

Parkinson's Post

to educate, inspire and empower individuals affected by Parkinson Disease

Happy New Year!

Julie Pavelka, MS, APRN-NP

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

Welcome to the January/February 2018 edition of Parkinson's Post! As we enter the beginning of a New Year, the Movement Disorder Team at Nebraska Medicine/UNMC continues to focus on improving the quality of life of all individuals affected by Parkinson Disease (PD) and striving to reach as many people as we can to educate, inspire, and empower the Parkinson Disease network. Multiple providers have been busy speaking at Parkinson Disease support groups and other PD community events. In addition, we have initiated the planning process for the 2018 PD Patient and Caregiver Symposium and will keep you updated with details as they evolve.

The January/February 2018 edition 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 UNMC/Nebraska Medicine, 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.

Dysphagia: What it is and When to Seek Help

Victoria Czerwinski, MS, CCC-SLP

Speech-Language Pathologist | Munroe-Meyer Institute for Genetics and Rehabilitation
University of Nebraska Medical Center

Q: What is dysphagia?

A: Dysphagia is the medical term for 'swallowing difficulty'. It can occur at any stage of Parkinson's Disease and can affect many parts of the swallowing mechanism. Symptoms of dysphagia include: painful swallowing, coughing/choking while eating, recurrent pneumonia, weight loss, and dehydration. It is important to seek help to help manage your dysphagia because if left untreated it can lead to aspiration pneumonia which is the #1 cause of death in those with Parkinson's Disease.

Q: I experience some of those symptoms, when should I seek help?

It is important to seek help with your dysphagia

whenever it begins to affect your quality of life. Everyone will experience an episode of coughing/choking while eating and drinking every once in a while, but if it is occurring often enough (e.g. every meal, every day) to affect your quality of life it might be time to seek help. It is also important to monitor your weight and if you've had any recent pneumonia as these may also be a sign of a dysphagia.

Q: But I've had my pneumonia shot, am I not safe from aspiration pneumonia?

No. The pneumonia vaccine you receive is effective in preventing bacterial and community acquired pneumonia. Aspiration pneumonia is directly caused by food and/

or liquid entering your lungs and is not prevented by your annual pneumonia vaccine.

Q: How do I seek help?

If you think you are experiencing any of the symptoms above, the first step is to speak with your Primary Care Physician or your Neurologist. They will listen to your concerns and refer to a Speech-Language Pathologist if they think it is necessary. The Speech-Language Pathologist will then complete a formal assessment of your swallow function and create a plan of care.



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Changing the Course of Your PD

Cheri Prince, DPT, DOR

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

As we kick off 2018 many of us will be setting New Year's resolutions. Have you thought about yours yet? Many people say they would like to lose weight, improve relationships, change jobs, or spend more quality time with family, etc. You have the exciting opportunity to change the course of your Parkinson Disease in 2018! More and more research is showing that exercise can slow the progression of Parkinson Disease as well as manage its symptoms. In order to do this your exercise routine must consist of the following:

Frequency — Daily exercise consisting of 30 minutes of aerobic activity and 30 minutes of extremity and core strengthening. You also need a daily flexibility/stretching program to combat the rigidity of PD.

Intensity — You need to be working at a high intensity level throughout your workout. You should be rating your effort as hard to somewhat hard (12-15) on the Borg exertion scale. Your therapist can teach you how to know what activities you can do to reach and maintain this level.

Target PD Specific Components —

You need to be completing exercise that addresses PD specific symptoms. A well rounded PD exercise program should have components addressing rigidity, flexibility, strengthening, balance, voicing and cognition at a minimum.

There are many modes of exercise that can meet this criteria. First, skilled therapy services. If you have not worked with a physical or occupational therapist that has advanced training in PD I would highly recommend that you see one and have them establish an appropriate exercise program for you. Once they have identified your specific deficits you can determine what type of exercise works for you. Second, there are many community based exercise classes that are PD specific and available in a lot of community's in Nebraska. Examples include Delay the Disease classes at your local YMCA, PWR! Moves classes and Rock Steady Boxing for Parkinson's. Many are free or low cost and you may want to utilize multiple classes for variety. Talk to your therapist or health care providers about classes available or utilize resource websites that are listed in this newsletter in the resource section. A third option would



be personal training. Some people prefer to work one on one with a trainer. Talk with your physical therapist for recommendations of trainers who have PD focused training. And finally, some people are able to manage their routine independently. I would only recommend this route if you are able to be self-disciplined about consistency and are willing to return to physical therapy at least every six months for a "tune up" to ensure your routine is still working for you.

