Welcome to the Spring 2019 edition of Parkinson’s Post!

The Movement Disorder Team continues planning our upcoming Symposium, *Parkinson’s Disease in 2019: A Conference for Patients, Family, and Caregivers* that is Monday, October 14, 2019 from 8 a.m. – 3:30 p.m. at Embassy Suites and Conference Center, La Vista, NE. The Symposium offers an excellent opportunity for all individuals affected by Parkinson’s to network with Parkinson Disease Experts; vendors representing treatments, products, and services specific to Parkinson Disease; and others who understand the daily struggles, battles, and triumphs that patients, families, and caregivers endure daily. The curriculum includes sessions presented by our Movement Disorder Team including our Physicians, Therapy Department (Physical, Occupational, and Speech) and Nutritionist.

Registration for the Symposium will begin August 5, 2019 and we will be emailing and mailing Registration Forms – it is essential to submit your registration in a timely manner as there will again be a space limitation to this very popular event. There also are Sponsorship, Vendor, and Donor opportunities for the Symposium available – contact me for further details.

As detailed in the previous Parkinson’s Post, our Keynote Speaker for the Symposium is Brian Grant who was an NBA idol, known for his tenacious rebounding and a fearless attitude on the court. During his 12-year career, he played for five teams and became a strong contributor to his surrounding communities. Today, Brian continues to inspire as a speaker, philanthropist, and a patient who insists on thriving with Parkinson’s disease. His mission is to help people become their best, even when it seems impossible. Brian started his career at Xavier University where he was Player of the Year twice for the Midwestern Collegiate Conference. He was drafted in the first round, eighth overall, in the 1994 NBA draft by the Sacramento Kings. His career continued...
Walk with Confidence
Jennifer McKune, PT
Physical Therapist | Nebraska Medicine

Walking is the primary means of locomotion for most people and often an activity that we take for granted. It is something we have done most of our lives. Walking is a wonderful method of exercise and can improve strength, endurance, and overall health. But what happens when walking is affected due to symptoms associated with Parkinson’s disease? Some individuals experience reduced arm swing and poor posture. Others have shortened step length and limitations with stride. Often, an individual develops a “running” type of gait (a person’s manner of walking) that leads to unsafe mobility and increased risk of falls. It may become difficult to transition over different types of flooring, to walk through a doorway, to walk in crowds, to turn around to change directions, to go up and down stairs, and even to initiate gait. When this happens, we realize just how challenging gait can be. There are strategies and techniques that can help with gait difficulties. Utilizing internal cues and external cues can be helpful.

Internal cues consist of self-talk to tell yourself to step big or step long, to stand tall, to take a step with the right leg, then the left leg, to step wider, and to shift weight. External cues may consist of visual or auditory stimuli such as tape on the floor, a laser light, a metronome, music, or counting. Working with a physical therapist is beneficial to learn and practice various gait strategies. The PT can teach techniques to work on balance and walking to reduce risk of falls. It might be necessary to trial different gait aids to improve safety with walking and increase independence. Learning specific strengthening exercises for your core and legs can also help with gait and balance.

5. When walking through a doorway, look beyond the threshold and focus on an object you are moving toward.
6. Place colored tape on the threshold of various doorways to serve as a cue for stepping over it.
7. Take wide steps when turning and avoid pivoting. Try using rhythmic movement and counting or say “right, left, right, left” to aide in turning.
8. To begin walking or re-start when freezing occurs—stop, take a deep breath, shift your weight, visualize stepping over an object, and tell yourself to step big.

So walk with confidence and keep moving!
What is new with voice and swallowing?
I very much enjoyed the session for the Parkinson’s Support Group in May “A Hard Pill to Swallow: What’s New for Swallowing for Patients with PD.” It was such a vibrant and interactive experience with many key questions from patients and family members which I’ll try to address with this post.

What do you have here at UNMC/Nebraska Medicine that is different from my ENT at another hospital?
Last year, I very enthusiastically joined an incredible laryngology program started by Dr. Chris Bingcang in 2013. This is a unique practice model with the only two fellowship trained Laryngologists in the state of Nebraska. Our entire practice is focused on voice, airway and swallowing so we are able to stay up to date on these topics. We enjoy collaborating closely with the movement disorders neurology group here. Together, we have a full range of medical and surgical voice, airway and swallowing services for patients. We very much enjoy collaborative practice with speech language pathologists in the region to develop personalized patient-centered treatment programs.

