

Parkinson's Post

to educate, inspire and empower individuals affected by Parkinson's

Welcome to the Winter 2021 Edition of Parkinson's Post!

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As winter is winding down, the official first day of spring was March 20! This past year truly has been very challenging, but also has included so many opportunities for all of us to endure and embark upon.

As we continue together on our Parkinson's journey, it's important to remind ourselves that we truly are resilient and will continue to take each day as it comes and embrace the constellation of things, we truly do have to be thankful for!

April is National Parkinson's Awareness Month which provides us with an additional opportunity to continue to raise awareness about Parkinson's with our family, friends, neighbors, and community. Education and networking

April is Parkinson's Awareness Month



can be very beneficial as we strive to improve and optimize the quality of life for all individuals affected by Parkinson's and as we continue to advance research towards a cure!

Our Movement Disorder team at UNMC/Nebraska Medicine 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, all are now virtual to accommodate our Parkinson's Community. We have continued our 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) which have been very well attended! We are always welcoming new participants to all our support groups and accepting new patient referrals to our Movement Disorder program. — Happy spring!



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What Should I Snack On?

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

Having some snacks between meals can help you achieve your nutritional goals. Snacks can provide diverse nutrients, give you energy, help productivity, and control blood glucose levels. But determining the right snack can often be the most challenging part! Below are examples of snacks in three different categories depending on what your nutritional goals are.

High Calorie Snacks

If you have lost weight unintentionally and need to gain weight, choosing high calorie snacks will be helpful. Try to plan snacks that have more than 300 calories.

- Smoothie (2 Tbsp peanut butter/ almond butter + 1 banana + 1 cup chocolate milk + 1 scoop protein powder) — **650 calories**
- 1 cup pudding (using heavy whipping cream and instant pudding mix) — **580 calories**
- 1 cup full fat yogurt + ½ cup granola — **460 calories**
- 1 avocado made into guacamole + 20 tortilla chips — **450 calories**
- 16 chocolate covered almonds — **440 calories**
- 1 English muffin + 1 Tbsp butter and 2 Tbsp peanut butter — **410 calories**
- ½ cup mixed nuts — **340 calories**
- 4 Tbsp hummus + 10 crackers — **300 calories**

High Protein Snacks

If you are looking to increase your protein intake to support your muscle mass, high protein snacks are a great choice. These snacks all have more than 10 grams of protein.

- 1 cup cottage cheese and fruit — **26 grams protein**
- 1 tuna packet — **18 grams protein**
- 1 cup shelled edamame **16 grams protein**
- 1 glass of high protein milk — **12-16 grams protein**
- 1 container Greek yogurt — **12-15 grams protein**
- 2 hardboiled eggs — **12 grams protein**
- Ready to drink protein shake — **protein content varies**
- Protein powder mixed with milk or water — **protein content varies**
- Protein bar — **protein content varies**

Low Calorie Snacks

If you are trying to maintain a healthy weight without gaining weight or are trying to lose weight, the low-calorie snacks would be good options. Look for snacks that have less than 200 calories.

- 1 cup grapes + 1 cheese stick — **140 calories**
- 21 almonds — **140 calories**
- 1 container plain Greek yogurt + ½ cup blueberries — **130 calories**
- 1 oz kale chips — **130 calories**
- ¼ cup roasted chickpeas — **120 calories**
- Celery sticks + 1 Tbsp peanut butter — **100 calories**
- 6 mini sweet peppers — **50 calories**
- 8 large black olives — **50 calories**
- 5 large green olives — **50 calories**

Swallowing Therapy in Parkinson's disease: Is Traditional or Intensive Therapy Right for Me?

Carol Gaebler, M.S. CCC-SLP

Speech Pathologist, Munroe Meyer Institute, UNMC

Parkinson's Disease and Swallowing Problems

There has been much written and discussed regarding the effect of Parkinson's disease (PD) on voice production, but you may not realize that more than 80% of those with PD report difficulties in swallowing, also known as dysphagia. These challenges are often the result of slowness and rigidity in the muscles involved in swallowing. When foods, liquids and medications are not properly swallowed, they can end up in the lungs, often resulting in infections leading to pneumonia. When materials enter the airway through the vocal cords, it is called aspiration. Many individuals with PD have reduced sensory awareness of foods and liquids remaining in the throat or passing through the vocal cords, which is referred to as "silent aspiration." Silent aspiration is a serious consequence of dysphagia for anyone but combined with the mobility challenges of those with PD, it can prove to be especially dangerous.

How is Dysphagia Assessed?

