed tomography) scan

This is the oldest and most basic brain scan. The CT scan was first developed in 1967, it combines a series of X-ray images taken from different angles around your body and uses computer processing to create cross-sectional images (slices) of the bones, blood vessels and soft tissues inside your body. Head CTs are very quick studies, taking on average just a few seconds in the scanner once the process is started. CT images provide more detailed information than plain X-rays do but are not nearly as detailed as an MRI. The most common situation of having a head CT performed is in the emergency department after a sudden change in symptoms or after a fall to assess for bleeds or bone fractures. Your neurologist may have you undergo a head CT in lieu of an MRI if you are unable to have an MRI performed due to presence of a pacemaker, bladder/spinal cord stimulator, or other MRI-incompatible device.

Normal head CT. *Image courtesy of radiopaedia.org*



Normal brain MRI. *Image courtesy of wikipedia.org*

MRI (Magnetic resonance imaging) scan

This is the most common type of scan that your neurologist may order to aid

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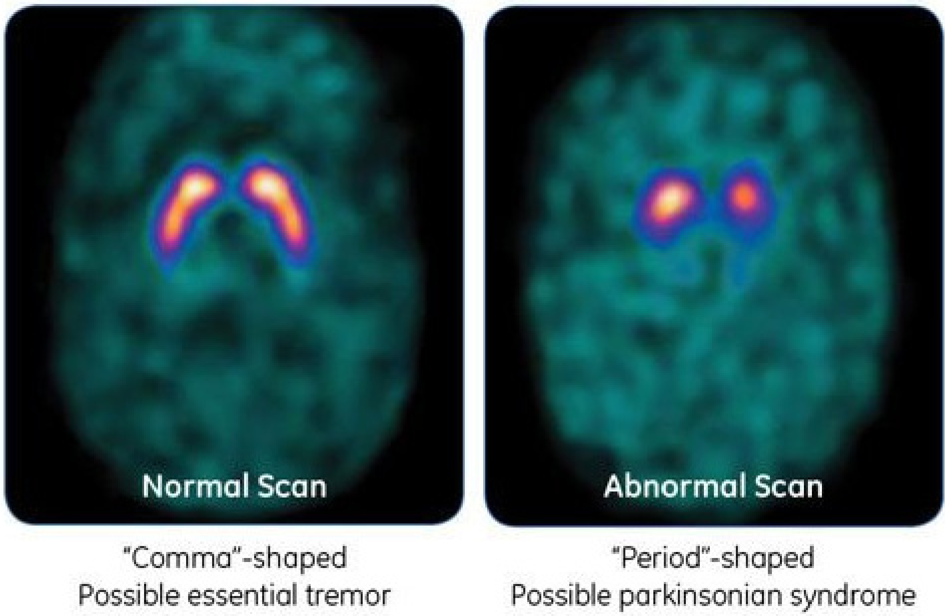
with the diagnosis of PD. MRI provides a much more detailed picture of the brain structure and any underlying abnormalities than CT and is currently the most helpful study in differentiating PD from other causes of Parkinsonism. As opposed to CT, MRI does not use x-rays or radiation but rather uses powerful magnets to form images of your brain. The MRI machine itself is slightly longer and the opening is smaller compared to the CT machine. The time to obtain complete MRI images is much longer than CT, averaging around 45 minutes inside the machine. If you are claustrophobic, your doctor may be able to assist you in relaxing during the scan.

DaTscan (Dopamine transporter scan)

This is a special scan that can help assess the health of the dopamine-containing neurons in your brain that cannot be seen on MRI or CT. The primary use of this scan is to help differentiate PD from other tremor syndromes, such as essential tremor, if the diagnosis is unclear.

The DaTscan unfortunately cannot differentiate PD from other Parkinsonian syndromes, such as PSP or MSA. This test takes several hours to perform, as you are given a special IV dye/contrast agent several hours ahead of time that takes time to concentrate in your brain before the scan. In PD and other Parkinsonian syndromes, the DaTscan is expected to be abnormal when compared to healthy patients (pictured below). The DaTscan is not perfect (accuracy of approximately 90%) and can be normal in the early stages of PD, so the preferred method of diagnosing PD remains a good clinical history and examination.

