Welcome to the Summer 2020 Edition of Parkinson’s Post!

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Summer officially arrived June 20 and we have definitely felt it over the past few weeks with sun and warmer temperatures. I am hopeful you have been able to enjoy some outdoor activities with family and friends while maintaining social distancing guidelines. Although none of us know what is ahead regarding COVID-19, it is essential that we continue to be active, both physically and cognitively, striving to maintain our new normal while maximizing the quality of our lives.

Our Movement Disorder Team at Nebraska Medicine/UNMC continues to provide state of the art care for our patients while utilizing a combination of Telemedicine and Clinic visits. The well-being of our patients, their families and caregivers continues to be one of our highest priorities. We also have continued our Parkinson’s Support Group; however, it is now virtual to accommodate our Parkinson’s Community. In addition, we have started a virtual PD Care Partners Support Group and virtual Women with PD Support Group (refer to Upcoming Events at the end of the newsletter for registration details). We are always welcoming new participants to all our support groups and accepting new patient referrals to our Movement Disorder program. Have a great summer!
So You’re Seeing a Movement Disorders Neurologist... What Does That Mean?

Erin Smith
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As a third-year medical student I stood in the hallway with the neurology team during rounds, watching other people as they obliviously walked by. “See how that person takes short, shuffling steps?” my attending Dr. Torres asked the group. “If you look closely, you can also see a very slight tremor in their right hand. That person probably has Parkinson’s disease.”

I quietly observed this gentleman, praying he would not turn around to catch me staring while trying to see what my attending had described. Had this person walked past me any other day I would never have had a second thought about the way he walked, much less fathomed that on the inside he was fighting a personal battle with Parkinson’s disease.

It was from that day that my love for Movement Disorders began to grow. As of July 1, I embarked on my second year of fellowship training to become a movement disorders neurologist.

Based on the name only, it may not be clear just what a movement disorders neurologist does. For many people with a new symptom like hand shaking or balance problems, their first stop is usually their regular family doctor, also called their primary care physician (PCP). While many PCPs feel comfortable managing straightforward cases of things like essential tremor and Parkinson’s disease, usually a referral to a Neurologist is the next step. A general neurologist has completed four years of medical school and 4 years of a Neurology residency. They see patients with all neurological conditions such as seizures, headaches, and strokes. They are also equipped to diagnose and manage many movement disorders; however more complex cases require the expertise of a movement disorders neurologist.

In addition to the training required to be a general neurologist, a movement disorders neurologist has also completed one to two years of fellowship training. Our field deals with any abnormality of movement, whether too much or too little. The scope of our practice covers many conditions such as Parkinson’s disease, essential tremor, dystonia, ataxia, Huntington’s disease, restless legs syndrome, myoclonus, orthostatic tremor, tics and tourette syndrome. We have unique skills in giving botulinum toxin injections to treat things like muscle tightness after a stroke or other brain injury (called spasticity), abnormal muscle activity in the neck and other parts of the body (called dystonia), spasming of the eyelids or face, and even migraine headaches. We also evaluate patients for advanced treatments like deep brain stimulation (DBS) surgery and baclofen pump therapy.

Nebraska Medicine in Omaha is home to the only Movement Disorders Center in the state and is the largest in our region. In addition to seeing patients with all types of movement disorders, we offer comprehensive care clinics for Parkinson’s disease and Huntington’s disease. In these specialty clinics, a movement disorders neurologist teams up with physical, occupational and speech therapists, nutrition specialists and social workers to provide same-day complete care for these patients and their families. Our Huntington’s Disease Center of Excellence also offers access to a genetic counselor and mental health provider. Our department includes not only fellowship-trained movement disorders neurologists but also nurse practitioners and case managers who are highly experienced in the field. We work closely with our colleagues in neurosurgery, neuropsychology, psychiatry, neuroradiology, and physical medicine and rehabilitation to provide comprehensive and compassionate advanced care.