A swallowing specialist, most often a speech pathologist, can assess the functioning of a person's swallow by examining the strength of the muscles involved (lips, cheeks, tongue, palate, larynx) and testing different foods and liquids. This swallowing assessment can be completed at the bedside (if the individual is in the hospital, rehab, home health care or skilled nursing facility), or as an outpatient in a clinical office. The evaluation can provide a clinical judgment of the severity of the dysphagia, the safest foods and liquids to consume and strategies which may reduce or eliminate the signs and symptoms of swallowing problems. However, in order to rule

out "silent aspiration," an instrumental swallow evaluation is necessary to provide an image (video x-ray) of the swallow function. A modified barium swallow study is a moving x-ray of the swallow using barium contrast (see image to the right).

While the individual swallows liquids and foods of varying consistencies and volumes containing barium, the video images are observed and any episodes of aspiration are able to be identified. During the study, food and liquid consistencies and volumes can be adjusted and swallowing strategies to eliminate aspiration events can be trialed, such as using multiple swallows, holding one's breath, or tucking the chin down to the chest.

Dysphagia Therapy

Following the swallowing assessment, dysphagia therapy may be recommended. Traditionally, in dysphagia therapy, food and liquid consistencies are modified to the safest and least restrictive level. This may result in liquids being thickened to eliminate aspiration and/or foods being thinned or ground up for easier chewing and clearance from the mouth and throat. In addition, swallowing strategies are trained and exercises are implemented to strengthen the muscles of the tongue and throat for safer and more efficient swallowing. These interventions have been widely researched in the PD population and found to be effective. During sessions, the individual with PD may work with the speech pathologist, trying different foods and liquids to assess tolerance, improving strength, speed and coordination of the swallow, and becoming more independent in use of safe swallow strategies. Sessions may be scheduled with variable frequency and



duration, depending upon the individual's dysphagia severity and independence with strategies and exercises. Once it is determined that the individual with PD has reached a level of safe food and liquid intake, and is independent with swallowing strategies, he/she is usually discharged from therapy. Annual assessments of swallow functioning are recommended given the anticipated decline as PD progresses.

During the past 10 years, some dysphagia research has focused on the potential benefits of retraining the overall swallow physiology, instead of focusing on separate muscle groups and swallowing strategies. The McNeill Dysphagia Therapy Program (MDTP) was created for this purpose, using an exercise physiology model focused on increasing load, repetition and muscle accommodation to improve swallow functioning in those individuals who are unable to meet their nutritional needs

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without supplemental supports (Boost, Ensure) or tube feeding. The intensity and frequency of the Lee Silverman Voice Therapy (LSVT) program was used as a model for MDTP, requiring individuals to participate in dysphagia therapy four times per week for four weeks. A Modified Barium Swallow study is performed before and after the program to instrumentally assess the pharyngeal phase of the swallow. The program uses an 11-step food hierarchy to establish which foods/liquids are safe for the individual to begin in therapy and moves through the levels in a systematic way. The goal is to achieve 80-100 swallows in each one-hour session, without evidence

of aspiration. While original research related to the McNeill program focused on treating those with dysphagia caused by head and neck cancer, the program was expanded to other groups impacted by dysphagia (multiple sclerosis, post stroke, cerebral palsy) and was found to improve swallowing functioning for many individuals, some of whom had already completed traditional dysphagia interventions. For some with PD, MDTP has shown success in improving the ability to safely eat more advanced food textures with increased efficiency (more food/liquids safely consumed in less time).

If you are interested in being evaluated and treated for dysphagia, you should contact your primary care physician to obtain a prescription for a swallowing assessment. That assessment will establish the safest diet for you and may indicate whether or not you would benefit from participating in traditional dysphagia therapy or the MDTP. Clinicians must be certified in MDTP in order to provide these interventions. UNMC's Munroe-Meyer Institute Department of Speech Pathology currently has three MDTP certified clinicians able to provide both traditional and MDTP assessments and interventions.

	Traditional Dysphagia Therapy	McNeill Dysphagia Therapy Program (MDTP)
Evidence-based	Yes	Yes
Criteria for candidacy	No	Yes — must have pharyngeal phase difficulties and need modifications to foods and liquids to maintain nutrition
Focus	Swallow safety using strategies and strengthening	Normalizing swallow physiology using load, repetition, and muscle accommodation
Frequency/Duration	Individualized	4x/week for 4 weeks
Modified Barium Swallow study required	No, but may be beneficial	Yes, before and after MDTP

 For more information contact 402.559.6460.

References:

Umemoto G, Furuya H. Management of Dysphagia in Patients with Parkinson's Disease and Related Disorders. *Intern Med.* 2020 Jan 1;59(1):7-14.

Gaeckle M, Domahs F, Kartmann A, Tomandl B, Frank U. Predictors of Penetration-Aspiration in Parkinson's Disease Patients With Dysphagia: A Retrospective Analysis. *Ann Otol Rhinol Laryngol.* 2019 Aug;128(8):728-735.

Lan Y, Ohkubo M, Berretin-Felix G, Sia I, Carnaby-Mann GD, Crary MA. Normalization of temporal aspects of swallowing physiology after the McNeill dysphagia therapy program. *Annals of Otol Rhinol Laryngology.* 2012 Aug;121(8):525-32.