During a visit, why do you talk about my voice and breathing why I’m having a swallowing problem?
The larynx is involved in separating the airway from the esophagus to keep food and liquid from going down the wrong pipe. Breathing, voicing and swallowing involve the voice box (larynx) as well. We will ask questions and assess all of those functions so that we can keep the entire system strong. Treatments like the expiratory muscle strength trainer (EMST.com) which seem focused on breathing can be used to strengthen swallowing. Also, there data to support Lee Silverman Voice Therapy can strengthen swallowing (Miles, 2017).

Why do I need a scope before I do Lee Silverman Voice Therapy?
Lee Silverman Voice Therapy is very effective for Parkinson’s hypophonia. The diagnosis of Parkinson’s hypophonia is made by listening to the voice, a patient history and an examination of the voice box (larynx). Patients have other diagnoses for their voice troubles such as cancer in the voice box and blood blisters (hemorrhagic polyps) that will not be treated, or made worse, by Lee Silverman Voice Therapy.

What simple things can I do for my voice and swallowing?
The appropriate amount of moisture for the mucous membranes is critical for swallowing and for voicing. It’s very much like Goldilocks and the Three Bears – hard for the body to get it “just right.”

Swallowing is like a water slide. If you swallow pills on a dry throat they are most likely to stick in the many nooks and crannies of your throat. Simple tricks like sitting down when swallowing pills and drinking a few sips of water prior to taking your pills to wet the throat can be helpful. Taking one pill at a time rather than a handful can be helpful. If you look at your pills and they are the size of nuts, consider adding slime in the form of sugar free pudding, yogurt or applesauce to prevent sticking.

Sometimes medications can be quite drying to the throat. Many patients with Parkinson’s experience decrease saliva and dry mouth. This can have implications for swallowing and voice and also dental health (Barbe, 2017, 2019). Having a humidifier on your nightstand or exploring nasal saline products like Ocean Saline Nasal Spray and Ayr Gel can keep the mouth and throat moist. The nose is the humidifier for the throat. The vocal folds vibrate much better if they are moist. Dryness can lead to thick mucous. Swallowing the mucous, rather than trying to clear the throat or “hock a loogie, can be more gentle for the voice.

Other patients may experience too much saliva (hypersalivation) or drooling which can be addressed as well (Ruiz-Roca, 2019).

Any new surgical techniques for voice and swallowing?
Vocal fold augmentation can be performed in the office or the operating room. This is performed for glottic insufficiency which there is too much air escape between the vocal folds. We inject a filler agent in the vocal folds to add bulk to the vocal folds. In Parkinson’s, this has been shown to help with voicing and has also shown some benefit in swallowing (Howell, 2019, Dashtipour, 2018; Sinclair, 2013).

Why do we advocate for singing?
There are now multiple studies that show that individual and group singing for patients with Parkinson’s can have a number of benefits. Benefits of singing include improvements in voice, breathing, swallowing, gait and mood (Tamplin, 2019, Han 2018, Stegemöller, 2017, 2018). These benefits can be seen in person or via telehealth (Stegemöller, 2019).
Fuel #2: Protein

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Nutrition Therapist | Neurological Sciences
Nebraska Medicine

Last newsletter, carbohydrates were highlighted as the first of our main macronutrients in our diet. The next nutrient is protein.

What does protein do for us? The first thing that usually comes to mind is that protein helps our muscle mass. Not only does it help build muscles, but it also helps our bones, cartilage, skin and blood. Protein can make enzymes, hormones and other chemicals the body needs. The Dietary Reference Intakes and 2015 – 2020 Dietary Guidelines recommendations are to consume between 10 to 35 percent of calories from protein.

Protein sources can come from animals or plants. Animal sources of protein include chicken, turkey, pork, beef, fish, eggs, milk, cheese, cottage cheese and yogurt. Plant-based protein is found in soy milk, peanut butter, almond butter, nuts, seeds, beans, lentils, quinoa, edamame, and tofu. Try to get a variety of these sources or pick something new to try! Protein can also be consumed in the form of protein shakes using protein powder, nutrition supplements (Ensure®, Boost®, Carnation Breakfast Essentials®, etc.) or protein bars.