Life is lived through movement – it is only through movement that we can use our voices to talk to each other, use our legs to walk around in the grocery store or run to keep up with our children, use our hands to eat and work, and so much more. Movement disorders are all around us, though to the untrained eye they are not always easy to see. Whether we are making a new diagnosis of Parkinson’s disease or guiding a patient and their family through end-of-life care in Huntington’s disease, we in the movement disorders department at UNMC are committed to further advancing research and treatment of movement disorders to improve the lives of our patients and their families in Nebraska and beyond. We are here to serve all patients for whom moving through life from day to day is never taken for granted.
Assessing Cognition in Parkinson’s Disease

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Cognitive changes occur relatively frequently in Parkinson’s disease. However, when the cognitive issues are mild, it can be difficult to determine whether they are due to PD or normal aging. It is not uncommon for neurologically normal older adults to occasionally forget the date or an acquaintance’s name or to have trouble with word retrieval. These cognitive “blips” can also occur with PD. Cognitive testing can be useful for assessing whether an individual is experiencing cognitive issues that exceed what is expected from normal age-related changes in the brain.

There are two types of cognitive testing that are typically considered. Cognitive screens are brief (10-20 minutes) tests that assess general cognitive status and that can be administered during a regular doctor’s appointment by a physician, nurse, or other trained healthcare professional. Screens are convenient, quick, and inexpensive. They are also easy for providers to interpret: screens usually involve a pre-determined “cut score” under which people with cognitive impairment typically fall, making it easy for the provider to determine whether the number of missed points may be normal or not. However, these strengths of cognitive screens may also contribute to their weaknesses. That is, because the tests are meant to be short and quick, they only assess a limited number of cognitive areas. They may also have limited reliability, depending on the scenario. For example, because there are fewer items, they may be more susceptible to influence by environmental (e.g., noise) or patient factors (e.g., fatigue) that may occur on the day of testing.

Neuropsychological assessment is another type of cognitive testing that is conducted by a clinical neuropsychologist, which is a doctor who specializes in brain-behavior relationships and cognition. Neuropsychological test batteries are more comprehensive than screens, in that they assess a broader range of cognitive abilities. As such, they can provide a finer-grained depiction of a patient’s cognitive strengths and weaknesses, and they can be helpful in determining where in the brain the dysfunction may be occurring, along with possible cause(s). Perhaps most important, the neuropsychologist may be able to provide specific tips on how best to compensate for the deficits seen on testing, which may positively impact a patient’s daily functioning and quality of life despite having cognitive weaknesses. The drawbacks of neuropsychological assessments are that they are lengthier than screenings (they can take hours to complete in some cases), which can lead to fatigue for some individuals, and professional neuropsychological training is required to interpret the tests (i.e., the evaluation cannot be completed during a typical doctor’s appointment).

For Parkinson’s Disease, cognitive screens and neuropsychological evaluations can be helpful, depending on the situation. In many cases, routine cognitive screenings are worthwhile for tracking cognition over time and for identifying any general changes that may occur. If no concerns are noted, then further testing is not necessary. If any concerns for cognitive changes are found, then the patient may be referred for a more comprehensive neuropsychological assessment to help determine the cause of the cognitive changes and to recommend treatments or compensatory strategies that may be helpful.

If you or a loved one think that cognitive testing may be helpful for you, speak with your treating provider(s) who may assist you with deciding whether to pursue a cognitive screening or a neuropsychological assessment.
Orthostatic Hypotension: Why Parkinson’s Disease can cause dizziness/lightheadedness

Mara Seier, MD
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Parkinson’s disease (PD) can be likened to an iceberg; others only see the obvious symptoms at the surface while a person living with PD can be experiencing so much more “under the surface.”

These insidious problems are termed non-motor symptoms and are often not as obvious to others, but can be just as troublesome and disabling as the motor manifestations of PD. These symptoms can include (but are not limited to): cognitive changes, constipation, urinary issues, fatigue, mood disorders, pain, sleep disruption and lightheadedness. We will focus on one common non-motor symptom: lightheadedness.

