

# Parkinson's Post

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

## Welcome to the November / December 2018 edition of Parkinson's Post!

Julie Pavelka, MS, APRN-NP

Memory and Movement Disorders | Department of Neurological Sciences | Nebraska Medicine  
parkinson.network@nebraskamed.com

Welcome to the November/December 2018 edition of Parkinson's Post and the last edition for 2018! As we come to the close of 2018, it's so rewarding to reflect over this past year's accomplishments by our Movement Disorder Team at UNMC/Nebraska Medicine; we have continued to participate in cutting edge research, attended and presented at many conferences across the United States and Internationally, continue to have an outstanding Movement Disorder Fellowship Program, continue to be the largest Movement Disorder Center in our Region and only Parkinson Disease Interdisciplinary Clinic in Nebraska, facilitate our monthly Parkinson Disease (PD) Support Group that is also available for live streaming, and continue publishing of the Parkinson's Post! We also continue to attend and present at PD Support Groups, most recently Adams, Neb., David City, Neb. and Life Care Center Elkhorn, Neb.

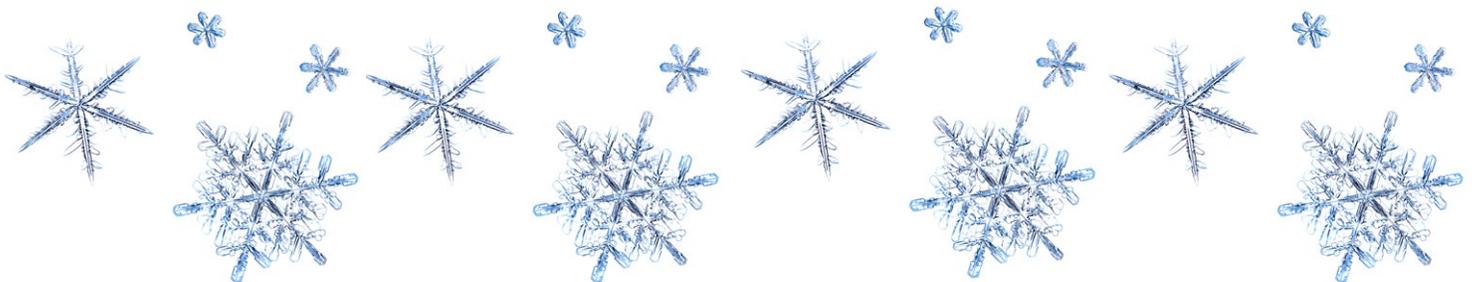
Our Monthly Parkinson Disease Support Group will continue to meet every third Friday, however, the time has changed to 10 a.m. Additional information regarding our support group is under "Upcoming Events" later in the newsletter. Anyone is welcome at this support group – we are encouraging RSVP's to ensure enough materials/handouts and refreshments available for everyone.

The November/December 2018 edition of Parkinson's Post includes a constellation of articles from Providers who are passionate about caring for individuals with PD. If there are any topics of interest that you would benefit from in future issues of Parkinson's Post, please don't hesitate to send an email with your request. At Nebraska Medicine/ UNMC, we are so fortunate to have Experts from many academic and clinical disciplines that are dedicated to the education, research, and treatment of individuals with PD.



### Inside this issue

- Cognitive Changes in PD
- Oral Nutritional Supplements
- Occupational Therapy in PD
- Caregiver Strategies
- Finger Tapping in PD
- Skate-A-Thon
- Upcoming Events
- Reliable Resources



# Cognitive Changes in Parkinson Disease

Daniel L. Murman, MD, MS, FAAN

Director, Behavioral and Geriatric Neurology Program | Vice Chair, Clinical and Translational Research  
Professor, Department of Neurological Sciences | University of Nebraska Medical Center

Changes in memory and thinking (i.e. cognition) are more common in patients with Parkinson's disease (PD) than once thought. James Parkinson's first description in 1817 of patients who would now be diagnosed as having PD described that "the senses and the intellect are uninjured." We now know that 50 to 60 percent of patients living with PD have some measurable changes in cognition.

Several aspects of cognition can change in patients living with PD. For example, in patients with PD it is common for patients to notice that; the speed of their mental processing slows down, it is harder for them to multi-task or divide their attention, harder to retrieve information or facts that they know, harder to perceive visual information, and their cognitive performance varies from day to day or even within a day.