People with Parkinson’s disease who are taking carbidopa-levodopa may need to be cautious with the timing of their protein intake and when they take their medication. Protein may interfere with the absorption of levodopa, causing the medication to work more slowly or less effectively. You may need to take carbidopa-levodopa 30 minutes before a meal or 60 minutes after a meal to help the medication work more effectively. Some people, though may need to take carbidopa-levodopa with a meal that has protein to help alleviate side effects, such as nausea. Talk to your doctor about the right timing of taking your medication and protein intake for best control of your Parkinson’s symptoms.

Look out for the next issue of the Parkinson’s Post to learn about the last macronutrient, fat!

Your Voice: How Parkinson’s Disease Can Affect It

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Your ability to communicate is one of the many parts of you that can be affected by Parkinson’s Disease. Some of the most commonly reported speech issues by those with Parkinson’s Disease and their loved ones are soft/quite voice, hoarseness, monotone, mumbled speech, and rapid speech. These are all things that can be targeted in speech therapy.

In the world of speech therapy and its role in the management of Parkinson’s Disease, there are two well researched therapies: SPEAK OUT! and LSVT LOUD. Both target the same deficits (soft voice, monotone), however they do it in very different ways.

SPEAK OUT! is a two-part therapy approach that helps you regain and maintain your speaking ability. It specifically targets your ‘intent’ and teaches you to speak with purpose, deliberation, and intention. It consists of twelve therapy sessions targeting six different exercises. Following the twelve therapy sessions you are able to join the ‘LOUD CROWD’ which is a weekly speech therapy group consisting of the SPEAK OUT! exercises. For more information please see www.parkinsonvoiceproject.org.

LSVT LOUD trains you to use your voice at a more normal loudness at home, work, or in the community. The key to treatment is the help you ‘recalibrate’ your voice so you know how loud or soft you sound to others. It consists of sixteen sessions targeting both structured tasks, ‘trigger’ tasks, and conversation. For more information please see www.lsvtglobal.com.

If you are interested in either of these therapies, you can search for a certified clinician near you on their websites. However, you do not have to complete one of these programs to receive speech therapy. Your local speech-language pathologist may be able to provide a more generalized care plan for you. A doctor’s order will be required for the speech pathologist to evaluate and treat you, either your primary care physician and/ or your neurologist will be able to fulfill this.
Exercise Your Mind: How Physical Activity Can Improve Brain Function and Mood

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Parkinson Disease is a condition that currently affects more than ten million people worldwide. I assume many of you are familiar with the common symptoms of Parkinson’s which include tremor, shuffling gait, forward flexed posture, and rigidity or stiffness. Although these are the most commonly treated symptoms, it is also estimated that up to 50 percent of people with Parkinson’s disease suffer with either depression, or mild cognitive impairment (difficulty with memory, language or thinking). Luckily, research has shown that aerobic and resistance exercise can be beneficial in improving brain function and overall mood!

Aerobic Exercise
Aerobic is a fancy word that means as you exercise you will be using more oxygen (you’ll be breathing faster). Research has shown that this form of exercise not only improves your endurance, but can help to improve your ability to problem solve, and remember recent events. There are a variety of ways to perform this type of exercise, but here are some common methods:
1. Walking
2. Boxing
3. Water aerobics
4. Cycling
5. Ballroom dancing

Not only do many of these exercises provide positive benefits for your brain health, but they are beneficial in slowing the overall progression of PD!

Resistance Training
Resistance training is exercise that is aimed at improving muscle strength. This training usually used weighted objects or machines, but can be done simply by moving the weight of your own body! In addition to aerobic exercise, resistance training has been shown to improve both mood and brain function.

Where Do I Start
While many forms of exercise can be performed with a low risk of injury, it is important to consult your doctor first to ensure that you are safe to begin an exercise program. If you are appropriate, you may be referred to Physical Therapy to begin working on strength and endurance, or you may be appropriate to start an exercise program on your own.

The current exercise recommendations for people with Parkinson’s disease include aerobic training three days a week for 30 minutes a day, and resistance training two to three days per week targeting all major muscle groups. Although 30 minutes is the recommended time per day, research has shown that as little as ten minutes of continuous exercise can provide beneficial effects for both mood and cognition.

Upcoming 2019 Events

Nebraska Medicine/UNMC Parkinson Disease Support Group
Every Third Friday at 10 a.m.
Fred & Pamela Buffett Cancer Center, 505 S. 45th St., Omaha, NE

June 21
Dr. Amrita-Amanda Vuppala  
Assistant Professor, Department of Neurological Sciences, University of Nebraska Medical Center
Eye Findings in PD: What Your Neuro-Ophthalmologist Can Do For You!