Left: a typical MRI machine. Right: a typical CT machine. *Image courtesy of philips.com*



Normal vs. Abnormal DaTscan results. *Image courtesy of apdaparkinson.org*

There is no test that can single-handedly diagnose PD or differentiate it from the other Parkinsonian syndromes. However, imaging studies such as CT, MRI, and DaTscan are useful tools to be used as pieces of the puzzle in conjunction with the history and exam to help with the diagnosis and management of PD. If you have more questions about the role of imaging in the management of PD, or if you would benefit from a brain scan, ask your neurologist during your next clinic appointment.

Sources:

Pagano G, Niccolini F, Politis M. Imaging in Parkinson's disease. Clin Med (Lond). 2016 Aug;16(4):371-5. doi: 10.7861/clinmedicine.16-4-371.

Bega, D., Kuo, P.H., et al. Clinical utility of DaTscan in patients with suspected Parkinsonian syndrome: a systematic review and meta-analysis. npj Parkinsons Dis. 7, 43 (2021).

Strategies to Increase Calorie Intake

Jenna Wuebker, MS, RD, LMNT
Nutrition Therapist | Neurological Sciences Department | Nebraska Medicine

Changes with Parkinson's disease (PD) can affect how much you eat and can lead to eating less than you usually do.

Having a lower appetite, losing the ability to smell and taste food, feeling nauseous, sleeping more during the day, difficulty chewing and swallowing and problems with the GI system such as constipation can all impact how much you eat. This can then contribute to weight loss, muscle loss, malnutrition, decreased energy levels and missing out on key nutrients your body needs.

If you notice unintentional weight loss, it is especially important to use strategies to increase your calorie intake and support the nutrition and energy your body needs. Many people with PD have a higher metabolism where the body is burning more calories than it used to. This would be another reason to increase the amount of calories that you consume.

The following ideas can be used to add more calories to your daily intake:

Have more frequent meals and snacks

- Create a schedule to eat 3 meals and 3 snacks between meals.
- Have something every 2 – 3 hours.
- Eat larger meals when your appetite is better. Appetite is generally the greatest in the morning.

Add calorie-dense foods

- Cook with milk instead of water when making hot cocoa, hot cereal, and pudding.
- Mix dried fruit, nuts, granola, honey, or dry cereal with yogurt and hot cereal.
- Add nuts and seeds to salads, pasta dishes, cereals, yogurt and ice cream.
- Use sauces and gravies on meats, potatoes, vegetables and noodles.
- Make casseroles with a soup or cream base.

Pick out protein foods

- Add beans and lentils to salads, soups, and casseroles.
- Include seafood, chicken, turkey, beef and pork in casseroles, soups, or as the entrée.
- Enjoy cottage cheese or yogurt.
- Have spoonful's of peanut butter or add to crackers, bread, waffles, apples, bananas and celery sticks.

Add fats to meals and snacks

- Drizzle olive oil over noodles and rice after cooked.
- Cook eggs, vegetables, and meats in pan with oil or butter.
- Add avocado or guacamole to sandwiches, salads, burritos, egg scrambles and smoothies.
- Make a meat or egg salad sandwich with extra mayonnaise.

