

Parkinson's Post

to educate, inspire and empower individuals affected by Parkinson Disease

Inaugural Parkinson's Post

Julie Pavelka, MS, APRN-NP

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

Welcome to the Inaugural monthly edition of Parkinson's Post! According to the Parkinson's Disease Foundation, Parkinson's Disease (PD) has affected as many as one million Americans (more than 10 million worldwide) and 60,000 Americans are diagnosed with Parkinson's Disease annually. The incidence of Parkinson's disease in Nebraska and across the Midwest is higher than most states. According to the Nebraska Parkinson's Disease Registry, in 2014 alone, 576 new cases were registered with Parkinson's disease at the average age of 73 years and more than 13,000 patients have been registered since data collection started in January 1997. It's essential that individuals affected by PD, including patients, family members, and caregivers, have a conduit of reliable information and resources, therefore, the UNMC/Nebraska Medicine's Movement Disorder Team will be publishing a monthly newsletter to educate, inspire, and empower individuals affected by PD. At UNMC/Nebraska Medicine, we are very fortunate to have Movement Disorder Specialists who are Neurologists that have received additional training in Parkinson Disease and other movement disorders including dystonia, chorea, tics and tremors. Our movement disorders program is the only one in Nebraska and the largest in the region. Our monthly newsletter will comprise of multiple topics submitted by providers who have a passion for caring for individuals affected by PD. We look forward to being your Parkinson Disease network hub to provide the most up to date education and research opportunities!



Inside this issue

- Nutrition Tips
- Annual PD Symposium Overview
- Fall Prevention
- Parkinson's Research
- Comprehensive Multidisciplinary PD Clinic
- Caregiver Tips
- Neuropsychology
- Reliable Resources

Simple Swaps for Healthier Choices

Jenna Paseka, MS, RD, LMNT

Nutrition Therapist | Neurological Sciences Department | Nebraska Medicine

Making changes to your diet can be overwhelming! Where to start?? Lifelong nutrition habits are best formed through small steps. Think about these changes as your new "normal" way of eating instead of a temporary change for a couple weeks. The key to success is making 1-2 small changes at a time instead of trying to change everything all at once. Here are a few ideas to get you started:

- Cook a meal at home instead of going out to a restaurant. A meal at a restaurant often has more than 1000 calories.
- Have a piece of fruit instead of fruit juice. You not only get more fiber, but also cut the amount of sugar in half by choosing the whole fruit.
- Try using spaghetti squash or zucchini noodles instead of pasta to increase your vegetable servings as well as cut back on the amount of carbohydrates in one meal.
- Use plain Greek yogurt instead of sour cream to get the same flavor, but reduce calories and saturated fat plus increase the protein content.
- Replace a serving of meat with fish such as salmon, tilapia or tuna. You will get a healthy serving of omega-3 fatty acids which is important for brain and heart health.

- Use sliced berries in replacement of jelly or jam on a peanut butter sandwich or toast. The berries will provide you with beneficial vitamins, minerals, antioxidants and fiber.
- Drink flavored waters with natural flavors instead of regular or diet soda. You can substantially decrease your sugar intake and avoid artificial sweeteners.
- And for a treat, pick out a couple small pieces of dark chocolate instead of cookies, cake or pies. Dark chocolate has beneficial antioxidants. But remember to keep your portion size in check!

Parkinson Disease Patient and Caregiver Symposium 2017

Julie Pavelka, MS, APRN-NP

Memory and Movement Disorders | Department of Neurological Sciences | Nebraska Medicine



The annual symposium hosted by UNMC/Nebraska Medicine, titled “Parkinson’s Disease in 2017: Improve the Patient Experience” was held on October 30th at the Embassy Suites by Hilton Omaha LaVista Hotel and Conference Center. This year’s record attendance included 950 participants from across Nebraska and the Midwest who came together to learn about Parkinson’s Disease. Dr. John Bertoni, MD, PhD, the director of UNMC’s Parkinson’s Disease program was the keynote speaker. Educational sessions included Living with Parkinson Disease: The Big Picture; Swallowing Difficulties and Nutritional Guidelines in Parkinson Disease; Medical Options for Parkinson Disease Including New and Emerging Therapies; Living with Parkinson Disease Stories of Courage; Lightheadedness and Unsteadiness in Parkinson Disease, Surgical Options for Advanced Parkinson Disease: Deep Brain Stimulation; Caregiver Solutions; and information on Nebraska’s Parkinson Disease Registry. The symposium also included light exercises between presentations and opportunities for participants to visit with various vendors who sponsored the conference.