Senior Moments or Something More?

What is Normal Cognitive Aging?

Trevor Wolterstorff, PsyD and Pamela May, PhD, ABPP-CN
Department of Neurological Sciences | University of Nebraska Medical Center

You walked into your bedroom for a specific reason but now cannot remember what it was you went in there to do. It just happened: the “senior moment.”

The fact is these events also happen when you were younger but likely went unnoticed with little worry. However, you are older, and these frustrating moments may make you wonder if they are now a cause for concern. So how do you know what is normal and what is not when it comes to memory and thinking skills? Below are a few questions that can help you navigate brain changes that occur with aging.

How does the brain change with age?

As people get older, their body systems, including their brain, naturally decline. Within the brain, a decline in brain mass and density are generally observed.

- The volume of our brain declines, with more changes observed in the frontal lobe and hippocampus with advanced age.
- Subtle changes in our neuronal structures, or the “wiring” within our brains, also occurs as we slowly lose the number of connections between the neurons.

How do memory or thinking skills change with age?

Given these changes, people often experience “brain blips” regarding their memory and thinking skills.

- **Common “brain blips” may include:**
 - » Occasionally forgetting where you left your keys or glasses, or why you walked into a room.
 - » Forgetting the name of a colleague you briefly met years ago.
 - » Accidentally calling your granddaughter your daughter’s name.
 - » Taking a little bit longer to complete

a task but still doing it accurately and successfully.

- » Having reduced efficiency in multitasking.
- » Occasionally forgetting a doctor’s appointment or to buy an ingredient at the store.
- » Occasionally struggling to find the right word.
- » Stopping to recall directions to a less familiar location.

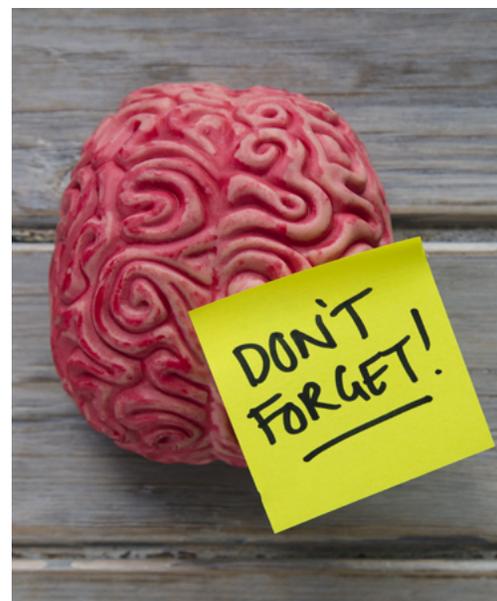
- **Uncommon “brain blips” may include:**

- » Regularly misplacing items in unusual places, such as putting the remote in the refrigerator.
- » Forgetting the names of well-known friends, family, or common objects.
- » Forgetting the functions of common objects.
- » Repeating questions.
- » Forgetting how to do a well-known procedure at work or forgetting a regularly schedule appointment like Sunday dinner at your friend’s house.
- » Conversation frequently includes words that are forgotten, misused, or muddled.
- » Being lost or disoriented in familiar locations.

How might changes in my memory and thinking skills influence my life?

Changes in memory and thinking can have varying levels of impact, depending on the severity of the changes. These generally fall into three levels:

- **Normal Cognitive Aging:**
 - » You occasionally experience common “brain blips” involved in aging.



- » You are able to complete your daily activities, such as driving, managing your finances, taking your medications, or cooking, by yourself and without concerns.

- **Mild Cognitive Impairment:**

- » You experience common “brain blips” and memory/thinking difficulties more frequently than others do your age.
- » You are still able to complete your daily activities independently, but greater effort and strategy may be needed.

- **Dementia:**

- » You regularly experience common and uncommon “brain blips” and have memory/thinking concerns that are uncommon for your age.
- » You struggle to complete daily activities by yourself and need help/support from others due to your thinking changes.

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- It should be reiterated that mild cognitive impairment and dementia are abnormal and do not reflect normal cognitive aging.

What should I do if I have concerns that my (or my loved one's) memory or thinking skills are changing?

Consult with your medical provider. They can:

- **Identify treatable or “reversible” causes that contribute to poor memory/thinking skills.** Such causes could include poor nutrition, underactive thyroid, infection, medication side effects, depression, sleep apnea, pain, etc.; once these factors are managed, memory/thinking could improve.
- **Assist with setting up specialized services that could further identify causes of poor memory/thinking or further characterize the nature of these difficulties.**
 - » Your doctor could make a referral to neurologist, to complete physical work-up and interpret laboratory and neuroimaging results to aid diagnosis and treatment for possible neurological causes for memory/thinking changes.
 - » Your doctor could also make a referral to neuropsychologist, to further evaluate the nature of possible memory/thinking weaknesses, aid diagnosis, and provide recommendations for improving thinking/daily functioning.
- **Assist with connecting you or your loved one with specialists that can provide behavioral/compensatory treatments or identify resources that may directly (or indirectly) aid thinking. Such providers include:**
 - » Speech and language therapists, who can help you or your loved one in optimizing memory/thinking with mental exercises and help identify compensatory strategies to work around known memory/thinking

problems.