Orthostatic hypotension is a term that describes a drop in blood pressure when changing position or standing upright for prolonged periods. If you imagine the body as a tube of water, the water is evenly distributed when the tube is lying flat but when the tube is shifted upright, the water will collect at the bottom due to gravity. This is what occurs in our body when moving to a standing position. Gravity pulls our blood down into the expandable venous system in the lower half of the body which then causes less blood flow return to the heart. This in turn causes a drop in blood pressure and reduce blood flow to the brain. Typically our vascular and nervous systems can overcome these fluid shifts, but due to dysfunction in the autonomic nervous system (the part of the nervous system that controls things under automatic control like heart rate and blood pressure) in people with PD, the body does not compensate well and a drop in blood pressure occurs. This drop in blood pressure can cause many bothersome symptoms, most often feeling dizzy or lightheaded but symptoms can also include:

- Fainting (passing out)
- Unexplained falls
- Generalized weakness
- Sleepiness or fatigue
- Dull pain covering neck and shoulders (“coat hanger” pain)
- Blurring of vision
- Cognitive changes (feeling slow, sluggish)

If you are experiencing dizziness or any of the above symptoms and have concern that you may be having orthostatic hypotension, it is recommended to record a log of your blood pressure and heart rate to show your doctor. Take the measurements when laying, then sitting after 5 minutes and finally when standing after 5 minutes. Someone with orthostatic hypotension will have a drop in the blood pressure (20-point drop in top number or 10 point drop in the bottom number) when there is a position change.

In addition to PD causing orthostatic hypotension, there are several medications that can exacerbate it. You should consult with your doctor regarding your medication list to see if you are on a medicine that could be making these symptoms worse. Other triggers for causing orthostatic hypotension include quick changes in position, prolonged physical activity with sweating, dehydration, alcohol intake, hot environments (including hot shower or sauna) or even eating a large meal. There are several treatment strategies to employ once the medication list has been assessed, including:

- Change positions slowly: Rise slowly from reclined to sitting; sitting to standing
- Increase salt consumption
- Increase water intake (up to 2.5 liters per day)
- Sleep with the head of the bed raised: 4-6 inches or about 30 degrees elevated
- Physical activity with recumbent exercises (stationary bicycle, rowing machine) or in a swimming pool
- Be careful about prolonged standing or exercise after a meal or when body temperature is elevated (fever, hot climate, hot shower/bath)
- Physical counter maneuvers (clenching leg muscles, leg crossing/uncrossing, buttock clenching)
- Compression waist-high stockings that produce at least 15-20 mm Hg pressure: Knee or thigh-high stockings do not cut it! Alternatively, an abdominal binder can be used
- Drink one to two large glasses of COLD water before provoking activity

There are also medications that are used to treat orthostatic hypotension if the above measures are not effective and can be discussed with your doctor.
Finally! The long, sunny days of summer are here. It is prime time for outdoor activities: biking and walking, strolling local festivals, and cooling off at the beach or pool.

But the common denominator among all these activities is sun exposure—something people with Parkinson’s disease (PD), who have an increased risk for developing melanoma—need to guard against.

The link between Parkinson’s disease (PD) and this potentially lethal type of skin cancer is well known. Most recently, a study published in 2017 in Mayo Clinic Proceedings found that people with PD had almost four times the risk of developing melanoma compared with those without.

The association went both ways, with the data showing people with a history of melanoma had four times the risk of developing PD.

Scientists do not yet understand the connections between the two diseases—some speculate common genetic, environmental or immune system issues could underlie both conditions.

Fortunately, questions on how to safeguard your skin from ultraviolet (UV) light exposure—one of the primary risk factors for melanoma—are easier to answer.

**Sunscreen is your best friend.**
Apply a broad-spectrum sunscreen (one that protects against both UVA and UVB light) daily, even if you are not spending significant time outdoors.

It is not just the high-intensity exposure of reflected UV light from city streets, sand or water that can up your risk for melanoma and other skin cancers—damaging UV light can reach you on overcast days and through windows.