About 25 percent of patients with PD have mild cognitive impairment (PD-MCI), where

they have mild changes in cognition, but are fully independent in their everyday activities. An additional 30 percent of patients with PD will develop more significant cognitive changes and develop dementia (ie Parkinson's disease with dementia or PDD). Patients with PDD have enough cognitive changes to interfere with their ability to do everyday activities such as finances, driving, or cooking without some assistance. Patients with PD who are older, have more severe disease, a longer duration of disease or a poor response to PD medications are at higher risk of developing PDD.

Let your PD provider know if you are having cognitive impairment symptoms. They can see if you have treatable conditions other than PD that are making your cognition worse (e.g. vitamin deficiencies, low thyroid levels, sleep apnea, etc.). They will also your review your medications to make sure you are not on medications making your memory worse (e.g.

anticholinergic medications such as Benadryl). Finally, there are FDA-approved medications that can improve cognition in patients with PDD.

If you are experiencing cognitive changes there are several practical things you can do to lessen the impact of these changes. For example, working on one thing at a time and decreasing distractions helps. Using a detailed planner and calendar can organize your day and should be kept with you so that you can refer to it as needed. Use a timer or your smart phone for important reminders, including medication administration times. Always place important items in the same place, so you always know where to find them. Finally, reflect on the events of the day as a memory exercise before you go to sleep.

## Oral Nutritional Supplements

Jenna Paseka, MS, RD, LMNT

Nutrition Therapist | Neurological Sciences Department | Nebraska Medicine

In Parkinson's disease, people may have higher calorie needs than before. Low appetite and poor food intake can contribute to unintentional weight loss and put someone at risk for malnutrition. Not only can calories be increased through the foods you eat, but good calorie sources can also come from the beverages you drink. Oral nutritional supplements (ONS) are designed to provide a good calorie and protein source as well as providing essential vitamins and minerals. In other instances, ONS can be used as an addition to the foods you eat at meals and snacks to help maintain a balanced diet. These can also be used for a quick and convenient breakfast on the go, drinking with a light lunch, having as an afternoon snack or refueling after exercise.

ONS commonly come in ready-to-drink bottles (liquid) or powders to be mixed with a liquid. You can find a variety of flavors including chocolate, strawberry, vanilla, butter pecan, coffee latte and banana. There are name brand and store brand versions of ONS.

The most important thing is to find a flavor you like. Try more than one brand to see what you prefer. Please consult with your doctor

or registered dietitian to determine which ONS may be best for you based upon your individual needs.

Here are some oral nutritional supplements available in grocery stores:

Supplement Name	Form	Calories	Protein
Boost® Original	Bottle	240	10
Boost Plus®	Bottle	360	14
Boost® Simply Complete™	Bottle	190	10
Carnation Breakfast Essentials® Original Powder Drink Mix with 8 oz Whole Milk	Powder	280	13
Carnation Breakfast Essentials® Original	Bottle	240	10
Carnation Breakfast Essentials® High Protein Powder Drink Mix with 8 oz Whole Milk	Powder	280	18
Carnation Breakfast Essentials® High Protein	Bottle	220	15
Ensure® Clear (juice)	Bottle	180	8
Ensure® Enlive®	Bottle	350	20
Ensure® Original	Bottle/ Powder	220	9
Ensure® Plus	Bottle	350	13
Glucerna® Shake	Bottle	180	10
Muscle Milk® Original	Bottle	320	34
Orgain Organic Nutrition Shake	Bottle	250	16
Orgain Vegan Organic Nutrition Shake	Bottle	220	16

# Occupational therapy for people living with Parkinson's Disease

Narmean Pedawi, OTR/L

Occupational therapist | Nebraska Medicine

Parkinson's disease (PD) affects every individual differently. Some people with Parkinson's may experience symptoms such as poor posture, impaired balance and mobility, low vision and increasing fatigue. One symptom commonly experienced by people with Parkinson's is tremor; more specifically tremor affecting their arm/hand. Those with this type of tremor know that aspects of their life are impacted with how they carry out their activities of daily living. Some individuals may experience this tremor in their arm or hand during rest or with activity of that extremity. Some other challenges with tremor may include getting their hand or arm to do what they want it to do. For example, like when trying to feed themselves, brushing their teeth, dressing themselves, cooking a meal, or even using a phone. Tremor can have an impact on everyday activities that challenges their motor control and ability to coordinate the

movement to use that extremity. Typically, if doing a task one handed is difficult, than a person would try to compensate by using their other hand to help. However, a person with PD may still find it challenging to complete that task even when using two hands. Though there may be challenges that people with Parkinson's face, it is important to know there are professionals that can teach you how to work through them. In this case, Occupational therapists (OT) can help reduce the effects the symptoms have on your life. Ultimately, an OT will assist you in ways to promote the maintenance of normal roles, continue your daily routines, and stay engaged in your social habits as much as possible.