- » Occupational therapists, who can help identify means of improving ability to function at home/work in the context of thinking and/or physical changes.
- » Social workers and/or behavioral health professionals (e.g., psychotherapist or psychiatrist), who can identify community resources for improving quality of life and treat mental health causes that contribute to poor memory/thinking skills.

What can I do to help my cognitive abilities?

Engage in healthy lifestyle choices.

- **Staying engaged in physical, social, and mental activities is critical for aging well.** Being physically active is extremely important for maintaining brain health. Staying connected with family and friends, volunteering and/or being part of organizations/community groups, engaging in lifelong learning (e.g., learning a new skill, such as cooking, digital photography, etc.), and completing mentally challenging tasks (e.g., reading, solving puzzles) are all important for maintaining thinking skills.
- **Follow your medical provider's recommendations for a diet that is healthy for you.** Typically, diets that are good for your heart are good for your brain. More specifically, diets rich in vegetables, fruits, and whole grains, and low in red meats, sweets, and other highly processed foods (e.g., fast food) help maintain thinking skills (and overall health). Maintaining good hydration with water is also important and often forgotten.
- **Understanding the effects of alcohol on the brain** is complicated. While it has been found that drinking red wine in moderation might have a protective effect against cognitive decline, this might not apply to everyone. As always, consult with your doctor regarding how alcohol could impact you, specifically.

- **Restful sleep is important for quality of life and thinking efficiently.** It is a myth that older adults require less sleep than younger adults do. National guidelines advise that people over 65 should obtain 7 to 8 hours of sleep.

Manage chronic medical problems to reduce harmful effects on your brain over time. While not exhaustive, a few things to consider are:

- **Reducing risk factors for stroke or additional vascular problems** (including managing chronic conditions such as atrial fibrillation, high blood pressure, high cholesterol, and diabetes mellitus; quitting smoking). If these conditions are not controlled, they may potentially impact your brain health and thinking skills.
- If you have **sleep apnea or sleep disordered breathing**, it is important that you wear your CPAP or other devices recommended by your doctor to help you breathe while you sleep. Your brain is dependent on a continuous flow of oxygen. If your breathing is not consistent, it can affect oxygen flow to your brain - leading to harmful effects to your brain's health, reduce your daytime energy and alertness, as well as have other harmful physical consequences.
- If you have **depression, significant anxiety, or other mental health concerns**, these can also impact how efficiently you think or remember information. It is important to consider means of improving your mood, whether it be via psychotherapy/counseling, seeing a psychiatric provider, and/or taking medication for mental health purposes. Your mood is also highly associated with your sleep quality, physical activity, social connectedness, and stress levels. There are many avenues towards improving mental health.

Don't Let What You Cannot Do Interfere with What You can Do

John M. Bertoni, MD, PhD

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

These words are from John Wooden, UCLA's winningest basketball coach. We take his advice seriously in treating Parkinson's disease (PD). Numerous disease-modifying medication trials to slow progression of PD failed according to strict criteria. Disappointment won't stop us from doing all we can do for our PD patients.

