Welcome to the September / October 2018 edition of Parkinson’s Post!

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Fall has arrived and our Movement Disorder Team continues to be working diligently! We continue to attend and present at Parkinson’s Disease (PD) Support Groups, most recently Lincoln’s PD Support Group. Our Nebraska Medicine/UNMC PD Support Group has continued to grow and we had a record setting 43 participants in September’s meeting. Our August support group presentation was completed by Nebraska Medicine Nutrition Therapy and Speech Therapy; September’s presentation was Advanced Therapies for Parkinson’s completed by Dr. Torres; and October’s presentation was Commonly Asked Questions about Parkinson’s completed by Dr. Seier. Our November 16th PD Support Group will be led by Dr. Magnuson, UNMC Geriatric Psychiatrist. 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 September / October 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.
The Movement Disorders Section Keeps Growing

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Since 2008, the Movement Disorders section has had immense growth within all the missions of the Department. Within the Clinical realm, we created the Dystonia and Spasticity clinic, now with four providers with expertise in all available chemodenervation agents. We have had continuous accreditation as a Huntington Disease Society of America’s (HDSA) Center of Excellence under the leadership of Dr. Amy Hellman. John Bertoni, MD, PhD, and Danish Bhatti, MD, have also organized a Comprehensive, Multidisciplinary Parkinson Disease Clinic, which has served many patients in the region. Beyond that, we have an Intrathecal Baclofen Pump evaluation program, and a general Movement Disorders Clinic caring for patients with Tremor, Ataxia, Myoclonus, gait disorders, dyskinesias, paroxysmal disorders, among others. We continue to be leaders in Deep Brain Stimulation Surgery and Continuous Levodopa gel infusion pump utilization for Movement Disorders.

The educational mission is taken seriously within our section. The Movement Disorders Fellowship program has been fully matching since 2013. This year again, two more fellows will be joining the DONS family for their training. We continue to have extremely successful Patient and Caregivers educational program. And the Parkinson Disease CME program will be in October.

More than 35 research projects are underway, and more than ten papers have been published this year. Participation on clinical trials is at an all-time high. Our group has members on the Parkinson Study Group, the Huntington Study Group, and the Tremor Study Group, some of the top research consortia in the movement disorders world.

Finally, we are very proud of our people. With five physicians, one nurse practitioner, two fellows, three case managers and one MA, we continue our path toward excellence and toward national and international recognition. Our most recent addition is Mara Seier, MD. Dr. Seier completed her medical school at the University of South Dakota, residency at the Oregon Health and Science University, and Movement Disorders fellowship at the Oregon Health and Science University. She is planning on organizing a Comprehensive Parkinson-Plus syndromes clinic.

Sialorrhea

David Whitney, MD
Movement Disorders Fellow | University of Nebraska Medical Center

Many people with Parkinson’s disease are bothered by excessive saliva or drooling, called sialorrhea (pronounced sigh-AL-oh-ree-uh). If this happens only at night, a wet pillow may be a minor annoyance, but excessive drooling during the day can be a social embarrassment and limit activity.

Though excessive drooling is considered a “non-motor” symptom of Parkinson’s disease, its underlying cause is a familiar motor problem. You may be surprised to learn that people with Parkinson’s disease don’t produce any more saliva than anyone else, and in fact they probably produce less! But every person with Parkinson’s disease knows that everything moves slower – walking is slower, completing tasks takes longer – and automatic movements like blinking and arm swings can be not-so-automatic. Slowed automatic swallowing leads to saliva pooling in the mouth. Add this to a stooped forward posture and an accidentally open mouth and you have a recipe for drooling.

Luckily, there are many tips and treatments that can help combat sialorrhea. Many people, especially those with more mild symptoms, find chewing gum or hard candies (sugar-free, of course!) to be helpful in keeping the mouth closed and triggering automatic swallowing. Others carry a handkerchief or wear a wrist sweatband to wipe saliva away. Speech therapy can sometimes provide tips for swallowing, especially if swallowing food, drink, or pills is also a problem. If these are not enough, an adjustment of regular Parkinson’s medications may improve automatic swallowing or help keep the mouth closed.