The American Academy of Dermatology recommends choosing a broad-spectrum, water-resistant sunscreen of 30 SPF or higher.

Apply 15 minutes before getting into the sun and use enough product (about 1 ounce, an amount that would fill a shot glass) to generously coat all skin not covered by clothing.

Do not forget your lips, ears, hands and feet. Reapply every two hours and right after getting out of the water or heavy sweating.

**Cover it up.**
The Skin Cancer Foundation reports that your clothing is the single most important thing protecting you from the sun. Sun-protective clothing, made with tightly woven fibers, shuts out harmful rays.

Look for clothes with a UPF (ultraviolet protection factor) label. A shirt with a UPF of 50 allows only one fiftieth of the sun’s UV rays to penetrate, for example. The Skin Cancer Foundation advises choosing clothes with a UPF of 30 or higher.

Today’s options for sun-protective gear include everything from beachwear to hats to casual wear and dresses. There also are many sports-specific options, from high UPF fishing and hiking shirts and pants to arm sleeves and jerseys for cyclists.

**Grab some shade.**
Take umbrellas or pop-up sun canopies to the beach and carry a parasol or shelter under a tree at outdoor events.

You will still need to wear sunscreen and/or sun-protective clothing but placing a barrier between you and the sun’s rays will reduce UV exposure and melanoma risk.

Make sure to take shelter between 10 a.m. and 2 p.m., when the sun’s UV light is at its most intense.

**Protect those peepers.**
Eyes need protection from the sun, too. Look for pairs that block both UVA and UVB light and styles that wrap around or cover the delicate skin around the eyes.

Get personalized guidance on your melanoma risk.

Factors other than PD, including family history, number of moles, and skin type, can affect risk for melanoma. Talk your doctor to understand your individual risk and how often you—or a dermatologist—should do a thorough skin check.
Parkinson’s Disease, Physical Therapy and Telehealth
Joel Esters, PT, DPT, MS
Parkinson’s Wellness Recovery Certified | Nebraska Medicine at Bellevue

With the recent outbreak of COVID-19, many physical therapy clinics providing treatment to Parkinson’s disease (PD) patients have either temporarily closed or modified their services. National and local guidelines regarding self-quarantine and social distancing have left many PD patients with a disruption in their regular ongoing physical therapy treatment. This left the patient in a state of isolation at home with the fear of worsening symptoms and a possible reduction in functional abilities.

It is well documented that PD patients benefit from specialized physical therapy treatment. Exercises and activities addressing strength, flexibility, balance, gait and coordination assist the PD patient in reducing the progressive nature of Parkinson’s Disease. Physical therapy directly promotes the patient’s overall function with improved survival and increased quality of life. Without physical therapy treatment the PD patient risks increased rate of regression and decline in independence.

One option is receiving physical therapy treatment via telehealth. Literature suggests that using Telehealth to treat PD patients is feasible and economically advantageous for both the patients and providers. Telehealth is the provision of a service by either audio or a combination of audio/visual. Audio is when the patient and provider can only hear each other, such as when talking on the phone. Audio/Visual is when the patient and provider can hear and see each other simultaneously, such as a zoom meeting or FaceTime visit using a computer, tablet, or smart phone. The latter allowing the provider and patient to interact both through talking and observation thus facilitating their interaction.
Important things to know when getting set up for telehealth services for both the provider and patient:

**Be prepared**
1. Good internet connection/service
2. Be familiar with technology (smart phone, computer, tablet)
3. Placement of camera (plenty of room to move and lighting)
4. Appropriate clothing
5. Assistance available if high-risk for falls
6. Keep visual focus toward camera
7. Session should have distinct end with future appointments and/or follow up

**Benefits for patients:**
1. Lower costs, fewer secondary expenses (childcare, gas)
2. Improved access to care
3. Convenient (access while at home, less time of work)
4. Slow the spread of infection and illness