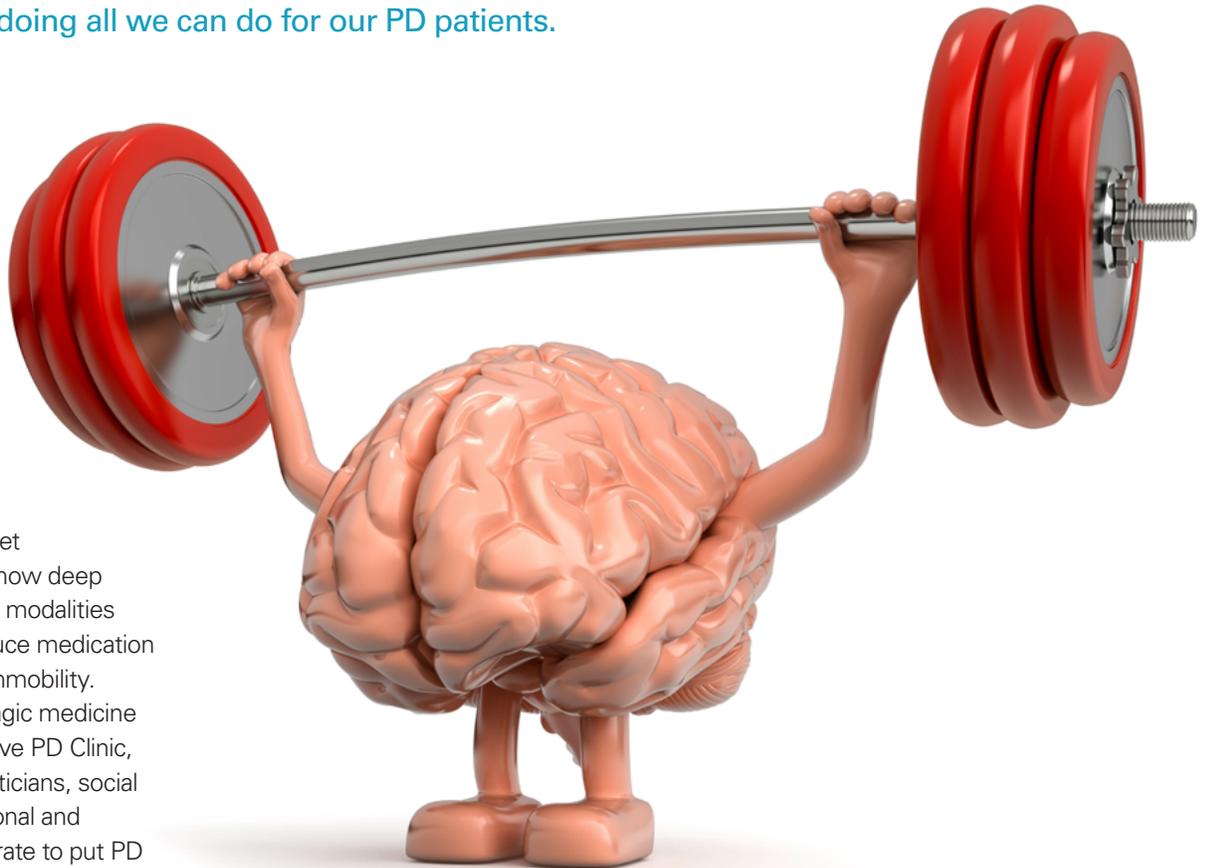
I read with interest and heartily recommend Neurosurgeon Sanjay Gupta's latest book *Keep Sharp*, which reviews studies that slow the course of neurodegenerative diseases including Alzheimer's and Parkinson's disease with daily exercise, optimism, socialization (support groups), proper diet and adequate sleep. We know deep brain stimulation and other modalities improve quality of life, reduce medication side effects, tremor and immobility. We cannot wait for the magic medicine bullet. In our Comprehensive PD Clinic, our physicians, nurses, dieticians, social workers, speech occupational and physical therapists collaborate to put PD patients on the right track immediately. PD impairs motivation, food preferences, physical and mental activity, sleep, gait, balance and causes tremors and falls. We work to reduce all of these. We used the *Harvard Food Preference Questionnaire* by Walter Willett, MD, who has more than 1700 publications.

We reviewed 167 patients from our Comprehensive PD Clinic and found that 36% of those tested were deficient in vitamin D, 26% were deficient in vitamin B6, 6% were deficient in vitamin B1, and 6% were deficient in vitamin B12. Low vitamin B1 or B6 or B12 causes

peripheral neuropathy which leads to gait disturbances and falls. Low vitamin B1 or B12 causes dementia and hallucinations if untreated. Low vitamin D leads to osteoporosis, which increases fractures with gait disturbance and falls. We can only prevent these problems if we think of them.

A disease modifying medicine for PD may be years away, but our patients may enjoy a higher quality of life until that day comes if they heed John Wooden's words. John Wooden was a mentor for

my brother-in-law who mentored Sanjay Gupta, who lived in the same small town in Michigan that I did. Walt Willett and I were fraternity brothers at the University of Michigan Medical Center, where Sanjay later went to medical school and trained to be a neurosurgeon. This is a small world.





Starting an Exercise Program: How to Begin

Maisie Habron-Wach, SPT

Lauren Kesteloot, PT, DPT

Rehab Services Lead | Nebraska Medicine – Bellevue

Exercise is a key element of treating Parkinson's disease (PD), but you may not be sure where to begin.

The American College of Sports Medicine (ACSM) recommends both aerobic activities, (and “cardio” activity like walking, running or biking) as well as muscle-strengthening activity (like lifting weights) several times per week. Specifically, the ACSM recommends aerobic activity be performed at least five times per week and strengthening activity be performed at least twice a week on nonconsecutive days.

How long should you be exercising? The first thing to do is determine your rate of perceived exertion (RPE). This is a scale from 0-10, with 0 being “no effort at all” to 10 being “as much effort as you can possibly exert.” If you are exercising at an effort level around 5-6, then aim for 30 minutes of aerobic activity; if you would rate your effort at 7-8, aim for 20 minutes. For strengthening, ACSM recommends performing 8-10 exercises with approximately 20-30 repetitions of

each move for each session. Your goal is to exercise with an RPE of 5-8 for strength training.