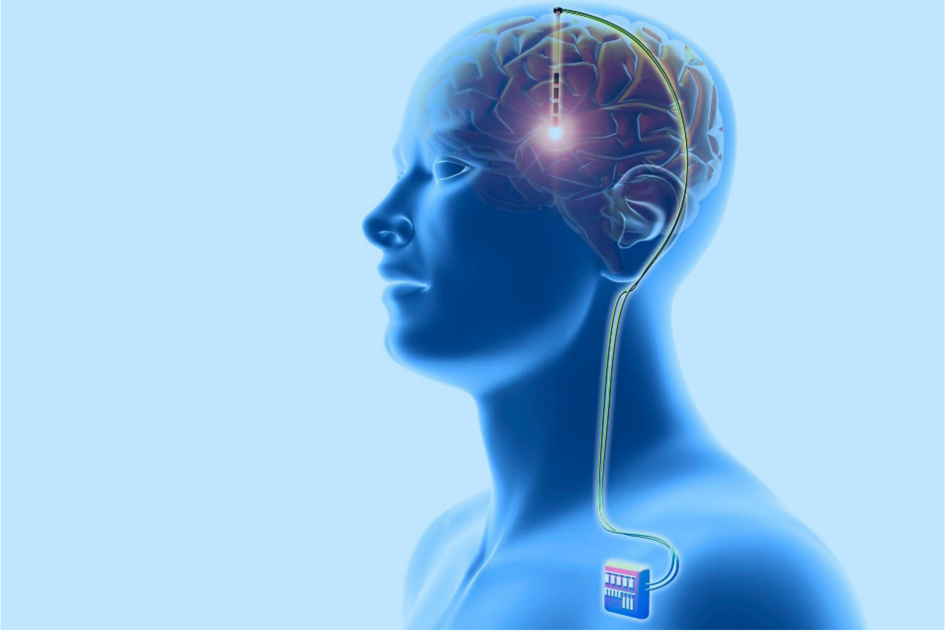
Drink liquids that contain calories

- Drink milk, chocolate milk and soy milk.
- Have smoothies with high calorie ingredients added such as heavy whipping cream, coconut cream, oils, peanut butter, cream cheese, avocado and honey.
- Include ready-to-drink shakes such as Ensure®, Boost®, Carnation Breakfast Essentials®, Orgain®, Bolthouse Farms®, and many other brands. Look for varieties that have the highest number of calories.
- Drink fruit juice, vegetable juice, sports drinks, Naked® juices and lemonade.

Is Deep Brain Stimulation Right for You?

Miguel Situ-Kcomt, MD
Assistant Professor | Movement Disorder Specialist | Department of Neurological Sciences | University of Nebraska Medical Center

While many patients with Parkinson's disease (PD) remain stable on medication therapy, as the disease progresses, and levodopa requirements and fluctuations increase, it begs the question on what to do next.



Understandably, more medication may not be enough, and it is about this time when your neurologist may consider advanced therapies for PD. Currently, the most popular, and well-studied option is deep brain stimulation (DBS).

DBS is a surgical procedure where two specially made electrical wires are implanted in specific targets of the brain. This provides lasting benefit to PD symptoms as well as potentially minimizing undesirable side effects. However, how do we know if a patient is the right candidate?

When a patient is being considered for DBS candidacy, there is a whole process performed here at Nebraska Medicine to ensure that we select the right patients while minimizing the risks. After all, it is still brain surgery! Here are the steps involved:

1. **Assess eligibility:** A patient considered for candidacy must have clinical suspicion of idiopathic PD. This means that it must fulfill the two of the clinical criteria for diagnosis (bradykinesia, muscle rigidity, resting tremor and gait instability), must have had it for at least three years since onset of symptoms, and has an excellent motor response to levodopa therapy, regardless of the side effects. The last part is paramount as DBS will only improve those symptoms where levodopa has provided benefit.
2. **Inpatient motor assessment:** Once a candidate is selected, he is scheduled for an elective admission to our neurology floor. In it, the patient will be tested when OFF medication, and then when ON medication. For that to happen, we usually request that the patient holds all levodopa (and depending on the medication combination, other agents) at least 12 hours before the morning assessment, which is done between 8 to 9 a.m. Admissions are usually performed on a Wednesday afternoon, so the last dose is taken that first night in the hospital, and the assessment done on Thursday. The motor assessment is done using the same grading scale that your movement disorder specialist does during a regular visit, called MDS-UPDRS (Movement Disorder Society-Unified Parkinson's Disease Scale). After the OFF testing is completed, the patient is then given 1.5 to double the dosage of their usual levodopa medication (so if you usually take two tablets each dose, we will give you three tablets), and then reassess with the same MDS-UPDRS scale when the patient feels the medication has kicked in, or he is ON. After the process, one of our case managers will provide detailed education about what to expect with the device programming, and how to care for it. Details about the surgical procedure will be explained by the neurosurgeon, should the patient eventually get selected for it.
3. **Adjunct testing:** During the inpatient admission, not only your motor symptoms will be assessed, but also your cognitive performance as well as your brain anatomy. For the former, a neuropsychologic testing is done the afternoon prior to the admission by a trained neuropsychologist. As for the brain anatomy, a brain magnetic

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resonance imaging (MRI) with and without gadolinium contrast will be performed after the motor assessment. It is important to gauge your cognitive performance as DBS surgery has the rare chance of precipitating an already latent cognitive impairment. Equally important is checking brain anatomy to gauge the best way to approach the wire implantation without causing disabling damage to the brain.