Occupational therapists help people who have a disability, illness or injury participate in "occupations" of daily living. Occupations can be defined as all the functional

activities someone participates in that is useful and purposeful to them; such as bathing, dressing, reading, driving, cooking and gardening. Occupational therapists have the education, knowledge base and trained skills using a Parkinson's specific approach to address the functional deficits of activities of daily living. Occupational therapy can make it possible for you to live day to day with symptoms of PD by teaching compensatory techniques, training on the use of adaptive equipment and show you how to modify the task or the demands of completing that task. It is important for your OT to know how the tremor affects your ability to perform or participate in your activities. This information will prepare the occupational therapist on how to teach people to continue day to day tasks that they enjoy doing, have to do and need to do whether that is at home, at work or socially.

## Common Challenges and How to Overcome Them with Occupational Therapy:

Your occupational therapists will evaluate and come up with a plan that is centered on you. The main objective is to make it possible for you to be as independent as able in order to carry out these tasks (occupations). Your OT can help make that task easier by showing you different techniques or even help modify the task using handy equipment to better support you while engaging in that occupation. Your well-being and self-management is important to your occupational therapist. Simple changes can go a long way into your daily routine.

**Handwriting:** One common area that is often a troubling issue for people with PD is their handwriting skills which grows smaller and less neat due to the decreasing ability to hold and use a writing instrument. Occupational therapists can teach a variety of hand exercises and movements to improve that control needed and the coordination to perform hand writing more confidently. Your occupational therapist may also determine the benefits of a handwriting aid and be able to evaluate the most suitable resource for you.

**Eating:** Many devices exist to make eating more simple and less of a chore. For some people, their tremor may be mild

enough that it may not affect their ability to scoop with a spoon, poke with a fork or cut with a knife. For others, eating can be so challenging that it leads to frustrations or even cause someone to be embarrassed to eat in public. An occupational therapist can help train an individual on using proper body mechanics, introduce a variety of modified tools such as weighted utensils or easy grip utensil, cups, plates or non-skid materials to keep bowls, plate or cups in place. It is worth considering these tools which do help people with Parkinson's. Speak to your OT to help decide which tool is most suitable for you. Not every individual is the same, so what works for one person may not work for another. Your occupational therapist can help you decide on what works best for you.

**Assistive Devices:** As the disease of Parkinson's progress, the motor and sensory symptoms such as tremors or shakiness, stiffness, slower movements and vision changes can make it difficult to manage electronic devices such as a tablet, a phone, a computer and mouse. For this, the goal of an occupational therapist is to enhance and enable an individual's participation in the use of technology. Your occupational therapist may include but not limit evaluating the

need, the process of acquiring the device, modifying or customize a device and provide training and technical support to the user and / or caregiver personnel. Having the right assistive devices or technological tools can increase, maintain or improve the functional capabilities for a person living with PD. Occupational therapists are understanding of occupational needs. An OT can facilitate the achievement of occupational performance to carry on activities of daily living as simply as possible and to help minimize barriers to carry out the functional skills needed to do so. There are a variety of principles that can be taught that may help functioning with a tremor easier. It is important to consider that an occupational therapist may be helpful. Talk to your doctor about some of the challenges you are facing. Your doctor can recommend an evaluation for individuals in need of this service.

# Moving Through Life, part 2

Anonymous Caregiver

Greetings to all readers. For the September 2018 issue of the Parkinson's Post, I wrote the first of my caregiver contributions, "Moving Through Life". In it I gave an overall history of my husband's experience with Parkinson's and the information and supportive behaviors I had learned through those years. If you are new to the newsletter, I hope you will go back to that issue, as it may be helpful in providing the "big picture" of symptoms and what caregivers can do.

From now on, I will offer information and ideas on specific symptoms. Please also talk to your Parkinson's specialist about these.

**1. Constipation:** this is often a symptom for many years before other Parkinson's symptoms appear. For all his adult life, my husband had to take stool softeners almost daily to assist with this problem. We accidentally found an answer for this when he had to take antibiotics about two years before he died. He also took probiotics during the time on the antibiotic and continued on them until he died two years later. He never had another problem with constipation after starting on the probiotics. No more stool softeners or bowel stimulants. Once in a while he would eat a small dark chocolate candy

bar, but that was the only assistance he needed. There is no way to know if probiotics will help your PD person, but if your physician does not object, it is worth a try. We used a Walgreen's 4X brand, but there are many types.