Other treatments can be used to reduce saliva production to a more manageable level. Atropine drops placed under the tongue or glycopyrrolate can be effective but carry a risk of side effects like any other medication. The most consistently helpful and best tolerated treatment to decrease saliva production is injection of botulinum toxin (brand names Botox, Xeomin, and Myobloc) directly into the salivary glands. These have been used “off label” for many years but were recently FDA-approved for treatment of excess salivation. Injections need to be repeated about every 3 months but are nearly painless and side effects are minimal.

If you or someone you know are constantly wiping away excess saliva from your mouth (or chin, or shirt), try some of these tips or talk with your Parkinson’s specialist about how to solve this common problem.
Keeping Fall as a Season and not an Action

Jennifer McKune, PT
Physical Therapist | Nebraska Medicine

Fall should be an enjoyable season and not a word that causes alarm. Unfortunately for some people, the word fall elicits fear and concern. There are ways to prevent falls and things that you can do to improve your confidence and reduce fall risk. It may be a good idea to start with a visit to your doctor. It is important to rule out any medical reasons that may be contributing to falls. Eye or ear disorders may lead to increased risk of falls. If you have dizziness, joint pain, numbness in your feet, or muscle weakness, you may be at increased risk for falls. Make sure to share with your doctor all the medications that you are taking to determine if any of them have side effects or interactions that could increase your risk of falling. Discuss with your physician if a referral to a physical therapist may be beneficial.

A physical therapist will evaluate your muscle strength, balance, and gait (walking style) to determine your fall risk. The physical therapist will develop a custom exercise program focused toward improving balance, flexibility, muscle strength, coordination, and gait. It may also be recommended that you use an assistive device, such as a cane or walker, to improve stability. It is important to get moving and stay moving. If you’ve seen a physical therapist, continue your home exercise program. Otherwise, find activities that you enjoy and that you can do at home or in a group setting. Consider walking, water exercise, bicycling, yoga, Tai Chi, and resistance exercises. There are Parkinson’s specific exercise programs, such as LSVT BIG, PWR! Moves, Rock Steady Boxing, that are helpful in reducing fall risk.

It is also important to evaluate your home environment for potential hazards that may lead to falls. Clear walkways of any tripping hazards such as electrical cords, throw rugs, miscellaneous clutter, or extra furniture. Repair torn carpet or loose wooden floorboards. Use non-slip mats in the shower or bathtub to prevent slipping. A shower chair or bath bench may be necessary to increase safety while bathing. Grab bars in the tub/shower and by the toilet provide a safe and sturdy support to hold onto when getting in/out of the shower and standing up from the toilet. Hold onto handrails when walking up/down the stairs. Placing a strip of bright tape on the stairs can help with depth perception and improve foot clearance to reduce tripping. Make sure to turn on the lights before going up/down the stairs. Nightlights are important to illuminate dark hallways, your bedroom, and the bathroom. Make sure outside pathways leading to your home are well lit and clear of debris. An occupational therapy consult for a home safety evaluation may be beneficial. The occupational therapist can provide recommendations to improve safety in your home.

Eating a balanced and nutritious diet with adequate protein can help maintain muscle strength and provide energy for your activities. Drink plenty of water to stay hydrated. Pay attention to timing your activities and exercise to when you have taken your medication. It is best to engage in social and recreational activities when you are feeling your best and moving well. Wear clothing that fits well and choose shoes that are supportive and have a non-skid sole. High heels, flip flops, or loose-fitting slippers may lead to a stumble or fall. As the weather changes and the potential for ice becomes more of a risk, consider adding more traction to your shoes.

Staying healthy, engaging in exercise to keep you strong and flexible, and making some modifications to your home can go a long way in reducing your risk of falling. Make sure to talk to a healthcare provider if you are falling or need help establishing a fall prevention plan to keep you safe.

Upcoming 2018 Events

Nebraska Medicine/UNMC Parkinson Disease Support Group
Every Third Friday | 2 p.m.
Fred & Pamela Buffett Cancer Center, 505 S. 45th St, Omaha, NE

Speakers:
November 16 Dr. Magnuson (UNMC Psychiatry)
December 21 Holiday Party

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

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

Introduction
My husband had Parkinson’s Disease (PD). He died at age 72, 13 years after diagnosis, from an illness unrelated to PD. I hope I can offer some helpful information and suggestions for all those moving through life with or in the presence of someone with PD.