4. **Multidisciplinary meeting:** Once we have a complete motor assessment with ON/OFF testing, a neuropsychologic report, and a good quality brain MRI with and without contrast, a file is created based on the patient's history and then the case is discussed in a Nebraska Medicine panel involving several movement disorders neurologists, functional neurosurgeons, neuropsychologists and case managers. We discuss the motor performance, cognitive evaluation, anatomical considerations and social aspects of the patient, and once a consensus is made, we make the decision to either consider the candidate eligible or not for DBS surgery. The criteria vary per case, but an ideal candidate is one who has had at least 30% improvement of their motor testing when taking levodopa, absence of significant cognitive or psychiatric comorbidities in the neuropsychologic report, and a brain MRI that shows no anatomical barriers to implant the electrodes, and no lesions that suggest an alternative diagnosis. Conversely, someone with significant cognitive impairment, poor response to levodopa, uncontrolled psychiatric comorbidities, anatomical variants that prevent implantation, or signs that suggest a diagnosis other than PP, are poor candidates for DBS.

The entire process from the office visit to the multidisciplinary meeting takes, on average three to four months, depending on the patient's as well as the hospital's availability. After all the steps are done, we communicate the results of our consensus to the patient by phone or during an appointment, and then refer them to one of our specialized functional neurosurgeons to schedule the procedure.

In summary, there are several aspects that must be considered before implanting a DBS device, but we keep the utmost care and standards of diagnostic quality to ensure that the patient receive the appropriate therapy without risk.

Social Work Role in the Outpatient Neurology Clinic

Colleen Hoarty, LCSW
Medical Social Worker | Outpatient Neurosciences Center | Nebraska Medicine

Sometimes when I meet with patients and families in clinic or call them on the phone, they seem surprised that a social worker is meeting with them or reaching out. You may be wondering, "Why would I need to talk with a social worker?"

A medical social worker in an outpatient clinic is a member of your healthcare team who can help address a variety of things that may be impacted by your health. In our neurology clinic, I reach out to patients and families to see how I can support you as you are navigating Parkinson's disease. Some of the ways that I do this include:

- Providing information and a connection to community resources for basic needs (e.g., financial concerns, transportation)
- Providing education and direction on Advance Directives
- Talking to people about disability benefits if you are unable to continue working
- Providing information and a connection to resources that can help with care needs in the home and/or respite care. As part of that, providing information on what programs or insurance coverage may (or may not) help with the cost of care
- Helping people adjust to an illness such as Parkinson's disease and discussing the ways it can affect patients and families. Helping people to develop coping strategies that can help with stress.
- Addressing long-term care needs and exploring care options both in the home and in the community
- Providing support to caregivers and discussing ways to care for both yourself and your loved one

If you feel that you could benefit from talking with a social worker, please let your healthcare provider know. You are not alone!

The Lewy Body Dementias

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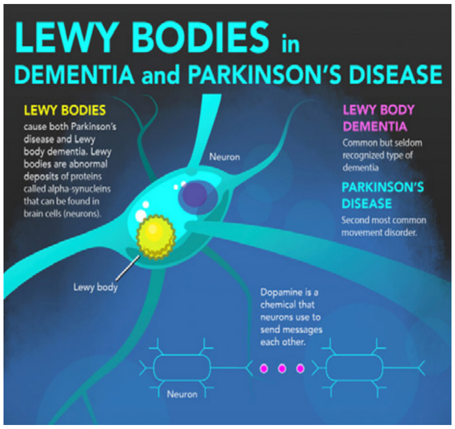