July 19
Lisa Day  
Sr. Manager Education and Clinical Development Global Kinetics Corporation
Measurable Change to Parkinson’s Management.

August 16
Dr. Khashayar Dashtipour  
Loma Linda University, Murrieta, CA
Parkinson’s Disease: More Than Motor Symptoms.

September 20
Round Table Discussion for Caregiving Strategies

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

Parkinson Disease in 2019: A Conference for Patients, Family, and Caregivers
October 14 | 8 a.m. – 3:30 p.m.
Embassy Suites Convention Center 12520 Westport Pkwy, La Vista, NE
Occupational Therapist Tips on How to Use Your Pets/Animals for Therapy

Narmean Pedawi, OTR/L
Occupational therapist | Nebraska Medicine

Research shows that regular exercise helps many people with Parkinson’s disease (PD) improve symptoms. Pets, trained service animals or not, can provide meaningful rewards in more ways than one. Having pets around the home not only provide that companionship but can also help incorporate physical activity, movement, balance and hand/arm functioning skills. Pets offer good distractions by allowing an individual with PD to focus on other things other than their disease. Pets can allow one to include a more positive routine in their day by forcing one to get up and get going. Here is list of activities that you could be doing with your pets while still engaging in movement and physical activity for your symptoms of Parkinson’s disease.

Walk your dog—an excellent source of exercise. Make it purposeful using large arm swings, heel strike and upright posture

Playtime with your cat—using fine motor skills for grip and repetitive big movements by using a laser light or toy wand waving it back and forth with emphasis through each joint of your arm from shoulder, elbow and wrist.

Play Frisbee or catch—focusing on using large movements, expanding the length of your arm and using full hand movements. Incorporate balance and working through stiffness by twisting through your hips while standing during the toss of the ball or Frisbee.

Horse lovers or owners—the connection between person and horse offers great emotional growth. Horses behave similar to humans in social and responsive behaviors so connecting with a horse is easy. Take it a step further by working on grooming a horse’s hair or mane. Work on standing balance and tolerance as you brush their hair. Using large or small arm movements, working on object stabilization in hand even with a tremor. You can also use fine motor control and coordination by trying to even braid/unbraiding their mane. Be aware of the caution and proper ways of braiding. If you are unfamiliar with horses then have the horse owner present with you for their tips and recommendations for horse grooming.

Yoga—what dog or cat does not like to see their loved one on the floor with them. Beware of extra excited dogs who see you on the floor and prepare for lots of kisses. Stretching is essential for management of joint stiffness and rigidity. Chair or assisted floor yoga help in stability of gait and reduces tremor. Include music with your yoga for improvements with endurance, strength, range of motion and hand coordination. Movements improve Parkinson’s symptoms when you work on crossing the middle of your body

No matter how little or how much you do, it is always better to use “it” rather than lose “it.” Movement is essential for Parkinson’s disease. Animals have a way of providing us with the care we need. With their devout loyalty, you as their owner and loved one should provide them with the same care back. In doing so, you also benefit in your own care and health in managing the Parkinson’s disease.

Gait in PD

Nabeel Muzaffar Syed
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Patients with Parkinson Disease (PD) face several challenges while walking. A seemingly routine task of standing up, walking to the kitchen to get a glass of water, turning, and then walking back to the chair is not so much smooth or automatic anymore. There are a number of reasons for that and we’ll try to describe some of them and then will briefly suggest recommendations.

The hallmark of PD is slowness of all voluntary movements and walking is no different. Patients tend to take longer to stand up and as the disease progresses, use their hands to push themselves up, until they are not able to stand up by themselves. When they stand, the posture is stooped, with varying degrees of neck and trunk bending forwards. The postural reflexes become impaired which means that sudden forces that tip the balance to a side tend to make it harder for patients to maintain their posture and not fall. When they walk, the steps are short, and the arms don’t swing as they used to. As the posture is stooped, the center of gravity is always falling forwards; the patients often must take multiple steps quickly to prevent from falling forwards. This is called festination and it appears mostly when the patients want to stop. Since the whole process of gait is not so much ‘automatic’ and rather requires attention, patients often stop walking before talking, especially if they must answer a question.
Using Wearable Devices to Evaluate Tremors

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One of the hallmark features of Parkinson Disease (PD) is a tremor that is present at rest and usually start on one side, typically in the arm but can be seen also as a starting in the leg. This PD tremor is very characteristic and can be separated from other tremors, the most common being essential tremor or benign familial tremor. It is a common mistake by most physicians especially primary care physicians to diagnose patients with the new onset tremor as essential tremor (ET) even when the tremor clearly is a Parkinsonian tremor. The ability to separate a Parkinson’s tremor from essential tremor needs to be learned with training that may be achieved only after a full fellowship in Movement Disorders to be able to pick them apart. There are many other causes of tremors such as this Dystonic tremor, Rubral tremor, Medication-Induced tremor etc. which makes diagnosing a PD based on the new onset tremor very hard and thus easy to be missed.