My husband’s symptoms that concerned him began in 2001 with a slight limp and toe twitches of one of his big toes and soon also a more slouched posture and a slack facial expression. Some time after diagnosis we were able to look back and see other symptoms from earlier in his life that may have been early signs of PD, although they did not impact his life seriously then. From college age on he had problems with constipation, followed several years later with occasional episodes of not being able to focus one eye or double vision in that eye. Learning new technology or tasks was difficult for him in the 90s and became more and more difficult into the 2000s. Around 2000 he had several puzzling errors in reasoning to do with money or math and with organizing his papers and belongings. Increasing problems with these symptoms and new symptoms developed as time went on, but the changes came slowly and for six to seven years medications and exercise and adaptations from both of us meant that life stayed pretty normal in many ways. He could still do most of the activities of daily living, including driving. As symptoms became more pronounced, there was more for me to do to assist and to cue him in daily activities and he needed someone in the house with him most of the time the last two years. But even then, he was still home walking, climbing stairs, eating by himself, able to have interesting conversations, and was very strong due to the exercise program. He never lost “himself,” keeping memories of his life and the world and watching the news and listening to music and audio books. Tremors of hands were relatively minor and did not interfere with tasks. Toe dystonia and the non-movement symptoms related to vision, elimination, cognitive function and anxiety were the biggest problems and required the most guidance and assistance from me or whoever was home with him. BUT HE WAS STILL ABLE TO BE HOME and wasn’t in a wheelchair.

Useful caregiving/helper assistance and support

In the early years after diagnosis:

1. Learn everything you can about PD, even if it’s tough to read that things will probably get worse in time. You need to plan ahead and know what you can do NOW to delay progression of the disease and improve your family member/friend’s functioning NOW. Your reading will help you recognize when symptoms may be part of PD and how to address them and when they might be from something else. It will help you ask questions at doctor’s visits.

2. Know your PD person’s meds and side effects and always ask questions of your medical provider. If new symptoms or side effects arise with any change in meds, do not assume that you just need to give time for adjustment. Call your provider. Be insistent—it can be hard to get prompt replies if you have just been there. One time I actually had to switch providers when there were significant side effects and I couldn’t get an appointment or a call back. Luckily, the new provider had a cancellation so we could get in. Sometimes a change in dose or addition of new medication makes things much worse. The doctor needs to know this.

3. Cueing—Help your person think BIG and MOVE. Walk, dance, participate in exercise classes, get a trainer. If your PD person is starting to shuffle or slow in pace, cue him/her to straighten up and take BIG steps. PD persons do not recognize that their movements and steps are smaller. Explain to your person that the cueing will help him/her do what his brain is no longer doing on its own. (Hint—find out how many long steps it takes to get across a room and several times a day have your person count steps and get across the room by that number.) You have to both be on the same page for this and you have to work out cueing so it doesn’t sound like nagging. Think BIG in cueing for speaking voice too. Practice in BIG movements and speaking will help prolong good function. Read about or participate in classes using LSVT LOUD and LSVT BIG. If handwriting is becoming tiny, have the person make big circular motions with hand and arm just before attempting the writing. This can make a huge difference.

4. Be patient. All those things that have annoyed you before about your PD person will still be there and will probably get worse. Snippy remarks will not help.

5. Recognize your own reaction to your person’s change in facial expression and posture. It can lead you to smiling less yourself and even slumping. He/she still has emotions — you just can’t see them as well. It is natural to be down yourself if you are around someone who doesn’t smile and looks disinterested. Remember that what he/she is showing on the face is not necessarily what is happening inside. Don’t stop smiling yourself. Find activities or TV to make him/her laugh. And keep up with interesting and stimulating activities inside and outside of home as long as you can — necessary for BOTH of you.

6. Using videos for guidance in exercises. My husband tried to use PD exercise videos independently in the first years after diagnosis, but he was unable to follow the directions and place his body and limbs in correct positions or do the motions correctly by just watching the video. That part of his brain functioning just wasn’t working. If I watched with him and cued him that helped, but even then the pace and chatter of the trainer would confuse him. Going to a physical therapist who taught the LSVT exercises and going also to a Delay the Disease class helped much more. Every PD person is different and response to videos may not be the same. Videos, however, WILL help the caregiver in guiding exercises for the person they are assisting. I will provide more tips and information in future issues of this publication. I hope these have been helpful. Best wishes and think BIG!
Apathy in Parkinson’s Disease
Erica Schmidt, PhD, Sarah Szymkowicz, PhD, and Amelia Nelson-Sheese, PhD, ABPP-CN

Apathy is a loss of motivation and interest, as well as a reduced ability to feel and express emotions. Hobbies and social activities may no longer bring enjoyment, and daily routines may seem more effortful. Basic tasks may be difficult to start and complete. This can be perceived as a lack of “get up and go” and can be misinterpreted as laziness, poor initiative, or depression.