Exercise is medicine! My hope for you in 2018 is that it will be the best medicine for you this year!

Upcoming 2018 Events



UNMC Skate-A-Thon for Parkinson's 2018

Fri., Jan 26, 2:00 p.m. —
Sat., Jan 27, 2:00 p.m.

UNMC Ice Rink
42nd and Emile Street, Omaha, NE

For more information please visit Parkinson's Nebraska at www.parkinsonsnebraska.org

Or contact Katrina at the Parkinson's Nebraska Office at 402-715-4707 or email info@parkinsonsnebraska.org

Parkinson's Moving Day Walk National Parkinson Foundation Heartland Chapter

April 28

9:00 a.m. Registration opens
10:30 a.m. Walk start time

Stinson Park in Aksarben Village
2285 S. 67th Street, Omaha, NE

For more information please visit <https://movingdaywalk.org/event/moving-day-omaha/> or www.parkinson.org/heartland

Or contact: Robyn Tota at 913-341-8828 or rtota@parkinson.org

State of Research on Parkinson Disease at UNMC

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's disease (PD) is the second most common neurodegenerative disease, with a life time risk of 4 percent. However, risk increases with age with a prevalence of one percent at age of 65 but rising to 20 percent after the age of 80 (Jane A. Driver. Neurology 2009) One out of twenty patients, is however, diagnosed before the age of 40. Parkinsonism alone is associated with a two-fold increase in the risk of death with a significant impact on mobility and balance. The first detailed description of PD appeared in English literature in 1817 that documented full clinical feature of this disease by James Parkinson. The disease was better recognized around turn of 20th century but for nearly 50 years was without treatment except for some bold surgical experiments from leading neurosurgeons involving cutting and burning various brain regions. However, treatment radically changed around 1960 with discovery of dopamine and its role in the brain. Since then scientist and physicians have done significant efforts in understanding its causes, better treatment options, and improve quality of life. The goals have turned out to be very elusive. Though we have made many strides in improving quality of life with symptomatic treatments and understanding changes in the brain, we are still unsure of the actual causes and ways to stop the progressive brain cell loss.

Research in PD is a big focus at University of Nebraska Medical Center where clinicians and scientists are focused on many questions about PD. In this series of articles, I would like to share with you some of the ongoing work in PD at UNMC. I would like to start with an overview of the ongoing work. Let's start with what are the big questions with Parkinson Disease that we are addressing at UNMC?

a. FUTURE OF DIAGNOSIS AND CARE:

How can we diagnose PD earlier and more reliably? How can primary care providers diagnose PD earlier and reliably? How can we monitor for effects of treatment and progression more easily and reliably?

b. NEUROPROTECTION: How can we slow down the disease or stop it from progressing? What should we target in the brain? What is the role of Immune system?

c. EPIDEMIOLOGY OF PD: How common is PD and how are patients managing PD? What made them more likely to get it? How is it affecting their life? How are people handling it and what is the impact on their quality of life?

In the table below, I have enlisted the current ongoing and recently finished studies at UNMC. In the coming articles we will be reviewing some of these studies individually to understand how they are adding to our knowledge.