**2. Double vision:** Before diagnosis, my husband had for years had occasional episodes of one eye not focusing correctly, and all docs said he must have a weak muscle, but not bad or frequent enough to do surgery or other treatment. But starting about the third year after diagnosis he had more and more trouble with double vision and with reading normal size print. This can be due to PD. He went to several ophthalmologists before one prescribed prisms for his glasses and that took care of the double vision problem for the next eight to nine years. Eventually even the prisms didn't help and he learned to adapt, although it was annoying.

**3. Reading difficulty:** PD can cause difficulties with reading for several reasons. The eyes muscles often do not work in coordination well for reading and focusing muscles may not work well. The normal eye exam will not necessarily pick up on this. Ask your eye doctor about prisms if

your PD person is having double vision.

Secondly, the brain may have difficulty remembering or making sense of what has just been read. This memory problem part of reading began to affect my husband more and more at about the tenth year after diagnosis. He turned more and more to TV and audio books and listening to music. I talked to one other PD spouse caregiver when she mentioned her husband's frustration with not being able to read and the eye doctor said his eyes were fine. She had not been told about the effects of PD on vision.

Thirdly, medications can affect the eye muscles and the brain's comprehension. Adjustments of PD meds can make things better or worse. Non-PD meds like oxybutynin for urinary problems can affect vision and mental functioning. Then it is a matter of trial and error to find the right doses with least side effects.

As always with PD, know that there is useful information to help you and that life adjustments and exercise and treatments can help you and yours to continue having a rewarding and interesting life.

Best wishes until next time.

## Upcoming 2019 Events

### Nebraska Medicine/UNMC Parkinson Disease Support Group

Every Third Friday at 10 a.m.

Fred & Pamela Buffett Cancer Center, 505 S. 45th St., Omaha, NE

#### Speakers:

January 18

Amelia Nelson, PhD, ABPP,  
Neuropsychologist

Department of Neuroscience, UNMC

February 15

Daniel Murman, MD, Director,  
Behavioral and Geriatric Neurology

Department of Neuroscience, UNMC

After entering the front of the Fred & Pamela Buffett Cancer Center, walk to the left of the registration desk and you will be directed to the appropriate meeting room which is on the **MAIN FLOOR (Conference Room 0.12.103)**. Available parking will be in **GREEN PARKING**, across the street from the Fred & Pamela Buffett Cancer Center – there also is a circle driveway in front of the Cancer Center that can be utilized for dropping off and picking up.

If you are unable to attend the support group, but would like to watch the meeting from your computer, please utilize the following link to watch the meeting live: [http://www.unmc.edu/livevideo/unmc\\_live2.html](http://www.unmc.edu/livevideo/unmc_live2.html)

Please contact Julie Pavelka, Facilitator, with any questions/concerns and RSVP (one week prior to meeting): [parkinson.network@nebraskamed.com](mailto:parkinson.network@nebraskamed.com)

### Parkinson Disease Patient and Caregiver Symposium

October 14

Embassy Suites Convention Center  
LaVista, NE.

# Finger Tapping for Parkinson Disease

Danish Bhatti, MD

Assistant Professor | Co-Director Comprehensive Parkinson Disease Clinic  
Director, International Neurology Program | Associate Director, Movement Disorders Fellowship program  
Department of Neurological Sciences | University of Nebraska Medical Center

Most common evaluations of Parkinson's disease (PD) in the clinic consist of motor assessments using some form of repetitive task. One such tool is use of a Unified Parkinson's Disease Rating Scale or UPDRS which involves multiple different activities such as repetitive finger tapping with first finger and thumb as fast as possible. The clinician observes for any slowing or decreasing amplitude or any irregularity with freezing of the movement.

Since the original description of PD, the assessment has relied heavily on clinical observation and requires significant detailed training of the neurologist to become good and effective in performing these assessments. The modern technology provides us possibilities of creating digital versions of these assessment. This will not only increase the sensitivity and efficiency of doing these assessments but would also make them reliable so that significant amount of training is not needed and thus available even to an untrained physician. This also opens up the possibility of performing these assessments at home by the patients themselves and sending them electronically

to their physicians or providers and keeping track of these assessments as a daily measurement over the long run rather than being assessed once every few months in the physician's office just like fitbit. One of the easiest and reliable measure of the motor performance of PD is finger tapping assessment using digital tools. Keeping that in mind, the movement disorder neurologist at University of Nebraska Medical Center (UNMC) created a smartphone application taking advantage of the sensitive touch technology of an iPhone to measure various components or characteristics of finger tapping of Parkinson's patient.