2017 brought important milestones to the Parkinson Disease world. To begin with, Parkinson Disease was initially discovered 200 years ago in 1817 by Dr. James Parkinson. Next, this year is the 20th anniversary of the Nebraska Parkinson Disease Registry which has tracked every case of Parkinson Disease diagnosed in Nebraska since January 1, 1997. Furthermore, in honor of the UNMC Parkinson’s Disease Symposium and the 20th anniversary of the Parkinson’s Disease Registry, Nebraska’s State Governor Pete Ricketts has proclaimed October 30, 2017 to be Parkinson’s Awareness Day.

The 2017 Symposium was definitely a success and we are so fortunate to have such an astute Movement Disorders Team and support staff! We are all looking forward to the 2018 Symposium; stay tuned for details!



Are You Falling This Fall?

Cheri Prince, DPT, DOR

Physical Therapist | Director of Rehabilitation Services | Life Care Center of Elkhorn

With cooler temperatures upon us and the changing color of the leaves we know a new season is here. The first day of fall is National Fall Prevention Day. Are you falling frequently or are falls an issue for you? Unfortunately, with Parkinson Disease, falls can be a significant issue. Sixty percent of Persons with Parkinson Disease (PwPD) fall annually and two-thirds of those fall recurrently. Of course, the first concern that comes to mind with a fall is an injury and falls can frequently cause a variety of fractures as well as head injuries. In addition to this, once you experience a fall, a negative cycle can begin that includes a fear of falling again, less activity to decrease risk, decreased muscle strength and balance due to less activity and then increased risk for falling when you do try to be mobile which then can lead to another fall. You do not want to enter this cycle!

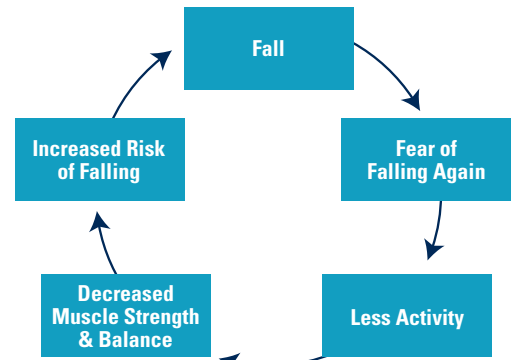
In PwPD, 36% of falls are caused by an episode of freezing of gait. Many of you may experience freezing of gait. Freezing is the

feeling that your feet are transiently glued to the floor while trying to initiate walking, turning, or when walking through narrow spaces or in crowded places. (Nieuwboer et al 2009)

What can you do to decrease your freezing episodes and in turn your risk for falls? Here are some common tips to reduce freezing that you can try right away:

- Utilize the 4 “S” acronym: Stop, Stand tall, Shift side to side, Step Long.
- If you were trying to move forward – try moving in another direction. Shift or step side to side and then try moving forward.
- Visualize stepping over an object
- Utilize an auditory signal such as a metronome, humming a song or counting “1-2-3-go” and then stepping forward.
- Whatever you do, don’t fight through the freeze by trying harder as this can cause a fall!

THE FALL CYCLE



As with any concerns you are having, you should discuss with your movement disorder specialist or physician. There may be medication issues that can be causing you difficulty with freezing that can be addressed. A physical or occupational therapist that has experience treating PD can give you very specific training and techniques to reduce your freezing. Whatever you do, reach out for help if needed. Stay safe and avoid the fall cycle!