**Benefits for providers:**
1. Reduced overhead expenses
2. Additional revenue stream
3. Less exposure to illness
4. Improved patient satisfaction

**Disadvantages for patients:**
1. Insurance coverage (not all cover telehealth)
2. Medical data security (possible unsecure network at home)
3. Technology concerns (strength of connection)

**Disadvantages for providers:**
1. Licensing issues (across state lines)
2. Technology concerns (strength of connection)
3. Limited examinations (no hands-on testing)

Although the recent coronavirus outbreak has brought telehealth to light, there are additional circumstances that may prevent PD patients from being able to participate in clinic based, face to face physical therapy. Four primary obstacles for PD patients receiving in-clinic face-to-face physical therapy include:

1. Geographical (how far you live from clinic)
2. Financial (cost of getting to and from clinic)
3. Transportation (can you physically get there)
4. Exposure to illness (coronavirus, flu, etc.)

Looking into the future these obstacles are anticipated to become even more significant as the projected growth of the PD patient population continues to grow.

To combat these obstacles, telehealth is a viable alternative to in-clinic face-to-face care. The primary advantage of telehealth is its accessibility. Patients can connect either through smart phones, computers or tablets set up with cameras via the internet from their home or residence. Then once connected, the therapist can guide them through exercises and activities designed to address their individual limitations. Telehealth has proven to have high patient satisfaction, decreased travel burden, equal clinical outcomes compared to in-clinic face-to-face treatments and improved health care compliance. Telehealth also makes it easier for specialized clinicians to reach out with services further into their geographic region to provide services to patients that would otherwise not have access to specialized care.

In summary, telehealth is becoming a more popular treatment option for PD patients. It is easily accessible and treatment outcomes are equal to in-clinic face-to-face treatments. Although telehealth is not for everyone, it does provide patients another viable option for their treatment.

**References:**
3. Can’t Get to the Parkinson’s Clinic? It May Soon be Coming to You. American Parkinson’s Disease Association, Posted August 7, 2018
Feeding Tube – Will I Need One?

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

Having a conversation about a feeding tube can seem overwhelming and scary but preparing yourself with the information you need to make that decision can make that process easier and more comfortable.

You may hear your doctor or member of your healthcare team talk about your advanced directive. Your wishes on whether you want a feeding tube or how you want it to be used can be stated in your advanced directive. This can help you and your family members make the right decisions for your care throughout your journey with Parkinson’s disease.

What is a feeding tube?
It is a small, flexible plastic tube that can be a route to safely receive nutrition and hydration. Feeding tubes often go directly into the stomach and are also called gastrostomy tubes, G-tubes or PEG tubes (percutaneous endoscopic gastrostomy). Sometimes feeding tubes will go into the upper portion of the small intestine.

What is a feeding tube used for?
A feeding tube is used for three main purposes: nutrition, hydration, and medications. There are liquid formulas designed to be given through a feeding tube that contain protein, carbohydrates, fat, vitamins, and minerals the body needs. Water can also be given to meet hydration needs. Some medications can be given through a feeding tube if they are in liquid form or crushed and dissolved in water. Medications to be given through a feeding tube need to be verified with a pharmacist first.

When should I consider getting a feeding tube?
• When you are not able to eat enough to maintain weight and energy levels.
• When hydration is insufficient.
• When Parkinson’s disease affects the muscles involved in eating (chewing, moving food through your mouth and swallowing).

Can a feeding tube be removed?
The feeding tube can be removed at any time, for any reason. The tube is removed by a healthcare provider and the skin closes over time.

Can I still eat with a feeding tube?
Some people with a feeding tube eat by mouth AND use their feeding tube. Your speech language pathologist and dietitian will discuss if it is still safe to eat or drink some foods or beverages and what would be safe to consume. Some people will eat some foods for pleasure and use their tube to meet most of their nutritional needs. A feeding tube can also be used as the sole method of nutrition and hydration if swallowing is unsafe.