Table 1. Recent and ongoing Research Trials in PD

A. Epidemiology:

1. State PD Registry of Nebraska
 - a. Study with hospital discharge data
 - b. Cancer registry
 - c. Agriculture registry study
2. PD inpatient care Study
 - a. Inpatient Nurses survey
 - b. DBS 5-year experience
 - c. Inpatient Quality measures
3. PD Epidemiology in a developing country
 - a. Characteristics of PD in Pakistan
 - b. Non-motor symptoms in PD in Pakistan
 - c. Treatment trends in PD in Pakistan
4. Effective utilization of therapy resources in PD

B. Living with PD/quality of life:

1. Naturalistic Driving study in PD
2. PD patient symposium survey
3. Vitamin deficiencies in PD
4. Wii balance board for PD
5. Effect of the Usage of Handrails on Gait Dynamics in People with Parkinson Disease

C. Drug Therapy trials in PD:

1. Use of Liquid Sinemet infusion gel in PD (DUOPA trial)
2. DUOGLOBE study (DUOopa/Duopa in Patients with Advanced Parkinson Disease a Global Observational Study Evaluating Long Term Effectiveness)
3. Improving gait patterns in PD with structured auditory stimulus

D. Neuroprotection trials:

1. STEADY PD3 (Safety, Tolerability and Efficacy Assessment of Isradipine for PD) (A phase 3 Double blind Placebo Controlled parallel group Study of Isradipine as a Disease Modifying agent in subjects with Early Parkinson Disease)
2. SURE PD3 (A randomized, double blind, placebo controlled trial of urate-elevating Inosine treatment to slow clinical decline in early Parkinson Disease)
3. Leukine Study (sargramostim for Parkinson Disease)
4. NILO PD (A Randomized, double blind, placebo controlled, Phase IIa, Parallel group, two-cohort study to define the Safety, Tolerability, Clinical and Exploratory Biological Activity of the Chronic administration of Nilotinib

E. Future of Diagnosis:

1. Assessment of motor state through smartphone applications: TapPD, Smart4Sure, mPower,
2. Temporal Variability of daily ambulatory activity as a non-invasive biomarker for Parkinson Disease
3. Wearable technology such as PKG and Actigraph use in evaluation of Parkinson Disease.

F. Education Research: Training the physicians of tomorrow:

1. Use of Blended learning for Residents for Movement disorders
2. Online Distance learning internationally in Pakistan for Movement Disorders

Jane A. Driver, MD, MPH, Giancarlo Logroscino, MD, PhD, J Michael Gaziano, MD, MPH, and Tobias Kurth, MD, ScD. Incidence and remaining lifetime risk of Parkinson disease in advanced age. Neurology. 2009 Feb 3; 72(5): 432-438. [PMC]

Make the Best of Your New Year's Resolutions

Jenna Paseka, MS, RD, LMNT

Nutrition Therapist | Department of Neurological Sciences | Nebraska Medicine

The start of a new year brings a time for people to focus on their health now that the hustle and bustle of the holidays are over. The beginning of a new year brings a great opportunity to make positive changes in our lives. Let's make the best of 2018 while keeping these things in mind:

2 – Pick **two** friends, family members or coworkers to keep you accountable. People are more successful with making life long changes by having a good support system. Share your goals with them and talk about your progress or struggles.

0 – **Zero** excuses! Start today with making healthy lifestyle changes. Don't keep pushing your goals off until tomorrow, next week or next month.

1 – Make **one** small, achievable goal at a time. New behaviors typically take up to a month to become a habit, so stick with it! Once you tackle one goal, look to make a new goal the next month. Remember, it is not realistic to overhaul your eating habits or exercise regimen overnight.

8 – Drink **eight** glasses of water every day. This is an example of one healthy goal you could make. Dehydration can be more common than you think, especially in older adults and in people with Parkinson Disease. As you age, your sense of thirst may lessen which can lead you to drinking less fluids throughout the day. Also, constipation is a common problem in Parkinson Disease which can be alleviated by drinking extra water.



Depression and Anxiety in Parkinson Disease

Pamela E. May, PhD

Clinical Neuropsychologist and Assistant Professor | Department of Neurological Sciences | University of Nebraska Medical Center

When the symptoms of Parkinson's disease were first described in 1817 by an English physician named James Parkinson, he not only described the motor/physical symptoms associated with the disease, but less obvious characteristics, including mood. Of note, he mentioned that patients appear to experience a disturbance in mood, which he referred to as "melancholy." This historical note is interesting to consider, as many people may think of Parkinson's disease as only a neurological disease. However, with research and observation, Parkinson's disease is now more clearly understood as a disorder with both neurological and psychiatric features. In fact, it has shown that more than 60% of patients with Parkinson's disease report experiencing one or more psychiatric symptoms (anxiety, depression, or other psychiatric/behavioral disorders) over the course of their illness, with mood changes (depression and anxiety) being the most common.