Where does the name Lewy body come from and what are "cortical" Lewy bodies? The Lewy body disorders are named after Dr. Friedrich Lewy, who discovered abnormal nerve cell inclusions in the autopsied brains of patients who died from Parkinson's disease (PD). These inclusions were found in the motor control parts of the brain (i.e., basal ganglia nuclei, especially the substantia nigra). Dr. Lewy described these inclusions starting in the 1920's and subsequently these abnormal inclusions were called "Lewy bodies." In the 1960s, "cortical" Lewy bodies were discovered in patients with PD motor symptoms and features of dementia and psychiatric symptoms. These cortical Lewy bodies were composed of the same aggregated protein (i.e., alpha synuclein) seen in basal ganglia Lewy bodies, but they had a different appearance and distribution. Cortical Lewy bodies are found in the emotion parts of the brain (i.e., limbic system) and the thinking parts of the brain (i.e., cerebral cortex). Cortical Lewy bodies are associated with the changes in thinking and psychiatric symptoms seen in patients with one of the Lewy Body Dementias (i.e., PD with Dementia abbreviated PDD and Dementia with Lewy Bodies abbreviated DLB). Thus, Lewy bodies found in the brain at autopsy have helped us define and understand PD and the Lewy Body Dementias.

What does the term dementia mean and what is the difference between PDD and DLB? Dementia is defined as a decline in memory and thinking that is severe enough to limit a person's ability to do every activity independently, such as driving, handle finances, shopping, cooking and taking medications. Dementia can be caused by many conditions, including cortical Lewy bodies and can be classified as mild, moderate and severe. The main distinction between PDD or DLB is the timing of the dementia symptoms in relation to the timing of motor features of parkinsonism (i.e., stiffness/rigidity, slowness/bradykinesia and tremor). In patients with PDD, motor symptoms appear first and typically for many years and then later a patient develops dementia symptoms. In patients with DLB, the dementia symptoms and the motor symptoms of parkinsonism develop together, or the dementia symptoms precede the motor symptoms.

What are the symptoms and features of the Lewy Body Dementias? The clinical features of PDD and DLB are very similar. Both conditions cause some combination of motor features of parkinsonism, including bradykinesia, rigidity, tremor and eventually poor postural balance. The dementia symptoms can include problems with executive cognitive function (e.g., planning, multitasking, decision making), memory (e.g., retrieving information you have learned), visual spatial abilities (e.g., decoding complex aspects of what you see), and language (e.g., coming up with names). Fluctuations in thinking are very common in patients with PDD and DLB. Frequently patients have increased problems with thinking and confusion in the evening. This is where the term "sun downing" comes from. Patients with Lewy Body Dementia commonly have visual hallucinations, delusions, and are more likely to have dream enactment behaviors called REM Sleep Behavior Disorder (RBD). Patients with Lewy Body Dementia are at increased risk of acute confusion called delirium in the setting of hospitalizations, surgery and medical illness.

What treatments are available for Lewy Body Dementia symptoms? The dementia symptoms of PDD and DLB can be improved with a group of oral medications called cholinesterase inhibitors. The brand and generic drugs names of this drug class include Exelon/rivastigmine, Aricept/donepezil and Razadyne/galantamine. These medications increase a brain chemical called acetylcholine and can help improve memory, attention, and everyday function and can decrease the severity of psychiatric symptoms such as hallucinations and delusions in some patients. Side effects can occur and include nausea, diarrhea and a runny nose. For patients with problematic visual hallucinations and delusions, we first try to adjust the PD medications that increase dopamine and are used to improve motor symptoms. The next option is to consider adding Nuplazid (pimavanserin), which is a medication that is FDA-approved for treating hallucinations in patients with PD. Problematic symptoms of dream enactment during sleep (RBD) can be treated with the over-the-counter medication melatonin or the prescription medication clonazepam/Klonopin.

Behavioral Management of Hallucinations in Parkinson's Disease

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Hallucinations and illusions are common in people with Parkinson's disease (PD), affecting 25 – 70% of patients with PD over the course of the disease (Parkinson's Foundation, 2018).

DEFINITIONS	
Illusions	Misperception of something that is actually there. An example would be mistaking a pile of clothes on the floor for your dog.
Hallucinations	Unusual sensory experiences in which one sees, hears, smells, tastes, or feels something that is not actually present.

In people who have PD, visual hallucinations/illusions are more common than those affecting the other senses. People with hallucinations commonly report:

- Seeing well-formed people, animals or objects, which are typically non-threatening, familiar and appear only briefly.
- Having a "passage hallucination," or a brief sensation that there is a person or animal moving by in the periphery of their visual field.

A few factors are thought to contribute to the development of PD-related hallucinations/illusions:

- Effects of medications used to treat PD.
- PD-related changes in the structure and activity of visual pathways in the brain.