The next step before you begin exercising is to talk to your doctor about any concerns you have about becoming more physically active. If you are over the age of 65, consult your doctor before you begin exercising. If you are under the age of 65, ask yourself these questions:

1. Has a medical professional ever told you that you have a heart or lung condition?
2. Have you ever felt pain in your chest when exercising or when you were resting?
3. Have you ever lost your balance or lost consciousness because you were dizzy or lightheaded?
4. Is your doctor prescribing medication that affects your blood pressure or heart?

5. Do you have any issues with your joints, muscles, or any other area of your body that you think could be negatively affected by increasing your activity?

If you answered yes to any of these questions consult your physician before you begin exercising. If you answered no to all of these questions, you could gradually begin increasing your activity level.

The next important step in beginning an exercise program is to learn how to monitor yourself for changes in your vital signs (things like your heart rate and blood pressure).

To check your heart rate, feel for your pulse on the inside of your wrist (the side closest to your thumb should be the easiest to feel a strong pulse) and count how many beats you feel for 30

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seconds. Multiply that number by two. This is your resting heart rate, and this number should be between 40-100 beats per minute (bpm). If you check your pulse while you are exercising, it should increase moderately. If you are concerned with how much your heart rate is increasing, take a 10-minute rest. If your heart rate remains above 120 bpm even after that rest, you should consult your doctor before continuing with exercising. Small fluctuations in your pulse while you are active is normal, but if it decreases by more than 10 bpm compared to your resting heart rate, then you should stop exercising and consult your physician before beginning again. Keep in mind that your heart rate will respond differently to different kinds of exercise. Your heart rate should increase more with aerobic exercise than with strengthening exercise, and as your RPE increases, so will your heart rate.

Another vital sign to monitor is your blood pressure. For this, you will need a blood

pressure cuff that goes on your arm. You can also find monitors that attach to the wrist, but these are not typically as accurate as an arm cuff. A normal value for a healthy adult at rest is 120/80 mmHg. The first number is your systolic blood pressure (SBP), and the second number is your diastolic blood pressure (DBP). If your blood pressure is 180/110 mmHg or greater when you are resting, you should wait to begin exercising and consult your doctor. When you begin exercising, notice how your SBP and DBP changes:

- If SBP decreases by greater than 10 mmHg or increases to greater than 250 mmHg, and/or;
- If DBP increases to above 110 mmHg

You should stop exercising and consult your doctor before you begin again.

As always, it is important to take any medications that your doctor prescribed to you consistently because these could affect your vital signs and how your

body responds to exercise. For example, medications like beta-blockers lower your heart rate and blood pressure. Therefore, it is important to talk to your doctor about the ranges in your vital signs that you should expect when you exercise.

CITATIONS:

Edward R. Laskowski MD. 2 easy, accurate ways to measure your heart rate. *Mayo Clinic*. Published October 2, 2020. Accessed January 31, 2021.

Ghadieh AS, Saab B. Evidence for exercise training in the management of hypertension in adults. *Can Fam Physician*. 2015;61(3):233-239.

Norman JF. ExPACC Proceedings: Exercise Training for Individuals with Heart Failure. *J Geriatr Phys Ther* 2012;35:165-172.

Riebe D, Ehrman JK, Liguori G, Magal M, eds. *ACSM's Guidelines for Exercise Testing and Prescription*. 10th ed. Philadelphia, PA: Wolters Kluwer; 2018.

Safety Issues Relating to Exercise Assessment. Safety Issues Relating to Exercise Assessment and | Pulmonary Rehabilitation Toolkit. Lung Foundation Australia. Published 2016. Accessed January 31, 2021.

Trending Topic: Physical Activity Guidelines. Physical Activity Guidelines Resources. <https://www.acsm.org/read-research/trending-topics-resource-pages/physical-activity-guidelines>. Accessed February 14, 2021.

Upcoming Events

UNMC/Nebraska Medicine Parkinson Disease Support Group

Every Third Friday at 10 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/tJwqcOyorzliG9Tpv20WhassRKCuROI9whTN>

UNMC/Nebraska Medicine Parkinson Disease Partner Support Group

Every First Monday at 7 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=Q1N6Y0dUUUZwaG5PV0dLOVpkZi9uZz09>

UNMC/Nebraska Medicine Women with Parkinson's Disease Support Group

Every Second Monday at 7 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=NWhYR0N1RlVDb0g4SXZZN1QwRXR0Zz09>

Parkinson Disease Patient and Caregiver Symposium

October 18 | 8 a.m. – 2 p.m.

Scott Conference Center, UNO Campus

Hybrid format including in-person and virtual event.