Apathy is quite common in Parkinson’s disease (PD), affecting about 40% of patients. The individual is not purposefully being lazy or unmotivated. Rather, symptoms of apathy are a consequence of the disease process and are associated with dopaminergic depletion in the brain’s motivational circuits.

Apathy can impact anyone at any time in the course of their disease. However, older age, worse disease severity, and cognitive impairment place a person at higher risk of developing apathy. In addition, those who already have depression and/or anxiety are more susceptible to developing apathy.

Oftentimes, people with apathy do not realize there is a problem, so it is important for friends, family, and medical providers to recognize the symptoms of apathy. While apathy is often a feature of depression, it can occur on its own in PD. Some medication treatments for depression may actually worsen symptoms of apathy, so it is important to differentiate between the two. Apathy is also associated with reduced daily functioning, increased relationship stress, poor treatment compliance, worse illness outcomes, and poorer response to treatment (such as after deep brain stimulation surgery).

Research studies have shown that some medications may be effective in reducing apathy. Other treatment options include behavioral interventions. Activities like dance and music therapy, exercise, cognitive training programs, and behavioral activation have all been shown to improve apathy.

In sum, apathy is often under-recognized or misinterpreted as depression in PD and tends to worsen over the course of the disease. It is important to recognize these symptoms and treat appropriately. If you or a loved one are experiencing apathy, you are encouraged to speak with your Movement Disorder specialists.

Managing Constipation
Jenna Paseka, MS, RD, LMNT
Nutrition Therapist | Department Neurological Sciences | Nebraska Medicine

Constipation is a common complaint among people with Parkinson’s disease. It has been reported that constipation can be a problem in up to 66 percent of people with PD and often occurs many years before any motor symptoms develop. Constipation is infrequent bowel movements or having difficulty passing stools. It is generally defined as having fewer than three bowel movements per week.

What might cause constipation in PD? Physical weakness, being less active, inadequate fluid intake, and medication side effects could all contribute to constipation.

There are three main lifestyle interventions you can make to either help treat any current constipation or prevent this issue from developing. Think of the three “F’s”!

1. **Fiber**: Add extra fiber to your diet. Fiber-rich foods include bran cereal, bran muffins, oatmeal, 100 percent whole grain bread, whole grain crackers, popcorn, beans, lentils, brown and wild rice, various grains (barley, buckwheat, bulgur, millet, quinoa, rye), fruits, vegetables and nuts. Increase fiber intake slowly to 25 to 35 grams per day. Check nutrition facts labels to determine the fiber content by reading the “Dietary Fiber” line. Adding fiber too quickly into your diet could worsen constipation symptoms. Add one new fiber-rich food every few days.

2. **Fluids**: Drink plenty of non-caffeinated fluids throughout the day. Set a goal to drink at least eight cups per day. Fluids can include water, fruit juice, sports drinks, milk and nutrition supplements/shakes. Fluids help your body process fiber without discomfort.

3. **Physical Activity**: Engage in regular exercise and movement. This helps stimulate the muscles of the intestines which will keep stool passing through more efficiently.

Other things that can help include creating a regular schedule to have a bowel movement, especially after a meal and not ignoring the urge to pass a bowel movement. If these lifestyle interventions do not work, talk to your doctor about medications that may help treat constipation.

Three Best Practices for Improving Apathy

| Behavioral Activation | • Maintaining engagement in physical, social, and cognitive activities and doing them even when you do not feel like it.  
> Ex: Crafts and hobbies, games, projects around the house, going on outings, regular exercise |
| Setting Goals | • Set goals that are specific, measurable, realistic, and ones you can do in a timely fashion. |
| External Cues | • Write down reminders for activities  
• Maintain a regular schedule  
• Use a calendar (either paper or electronic)  
• Engage a friend or family member to help keep you accountable and stick to your goals. |
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

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