TapPD is a simple application that provides a circle on a screen with a cross in the center to the patient for tapping for 20 seconds, repetitively as fast as possible. The tapping is done with one finger at a time and also alternate tapping with index finger and middle finger for each side. The application measures the characteristics of finger tapping such as time interval between each tap, the time that the fingers stayed on the screen for each tap and thus picking up freezing and also gradually decrement or slowing of

the movements with repetitive movements. In addition, it looks for the accuracy of finger tap as distance from the circle center. UNMC will be launching studies using this application over the next few months looking at its effectiveness and correlation with the clinical assessment. One such ongoing study is linking real life driving changes in PD with finger tapping app to look at the motor state of patient as they drive every day. Similarly collaboration between UNMC and Biomechanics experts at University of Nebraska at Omaha (UNO) is looking at comparing the changes in finger tapping with walking or gait. They will also be evaluating the comparison between the finger tapping characteristics and UPDRS in each clinical visit to see if we can find correlations that are useful. We will be hopefully updating our readers in the future with interesting findings from these projects further or new project design using this application and the outcome from these studies. This application is available for free on iTunes store as "TapPD\_Physician" and "TapPD\_Patient." The application is being shared for free with other researchers across the country or in order to promote research of this kind.



This year's event will take place from January 25 – 26 at the UNMC Ice Rink for 24 hours from 2:00 p.m. on Friday to 2:00 p.m. on Saturday.

The Skate-a-thon is a unique, family-friendly, outdoor ice-skating event!

## Registration Information

Tickets include unlimited skating—stop by any time to skate, and skate for as long as you'd like!

- **Individual: \$15**  
Price includes registration and skate rental.)
- **Family: \$50**  
Price includes registration and skate rental for two adults and up to 8 children (under the age of 18) from the same household.

## Rock the Clock Team Registration

Rock-the Clock Skaters are teams committed to being out on the ice for the full the twenty-four hours! Recruit your family, friends, and co-workers to form a team. Divide up the twenty-four hours to have a representative out on the ice throughout the entire event.

## Rock the Clock Team Member: \$15

Price includes registration, skate-rental, free food, motivation, and recognition throughout the event.

For Registration or Sponsorship information, contact Amber at the Parkinson's Nebraska office at 402-715-4707 or email [info@parkinsonsnebraska.org](mailto:info@parkinsonsnebraska.org).

## 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](http://www.apda.org)

**Davis Phinney Foundation for Parkinson's**

[www.davisphinneyfoundation.org](http://www.davisphinneyfoundation.org)

**International Parkinson and Movement Disorders Society (WE MOVE)**

[www.movementdisorders.org](http://www.movementdisorders.org)

**Michael J. Fox Foundation for Parkinson's Research**

[www.michaeljfox.org](http://www.michaeljfox.org)

**Movement Disorder Society**

[www.movementdisorders.org](http://www.movementdisorders.org)

**National Institute of Neurological Disorders and Stroke**

[www.ninds.nih.gov](http://www.ninds.nih.gov)

**Parkinson's Action Network**

[www.parkinsonaction.org](http://www.parkinsonaction.org)

**Parkinson's Foundation**

[www.parkinson.org](http://www.parkinson.org)

**Parkinson's Foundation Heartland Chapter**

[www.parkinson.org/heartland](http://www.parkinson.org/heartland)

**Parkinson's Nebraska**

[www.parkinsonsnebraska.org](http://www.parkinsonsnebraska.org)

**Parkinson's Resource Organization**

[www.parkinsonsresource.org](http://www.parkinsonsresource.org)

**The Parkinson Alliance**

[www.parkinsonalliance.org](http://www.parkinsonalliance.org)

**The Parkinson's Disease Foundation**

[www.pdf.org](http://www.pdf.org)

**The Parkinson's Resource Organization**

[www.parkinsonsresource.org](http://www.parkinsonsresource.org)



To download a copy of ALL *Parkinson's Post* newsletters, please visit:

[www.unmc.edu/  
neurologicalsciences/  
news/newsletters](http://www.unmc.edu/neurologicalsciences/news/newsletters)