Vision Deficits with Parkinson's disease

Anne Mahnke

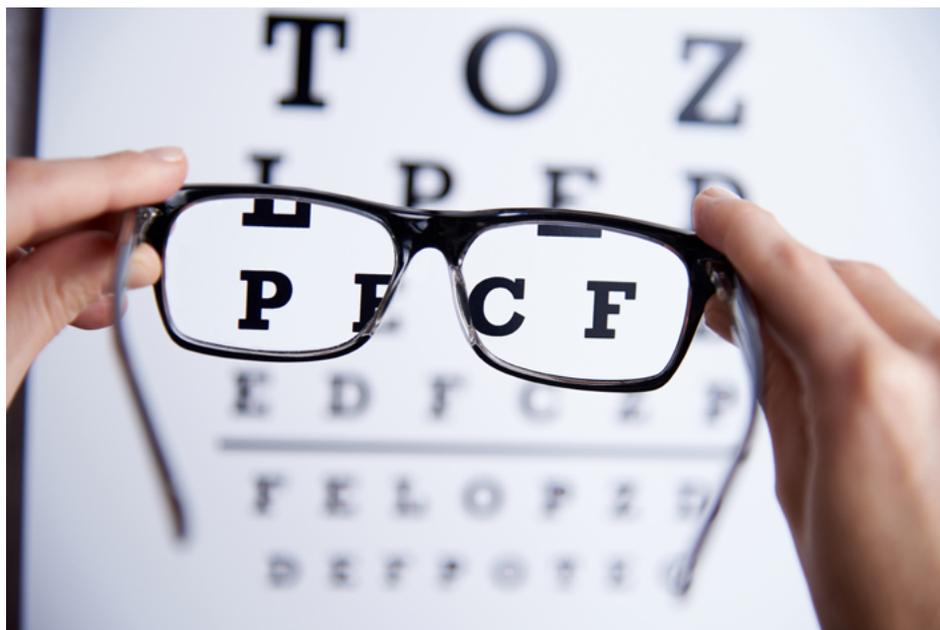
Occupational Therapist | Nebraska Medicine

When thinking about a movement disorder such as Parkinson's disease (PD), most commonly thought of problems are with big movements like walking, going up and down stairs, or tremors in the hands.

Less common, but still very prevalent, are deficits with some of the smallest movements we make such as moving our eyes. There are many typical age-related changes that occur with vision, however, some may be exacerbated or related to PD.

According to the Parkinson's Foundation, some of the changes that can occur include double vision, convergence insufficiency or difficulty focusing at near, dry eyes, and a low rate of blinking. Smaller and slower eye movements needed for tracking objects and looking from point to point can also occur. In the day-to-day routine, these issues translate into difficulty with reading, trouble keeping up with moving cars or people around you and can even contribute to balance and coordination problems when walking, going from sitting to standing, and completing basic self-care tasks.

So, what do you do if you have PD and notice changes in your vision? One of most important things is to keep regular visits with your optometrist. Routine visits will monitor changes in your vision and catch issues that may be related to PD. Speaking with your neurologist or PD provider should also be a priority, so they are aware of visual changes and can make an appropriate referral to an ophthalmologist or therapist as needed. The ophthalmologist can complete a more in-depth assessment of visual skills and make recommendations for medications and lenses based on their assessments.



An occupational therapist can also help to address vision deficits and their impacts on someone's daily routine. The occupational therapist should be someone who specializes in vision or neurological disorders. During occupational therapy, the focus can be both on exercises to maintain functional movements of the eyes, as well as adaptations to assist with maintaining independence during daily tasks. As we know with PD, exercise is a form of medicine and this includes the eyes. Programs such as LSVT-BIG and PWR! that are taught by a certified therapist, as well as specific eye movement exercises using the same principles, can improve and help maintain eye movements for better function. When using adaptations for visual deficits, some

examples of items provided could include environmental modifications like lighting and contrast, glasses for glare, filters, or magnifiers. Occupational therapists specializing in PD and visual deficits would be most appropriate to see for this kind of care.

The complexity of PD is vast and ever changing for each individual. Make sure to mention any visual changes to your providers in order to get you set up with the resources you need in a timely manner. And remember, keep moving! Your muscles both big and small will benefit from any exercise you do!

Supporting the University of Nebraska Medical Center/Nebraska Medicine Mission

Edwin V. Lyons

Director of Development | University of Nebraska Foundation



University of Nebraska
Medical Center™

Nebraska Medicine

It is no exaggeration to say that the University of Nebraska is helping people around the world lead healthier and more productive lives.

At the University of Nebraska Medical Center (UNMC) and Nebraska Medicine, our mission is to lead the world in transforming lives to create a healthy future for all individuals and communities through premier educational programs, innovative research, and extraordinary patient care. With your support, this vision is within reach.

Private gifts and funding help ensure that the university can offer competitive merit scholarships to recruit and retain the best and brightest from around the country, and around the world.