To many, depression may seem like an ambiguous term. However, if you have been experiencing persistent sadness, reduced interest or pleasure in hobbies and activities, along with other mood/behavioral/thinking

changes, you may benefit from further evaluation by your healthcare provider for depressive symptoms. Depression in patients with Parkinson's disease may in part be caused by, or associated with, 1) psychological factors (including difficulties adjusting to chronic illness and increased social isolation) as well as 2) biological factors (including genetics, prior lifetime history of depression, and disease-associated changes in brain circuitry and chemicals). Along with depressive symptoms, patients with Parkinson's disease may also experience anxiety. In fact, depressive symptoms and anxiety often co-occur. Anxiety may present in different forms, whether it be in the form of worries that seem out of control, anxiety/panic attacks, fear of being in social situations, and/or obsessive-compulsive symptoms (i.e., repetitive thoughts and behaviors that may be illogical). Anxiety in Parkinson's disease may stem from again, 1) psychological factors (including fears of being unable to function in context of motor symptoms and concern about experiencing Parkinson's symptoms in public), as well as 2) biological factors (including brain changes associated with the disease).

Once diagnosed with depression or anxiety, there are ways to treat these conditions. One avenue is with medications, while another is with counseling or psychotherapy. In fact combining medication with psychotherapy may be particularly fruitful for some patients. In addition, engaging in physical exercise, under safe parameters, has also been shown to be effective for improving mood and overall physical health. When left untreated, elevated symptoms of depression and anxiety may be associated with worsening of Parkinson's physical symptoms, reduced daily functioning, as well as greater difficulties with thinking clearly – thereby, reducing overall quality of life.

In summary, depression and anxiety are often part of the Parkinson's disease presentation, just like the motor/physical symptoms, and they can even exacerbate physical symptoms. Please speak to your health provider about any mood concerns you have, to further address these concerns and move towards improving your quality of life.

Caregivers: Taking Responsibility for Your Own Care

Julie Pavelka, MS, APRN-NP

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



Over the next 9 issues of Parkinson's Post, we will be reviewing strategies and tools for caregivers to utilize when providing care for individuals with PD. In this issue, we will focus on the effects of caregiving on the health and well-being of the caregiver; subsequent issues will focus on reducing personal stress, setting goals, seeking solutions, communicating constructively, asking for and accepting help, talking to the health care Provider, starting to exercise, and learning from our emotions.

Most of you have traveled by airplane and aware that after the airplane doors have been closed and prior to take off, a flight attendant proceeds with instructions for all passengers:

"In the event of decompression of the airplane cabin, an oxygen mask will automatically appear in front of you... SECURE YOUR MASK AND THEN ASSIST OTHERS WHO REQUIRE ASSISTANCE." As caregivers, it's essential to take care yourself FIRST so you can efficiently and effectively take care of others. Regardless of age, sex, race, and ethnicity, caregivers report problems maintaining their own health and well-being while managing caregiving responsibilities. Caregivers have reported

"Being positive doesn't mean ignoring the negative. Being positive means overcoming the negative. There's a big difference between the two." — *marcandangel*

sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when acutely ill, and postponement of or failure to make medical appointments for themselves.

Initially, caregivers are encouraged to identify personal barriers that may impede the way they care for themselves. For example, often caregivers feel they are being selfish if they place their needs first. Caregivers often have misconceptions that may include not feeling that anyone else could do a good job, believing that seeking outside assistance isn't appropriate, or they have made a promise to a loved one they would be their caregiver. Many times, attitudes and beliefs form personal barriers stand in the way of caring for yourself. Not taking care

of yourself may be a lifelong pattern, while taking care of others is an easier option. However, as a family caregiver you must ask yourself, "What good will I be to the person I care for if I become ill? If I die?" Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done—regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. After a caregiver has identified their personal barriers, it's essential to make an effort to change by formulating a plan that may include other family members, friends, or reliable agencies to assist the primary caregiver.

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 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



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