Neuroprotection in Parkinson Disease – THE HOLY GRAIL

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

Parkinson Disease is a Neuro-degenerative disease which means that it is seen due to gradual loss off neurons or brain cells in certain parts of the brain. This process starts years before the diagnosis and an estimated 60% or more of the brain cells are lost before clinical diagnoses of Parkinson’s disease can be made due to motor symptoms. Once this process is initiated it continues on its own pace, which is different for each patient. Once this was recognized there have been ongoing efforts to figure out ways to stop this and we have looked at multiple medications with various mechanisms and so far, everyone has failed.

The search for Holy Grail in Parkinson’s disease is a drug that will slow down or stop the progression of cell loss continues. We are using understanding of the mechanisms of brain cell loss to test new agents something called translational medicine that is translation of work from the laboratory using Petri dishes and test tubes into human trials. One such approach has been by using strong immune

modulating agents mostly used in patients with cancers. One such innovative trial was done within the University of Nebraska Medical Center (LEUKINE STUDY) where immune-modulating medication was used to look for its safety and potential for future studies in PD. The work was successful and was published in Nature Partner Journal. Another such study starting at UNMC as a part of national consortium of 30 universities is NILO-PD. This will use drug for chronic myeloid lymphoma (CML) to reduce inflammation in the brain and slow down Parkinson Disease.

A different approach is being studied in the trials currently ongoing at UNMC as part of Parkinson’s study group, the largest research organization for Parkinson’s internationally. STEADY-PD3 trial is looking at final common pathway of cell death in body which requires inflow of Calcium into the cell. The study is using a drug that inhibits calcium intake of cells and can go into the brain, to slow down brain cell loss, regardless of the cause. While



in SURE-PD3, a very different approach has come out of findings on large epidemiological studies that people without PD tends to have high Uric acid levels; while the ones with PD tends to have lower Uric Acid levels. This might be related to changes in gut microbes in PD patients which is well established. This study is looking at giving dietary supplement to increase Uric Acid levels in PD patients (when low) to a high normal level and see if this will slow down progression of Parkinson Disease. Both of these studies are Phase 3 studies, and thus last step before getting approval from FDA to be used regularly in PD patients.

Comprehensive Movement Disorders Clinic

John Bertoni, MD, PhD

Professor | Co-Director Comprehensive Parkinson Disease Clinic | Director Parkinson's Disease Department of Neurological Sciences | University of Nebraska Medical Center

The UNMC Department of Neurological Sciences provides a patient-centered Comprehensive Movement Disorders Clinic every Monday to serve the complex needs of new or advanced Parkinson's disease (PD) patients. Patients and their families remain in one room and caregivers including Movement Disorders specialists Danish Bhatti MD and John M. Bertoni MD PhD, Movement Disorders fellows, our Movement Disorders nurse Bobbi Roeder R.N., Speech Therapist, Occupational Therapist, Physical Therapist, Dietician, and Social Worker take turns doing formal standardized examinations. The referring physicians and the patients all receive written or electronic evaluations—some of which can be provided before they leave the clinic!

This is especially valuable to the patients and families early in the course of PD:

valuable information is provided, and the now proactive patient is well equipped to manage their PD for the rest of their lives!

Patients and their families in later stages of PD with multiple issues benefit enormously from the expertise and experience from each member of the team in handling very complicated and challenging cases. The Comprehensive Movement Disorders Clinic then outlines a comprehensive plan of care tailored for the patient to emphasize wellness and a better quality of life.

In a typical morning six patients are evaluated in this clinic with all specialists involved in discussions and planning. The feedback from patients and families is excellent. This Comprehensive Movement Disorders Clinic streamlines what would otherwise require several trips to several



different providers—and delivers a unified coherent plan toward wellness for the patients, families, and referring physicians.

Emphasis on combining optimizing quality of life, quality of care with trained specialists, and efficiency makes this clinic a real winner for the patients and their referring physicians!