With development of wearable devices or smart watches there is an interest to see if they can pick up the tremor and other features of PD. We looked at use of applications or apps in a smartphone such as iPhone to see if those are good enough to pick off tremor at bedside. For this project we studied Orthostatic tremor as that tremor is particularly hard to diagnose and is extremely dependent on an accurate analysis requiring surface electromyography or muscle recording. In this project we evaluated 24 confirmed orthostatic tremor patients and 15 age matched controls, using two different smartphone application called Lift pulse (by Lift Labs now owned by Google) and iSeismometer (by object graph LLC) both of them available for free from iTunes app at that time. (Off note the Lift Pulse was made by liftlabs which also make the tremor spoon to reduce the effect of tremor on eating with tremor cancellation due to a specially designed motor and a sensor and also off note that both of these applications are not available on the iTunes store anymore and are not compatible with the current iOS version). We found that the App1 detected OT tremor in 22/24 patients and App2 detected tremor in 21/24 patients. When we combine both applications together, all 24 patients had tremor on at least one of the two apps but most of the time on both apps giving a sensitivity of 100 percent. This led us to conclude that smartphone applications either on the phone or in wearable watches can be used in a reasonable way to screen for rare tremors that are hard to diagnose such as orthostatic tremor. The movement disorder team at the University of Nebraska Medical Center also partnered with the electrical engineering student in Pakistan to look at developing a wearable watch that can be paired up with a smartphone to pick up tremor and see if it can pick up tremor frequency reliably which will be useful for making a diagnosis and also tremor amplitude which could be used for looking at response to treatment. The idea was very successful and the team won many awards internationally and many accolades. However, the project was eventually given up as keeping up with updates on the hardware was an unnecessary burden and very reliable hardware is already available on the market such as Apple watch.

The next plan is to develop a customized software or application for an Apple Watch that could potentially use built-in sensors to pick up the tremor reliably and can differentiate between a Parkinson’s tremor an essential tremor thus making it a useful tool to be used at bedside by an untrained physician such as primary care physician or nurse practitioners to make or increase the reliability of a diagnosis of Parkinson’s disease and decreasing misdiagnosis.

Freezing means that the feet seem to get stuck on the floor are difficult to lift. The patient can be seen as struggling with this, with repeated attempts to lift their feet. Freezing is especially problematic at the beginning of the walk, before the first step is taken and also while turning and passing through narrow doorways. In most patients, freezing is worse in the off periods (when the levodopa is not working) and after the next dose of levodopa kicks in, the freezing improves. Such patients benefit from increasing their dopaminergic medication (levodopa and other drugs used for PD), either by increasing the dose or frequency. In other patients however, freezing is not affected by the ON and OFF states and may even get worse in the ON state. The latter, so called ‘ON freezing’ might improve by lowering the dopaminergic medication. Apart from adjusting dopaminergic medication, numerous maneuvers or tricks have been shown to counteract freezing. Some of them are: taking a step back before going forward, counting loudly or in their head with each step, stepping over the handle of an inverted cane and having visual cues on the floor to overcome for example stripes or a laser pointer.

If the gait is overall better in the ON state, then increasing the dopaminergic medication generally helps. Rhythmic visual and auditory cues including singing have shown to improve the gait. Physical therapy is very helpful in improving the overall gait performance and reducing falls. Repeated reminders to the patient to ‘keep their head up’, ‘take bigger steps’ and ‘swing their arms’ help.

Unfortunately, PD is a progressive disease and the gait problems worsen over time. It is imperative to realize when the patient is no longer safe to walk on their own. As time goes on, the patients might need to use a cane and then a walker. Falls can have devastating consequences including fractured hips and subdural hematomas. We should make every effort to prevent them, even if it means having to use a wheelchair.

Reference:
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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