When hallucinations first appear, individuals with PDe usually have insight. That is, they understand that this unusual sensory experience is a symptom of PD and not reality. As the disease progresses, people sometimes lose insight. This may lead to changes in behavior, which put the person and their caregivers at greater risk.

Fortunately, there are several behavioral strategies that can be helpful in managing hallucinations in PD. The strategies that will be effective to manage hallucinations and illusions in PD depend on each person and the characteristics of the illusions/hallucinations.

Before attempting to manage symptoms behaviorally, any sudden or drastic change to mental status (i.e., sudden confusion that is significantly different from baseline for that person) should be disclosed to a healthcare provider to rule out reversible causes of psychosis such as delirium or recent medication changes. Annual exams to evaluate hearing and vision are also important as normal, age-related declines in vision and hearing can contribute to experiencing hallucinations and illusions.

Changes to the Environment:

- Keep dark areas well-lit, such as hallways and staircases and turn on extra lights at night to help reduce visual hallucinations/illusions.
- Remove or secure any dangerous/hazardous items (e.g., weapons, cleaning products) to prevent accidents or injuries.
- Hallucinations can reduce a person's ability to pay attention to their environment. Remove or move any items that could present a tripping hazard.

When Experiencing Hallucinations:

- Keep a detailed record of hallucinations to help identify if there are any triggers. This may improve predictability of hallucinations, make them less distressing and facilitate productive conversations with medical providers.
- Engage in reality-testing such as attempting to touch what you are seeing. If the hallucinations are people, you could have them interact with the environment. If they do not, that is a good sign the person is a hallucination.
- Sleep deprivation can increase the occurrence of hallucinations/illusions.
- People often feel embarrassed by mental health symptoms, but hallucinations/illusions are common in PD. Not disclosing them can lead to social withdrawal and prevent conversations about treatment options. Talk about your hallucinations with loved ones and your medical providers.

For Caregivers:

- If the person has preserved insight, gently pointing out that they are experiencing a hallucination may be sufficient.
- If insight is poor, arguing with someone will only increase their agitation. Instead, go along with what they are saying or attempt to distract the person.
- If someone becomes agitated or aggressive, just remember the "**5 S's**."
  - » **S**tay calm
  - » **S**upport: Attempt to reassure the person they are safe, and engage in active listening
  - » **S**low: Try not to make any sudden movements
  - » **S**pace: Do not crowd the person
  - » **S**afety: If you feel your loved one is a danger to themselves and/or others, call 911.
- Tell medical providers and trusted loved ones about the hallucinations.

You can also discuss with your neurologist whether there are additional medical interventions for hallucinations.

MY PD-CARE, a Parkinson's Disease Resource to Support Confident Discussions with Your Doctor

What is Parkinson's disease?

TERM	WHAT DOES THAT MEAN?
"Off" time	A period when Parkinson's symptoms return. Symptoms of "off" time present in many different ways and are often described by patients (but not limited to) as:[1] • Slowness • Stiffness • Motor fluctuations • Freezing • Unsteady • Trouble walking • Tremor • Shakiness • Jittery • Restlessness • Difficulty getting in and out of a chair • Less hand coordination • Tightening of muscles • Anxiety
Dyskinesia	Bothersome extra movements that you don't have control over, especially after your oral medication dose, and can interfere with your day-to-day activities (can occur, for example, in your arm, leg or trunk)[2]
Fluctuations	Times when you are feeling well for part of the day (when your Parkinson's symptoms are well controlled) and not feeling well for the other part (when your PD symptoms have returned).[3]

Parkinson's Disease (PD) is a progressive neurological disorder with defining clinical symptoms that include tremor (involuntary shaking), bradykinesia (slowness), rigidity (stiffness) and balance problems.

How can MY PD-CARE help?

MY PD-CARE is designed to assist you in tracking your PD symptoms and "Off" time. This tool can aid you and your health care provider to better understand your current symptom status to determine the best course of treatment for you. MY PD-CARE was developed in collaboration with Parkinson's Foundation, an international group of Movement Disorder Specialists (a neurologist with additional training in PD) and AbbVie Inc. The MY PD-CARE questionnaire is intended for patients and/or care partners to complete and discuss the results with their treating health care provider. The questionnaire takes approximately 5 minutes to complete. It's designed for patients to complete before coming into the office or while waiting in the office to enable a more meaningful discussion and help you and your provider identify whether adjustments to treatments may be needed.