Having a feeding tube can help improve quality of life when nutrition or hydration status is poor, or it is unsafe to swallow. It is important to have a conversation early about whether you would ever want a feeding tube before you would even need one. Talk to your doctor, dietitian, or speech language pathologist for more information. They can show you what one looks like and explain in more detail how it could be used specifically for you.
Staying inside during the summer heat and the coronavirus pandemic has been wearing on us all.

For those with Parkinson’s disease, you are being told to stay put, but it is vital to keep moving! The good news is that this is a great time to incorporate Parkinson’s specific exercises like PWR! or LSVT-BIG into your daily routine. By making exercise a habit throughout the day, you can improve your ability to move during other activities, it can help break up the day, and exercise has been proven to help boost overall mood.

Getting into any exercise routine is easier said than done. Here are some tips and tricks to help make the transition smoother and something that you can look forward to doing throughout the day:

• Create a schedule for exercise and write it down. Having a checklist or writing the workout in a planner/calendar can solidify that it needs to happen during the day.
• Make a routine by completing exercises at the same time each day i.e. before each meal, after waking and before bed.
• The more the merrier! Ask a spouse or friend to do the exercises with you. It can be more fun to shout the numbers LOUD with someone else!
• Try an online PWR! or Parkinson’s exercise session from YouTube or a zoom class (resources provided in previous newsletter).
• Add music to any of your exercises to help improve timing of movements and make it more enjoyable.

Another important consideration for using your exercise as medicine to improve function, is to ask yourself what tasks are difficult. For example, if cooking a meal in the evening is typically challenging, take 5-10 minutes and do some PWR! or LSVT-BIG exercises first. If getting dressed in the morning often feels like running a marathon, do your PD exercises first to get moving bigger and better. Remember, the goal of PD specific exercise is to move BIG. This can help with moving BIG even for small activities like doing buttons, zippers, eating, and handwriting.

Consciously adding in exercise throughout the day and around your other activities, does not take long to do and there are multiple benefits. If you are unsure of what to do or need a refresher on some PWR! or LSVT-BIG exercises, now is the time to ask for a therapy referral from your provider or look into community resources for classes to join!
Kynmobi – Newly Approved Treatment of Parkinson’s Disease

A sublingual film of ‘Apomorphine’ is approved by FDA for use in Parkinson’s 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

It is a thin film placed in the mouth (under the tongue) and quickly dissolves and is absorbed in the mouth. It kicks in quickly to provide relief of Parkinson symptoms like freezing, tremors, or walking difficulty, within 15 minutes or less. It also lasts a short time (usually 2-3 hours) and thus was studied for what we call wearing off, or loss of benefit of scheduled medications (such as carbidopa/levodopa) on an as needed basis. Another option for similar situations that was recently FDA approved (December 2018) is Inbrija (inhaled levodopa).

Apomorphine is a dopamine agonist (others include ropinirole, pramipexole and rotigotine from 3rd generation and bromocriptine from 2nd generation). It does not increase dopamine levels in the brain but works like dopamine inside the brain. It is used in addition to the patient’s current medications such as Carbidopa/Levodopa.

The strips are very narrow (smaller than a penny for the small size and the size of a quarter for the largest size). However, they are about one finger in length.

They may cause nausea and vomiting and a patient can use anti-emetic (nausea) medications if needed. In one study, it was seen in 20-30% of the patients (2-3/10 patients).

In the study for approval, side effects noted were soft tissue swelling in lips, as well mouth and throat in a few patients (about 15-20%). Other side effects included some orthostatic hypotension or drop in blood pressures on standing. (About 10%) One bothersome effect could be sleep attacks or somnolence and thus when starting this new drug one should watch for a few days as it can happen even while doing some activity such as driving (11-13% in the study). Injuries and falls were seen in 4-6 %.

This does contain sulphites (form of Sulphur) and people who have a Sulphur allergy can have a reaction on this drug (Sulphur allergy is not always for sulphite however). Another drug that contains sulphite for PD is NeuPro patch.

Like other dopamine agonist, it can cause Impulse Control Disorders.