Clinical Neuropsychology

Amelia (Aimi) Nelson, Ph.D., ABPP

Board Certified in Clinical Neuropsychology | Training Director, Clinical Neuropsychology Residency Program Assistant Professor & Neuropsychology Division Chief | Department of Neurological Sciences University of Nebraska Medical Center

Clinical neuropsychology is a specialty within the field of psychology that focuses on the relationship between the brain and behavior. Neuropsychologists assess how the brain functions by testing cognitive skills (i.e., mental abilities such as memory, attention, thinking speed, language, visual-spatial/perception skills, reasoning, problem-solving, etc.). The examination is interactive, in that the cognitive “paper-and-pencil” tests are administered to the patient by the neuropsychologist or by a technician, although some tests may be computerized. Sometimes, tests and questionnaires that assess mood and functional abilities (e.g., counting change, telling time, etc.) are also given. The neuropsychologist uses the test results to make diagnoses and to plan appropriate treatments. Some neuropsychologists may also provide treatment themselves, such as psychotherapy or cognitive rehabilitation.

Parkinson's disease (PD) can cause cognitive changes in some individuals, such as slower thinking, forgetfulness, and word-finding problems. Parkinson's disease can also cause mood changes such as depression, apathy, or anxiety. As such, it is not uncommon for individuals with PD to undergo a neuropsychological evaluation to better understand these issues.

The neuropsychological evaluation involves a clinical interview with the patient and a family member (30-60 minutes long) and the neuropsychological testing itself (usually between 2 and 5 hours long). Behind the scenes, the neuropsychologist will review medical records, interpret the test results, and write a report that explains the results and the recommendations. Oftentimes, a feedback session (usually 30-60 minutes) is scheduled on a separate day in order to discuss the findings and treatment options with the patient and family.



For individuals with PD, a neuropsychological evaluation can be most useful for: 1) assessing whether the cognitive changes are due to “normal aging,” Parkinson's disease, or another cause; 2) determining whether the cognitive changes are severe enough that the individual needs help from family or others with daily activities; 3) providing recommendations on how to treat, compensate for, or cope with any cognitive, mood, or functional changes that have occurred. Each evaluation is tailored for the individual patient to help with his or her care.

Tips for Parkinson Disease Caregivers

- 1. Be organized.** Devise an organizational strategy to keep track of the patient's medical notes, insurance, records, appointments, phone numbers of providers, etc, so they are easily accessible and transportable.
- 2. Remember to care for yourself.** You can't adequately care for another person if you are neglecting your own physical and emotional needs. Schedule time for yourself to unwind and relax. Ask for help from others if you need a break. Regularly treat yourself to activities/hobbies that you enjoy.
- 3. Be aware of the patient's medical insurance.** It is helpful to educate yourself on the patient's medical insurance policy—what is and is not covered and how to make sure available reimbursements are taken advantage of. This is especially important for family caregivers to know.
- 4. Join a support group.** Becoming part of an active support group in your area may be able to provide you with emotional and practical support, allowing you to share your experiences and gain advice from others going through the same challenges.
- 5. Educate yourself on Parkinson disease.** Studies and advancements make medicine an ever-changing field, so keep up-to-date on the latest news and recommendations on the disease. Talking to the patient's doctors is also a great way to stay informed on news and guidance specifically applicable to your patient.
- 6. Expect patient moods swings.** Parkinson disease is often accompanied by mood swings and depression, which may strain your relationship. Open and honest communication is critical in order to maintain a healthy and productive relationship.



“There are four kinds of people in the world: Those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.” — *Rosalynn Carter, Former First Lady*

- 7. Watch for changing symptoms.** As a caregiver, you will likely be the first person to observe any changes in or worsening of behaviors or symptoms. Report changes to the patient's physician as soon as possible.
- 8. Encourage independence.** Your job is to care for your patient, but try to help them hold on to their independence for as long as possible. Ask them if they need help and respect their answer.
- 9. Know your rights.** Make sure you know and understand caregivers' rights and disability rights. As a family member caregiver, you may be entitled to disability and/or caregiver benefits.
- 10. Don't procrastinate advance care discussions.** Discussing future care and end-of-life care is difficult to approach, but it is important to understand what your patient may or may not want in the future. Discuss wills, treatment options, and end-of-life preferences.

Source: Parkinson's News Today based on information from the Michael J Fox Foundation and Partners in Parkinson's (published online October 19, 2017).

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

National Parkinson Foundation

www.parkinson.org

Parkinson's Action Network

www.parkinsonaction.org

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



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