Upon completion of the online questionnaire, a summary will be generated that you can use to help guide a conversation with your PD health care provider at your next visit. The website includes patient education around PD progression and links to resources from the Parkinson's Foundation (**www.mypd-care.com**). Similarly, your health care provider has access to a related, clinician tool, known as MANAGE-PD to further assess your PD symptoms.

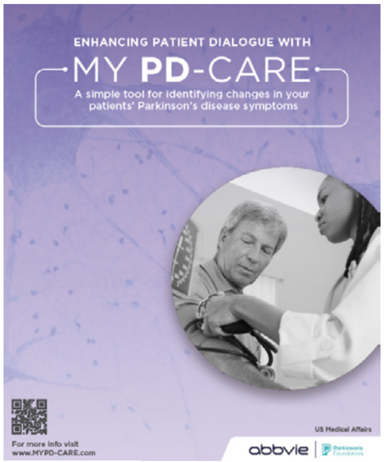
While PD is primarily referred to as a 'movement disorder,' it is also becoming clearer that PD impacts areas beyond movement. These symptoms are called 'non-motor' symptoms and examples include but are not limited to depression, anxiety, sleep and gastrointestinal issues. The symptoms of PD can present differently for everyone and can also progress differently for everyone. Therefore, it's important to identify the issues that are bothersome to you when speaking with your HCP.

How might symptoms change over time?

As the disease progresses, medications for motor symptoms may no longer work as well and may need adjustments or changes. Your health care provider may start using terms like "Off" or "On." "Off" time is when your medication is not working well, and you experience motor symptoms. When you're "Off," you might feel stiff or slow, and may describe it as sluggish, or like your limbs are resisting the ability to move. You may feel fatigued or have trouble walking, where you have a hard time picking up your feet or your legs might feel "rubbery."

It is important to monitor and document the frequency and duration of these "Off" periods and talk to your health care provider at every visit about your symptoms to support shared decision making with you and your provider.

Example questions within the questionnaire include, "How many times a day do you take oral levodopa pills?" and "Do you experience random fluctuations of motor symptoms with your current oral treatment?" It also includes definitions to better help you understand the questions, as well as common terms your health care provider uses to describe your PD symptoms.



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v1.0 approved 10/2022

Please be sure to always speak with your healthcare provider about your medical questions. Only you and your healthcare provider can determine whether a tool like this is right for you.

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1. Chahine, et al. Movement Disorders Clinical Practice 2020; 7(3):284-292.
2. Dyskinesia. Parkinson's Foundation. Accessed February 16, 2022. https://www.parkinson.org/Understanding-Parkinsons/Symptoms/MovementSymptoms/Dyskinesia.
3. Motor fluctuations. Parkinson's Foundation. Accessed February 16, 2022. https://www.parkinson.org/pd-library/fact-sheets/motor-fluctuations.

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Reliable Parkinson Resources

NOTE: This list is not complete, nor is it endorsed by UNMC or Nebraska Medicine

American Parkinson Disease Association
www.apda.org

Davis Phinney Foundation for Parkinson's
www.davisphinneyfoundation.org

International Parkinson and Movement Disorders Society (WE MOVE)
www.movementdisorders.org

Michael J. Fox Foundation for Parkinson's Research
www.michaeljfox.org

Movement Disorder Society
www.movementdisorders.org

National Institute of Neurological Disorders and Stroke
www.ninds.nih.gov

Parkinson's Action Network
www.parkinsonaction.org

Parkinson's Foundation
www.parkinson.org

Parkinson's Foundation Heartland Chapter
www.parkinson.org/heartland

Parkinson's Nebraska
www.parkinsonsnebraska.org

Parkinson's Resource Organization
www.parkinsonsresource.org

The Parkinson Alliance
www.parkinsonalliance.org

The Parkinson's Disease Foundation
www.pdf.org

The Parkinson's Resource Organization
www.parkinsonsresource.org

If you would like a downloadable copy of any past *Parkinson's Post* newsletters, please email:
unmcneuroconf@unmc.edu

University of Nebraska Medical Center