Cannot be use in pregnant patients due to concerns for congenital malformations in animal studies.

Upcoming Events

Nebraska Medicine/UNMC Parkinson’s Disease Support Group
Every Third Friday | 10 – 11 a.m.
Please use the following link to register (after you register, you will receive a confirmation email from Sallie Weathers with ZOOM connection information): https://unmc.zoom.us/meeting/register/uZElfu6srjwuvUy26q79yT6nk3B4r2IUG

August 21
Dr. Diego Torres, Movement Disorder Neurologist, Nebraska Medicine/UNMC

September 18
TBD

October 16
Dr. Mara Seier, Movement Disorder Neurologist, Nebraska Medicine/UNMC

November 20
TBD

December 18
TBD

Nebraska Medicine/UNMC Parkinson’s Disease Care Partner Support Group
Every First Monday | 7 – 8 p.m.
Please use the following link to register (after you register, you will receive a confirmation email from Sallie Weathers with ZOOM connection information): https://unmc.zoom.us/j/96134594876?pwd=O1N6Y0dUUZXwAG5PV0dLOVpkZI9uZz09

Nebraska Medicine/UNMC Women with Parkinson’s Disease Support Group
Every Second Monday | 7 – 8 p.m.
Please use the following link to register (after you register, you will receive a confirmation email from Sallie Weathers with ZOOM connection information): https://unmc.zoom.us/j/93447704600?pwd=NWhYR0NTRIVDbo0g4SXZNN1QwRXR0Zz09
Dad – Parkinson’s
by Maria Harding

Someday I’ll wish I could just pick up the phone and chat with you,
But you’ll be gone.
You’re already gone. I missed my opportunity.

But how and when did this happen?
It seems that not long ago we could still giggle together at a Road Runner cartoon,
Or congratulate ourselves on our quick-wittedness.

You were the sweaty backyard gardener,
The opener of vacuum-sealed jars,
A sawdust-covered engineer of endless home improvements.

I’d love to be annoyed at you for only reading fishing magazines.
I would adore rolling my eyes at you as assistant-coach of my soccer team.
How happily I’d endure the humiliation of riding to school in your spooler-rig truck.

I used to love the smell of Stetson on your freshly shaven face.
Now I can’t stand the scent of urine that clings to you.
I disgustedly pick dandruff flakes from my lips after I peck your cheek.

I’m trapped in this grey cloud of pretending.
Pretending that I’m enjoying our slow conversation,
Pretending like photos or flowers could ever brighten this nursing home.

But you are trapped, too.
Trapped in a body that no longer responds in a predictable way,
Trapped in a state of confusion that flips day and night, that erases names.

I keep a favorite childhood photo of us nearby.
We are both asleep, and your heavy hand is resting on my forehead--
A summertime nap after a trip to the lake.

I need to remember that this is who you truly are.
If you could, you would soothe my worries with the warmth of your steady hand.
In your dreams, your legs are still sunburned and strong.

So I will slow my conversation, too.
I will repeat information as necessary, without shaming you into silence.
Let’s laugh together at the cruelty of soup or green peas in your meal plan.

I won’t forget to ask for your guidance.
I will cherish every “good morning” phone call from you at dinnertime.
I’ll comb your thinning hair and rest my hand upon your brow.

Saliva
by Marilyn June Coffey

The thing
I hate most
about Parkinson’s
is dro-o-o-o-ling
the way saliva balls
in a corner
of my mouth
POPS
thru my smile
skitters down
my chin
Oh my God
did anyone SEE?
Reliable Parkinson Resources

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

American Parkinson Disease Association
www.apdaparkinson.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

To obtain access to our Nebraska Medicine/UNMC Parkinson’s Disease Patient, Family, and Caregiver Symposium (October 2019) PowerPoint presentations and video playlist on YouTube (scroll to the bottom): unmc.edu/neurologicalsciences/patient-care/programs/movement-disorders

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

www.unmc.edu/neurologicalsciences/news/newsletters