Gifts come in many forms. Gifts can be made with cash, personal checks,

or credit cards; they can be a gift of commercial, residential, or agricultural real estate; or they can be gifts of securities, such as stocks, bonds or mutual funds. One very important pillar to remember is, at the University of Nebraska, all gifts are greatly appreciated and valued. Donations of any amount enhance and leverage other available resources. Giving a little will always accomplish a lot.

Among the areas of need where you can designate your gift, include student scholarships, academic programs, faculty recruitment and retention, medical research, and patient and family support, just to name a few.



If you would like to begin the process of making a gift in support of Parkinson's disease research and education in the Department of Neurological Sciences at UNMC, our trusted charitable partner, the University of Nebraska Foundation, would be honored to assist you.

Please contact the Director of Development Edwin V. Lyons at edwin.lyons@nufoundation.org or 402.504.3339.

Your generosity will positively impact the UNMC campus, faculty, staff, students, patients and visitors for generations to come.

In advance, thank you.

Creations by our Parkinson's Community

Partnership

by Joyce Starr, LPDSG Care Partner

Our marriage has always been a partnership. Not in a business sense, as we each had our own professions, but we are partners in life and in raising our three daughters. Most of the time, I did the calendar, clothing, and hair "stuff" while he coached the sports teams and/or took them to practices and planned fun activities.

Those are a couple of examples of our partnership but then, in 2014 we formed the PD partnership. Like our other partnerships, we are in it together! Like those other partnerships, there is fear of the unknown!

There was/is a need for more education; there was/is a need for the better communication; there was/is a need to realize life has been and will be unpredictable. There was/is a need to know every day will not be the same and just because there is a challenge today, doesn't mean tomorrow won't be better! In this particular partnership, we can hate the disease but love each other!

I have tried to take on the advocate roll. I immediately began to suggest therapy evaluations especially in the Big/Loud Programs. Rich has been "soft spoken," and he has always loved to play tennis and take walks. Fortunately, he is self-motivated to exercise, and he is the partner who has motivated us to go to exercise and to take walks.

It took us about a year to start going to the Lincoln Parkinson's disease Support Group (LPDSG). By this time, we had switched physicians and were now going to UNMC, Movement Disorder team. What a team!! Anyway, they told us about the support group here in Lincoln. We were not sure what we would experience but finally decided to give it a

try. And we are glad we did!

Why you ask? Because wonderful opportunities began to come our way! Educational opportunities, friendships, fun, laughter, and understanding just to name a few. We left that first meeting with a commitment to continue, so this partnership has participated ever since.

At the meetings, we had announcements, educational presentations which included a variety of topics, a refreshment break (yummy!) then divided into two groups. Rich attended the one for those diagnosed with PD and I with the caregivers. Recently, the "caregiver" term began to interchange with "care partner." When the disease begins, a partnership develops but as the disease progresses and tasks become more challenging, we need to give.

Life was going well. We had completed the Big program and went to a weekly follow-up class where we met some wonderful classmates; we attended a "Delay the Disease" class twice a week with a knowledgeable instructor and again wonderful classmates. Rich had begun a month-long speech program with the opportunity for a weekly follow-up class after completing that month. This was a blessing as the "soft spoken partner" was speaking louder and the "hearing challenged partner" continued to love her hearing aids!

AND THEN!

The pandemic! Scary! Horrible! Cancelled exercise classes, cancelled speech class, cancelled LPDSG — cancelled everything! "This won't last long." "Life will return to normal." "For the next couple of weeks, while this lasts, we will mask up and take walks outside, maybe

add some Big movements." "Perhaps some May, Me, My, Moe, Moo exercises would be a good idea." "Oh, and we could watch some webinars."

Then, the Starr Partnership heard the word "Zoom." What does that mean? One of our exercise instructors would set up a Zoom link. The next thing we know, we are having our class right in front of our computer. Not like being together but it was better than we would have ever thought. That was a great beginning!

We started finding other Zoom possibilities. Now we are doing speech, book club, and several exercise opportunities and yes, LPDSG once again meets on the fourth Sunday at 2:00 p.m.—via Zoom.

As a care partner, I've gotten involved with several care partner support groups. All have much to share and are beneficial for me! Davis Phinney's wife Connie has a monthly one, UNMC has a monthly one, PDWell has a weekly one, and for the last several months, I've set up a Zoom for LPDSG Care Partners.

Zoom may not be ideal, but I've benefited from each of these groups. I could not have "attended" the wonderful meetings in Colorado; I never had and probably would not have traveled to join the Omaha groups. Now, I would never want to be "without these opportunities."

Why, you ask? Each group has its own personality. But there is a common thread; we are all in this together; it is calming to know there are others who have some understanding of our situations, who understand our concerns about the future; and who offer compassion. Going back to "if you've seen one PD person, you've seen one

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PD person," that may be true but as care partners, we can educate each other about the disease; we can offer "this worked/works for us" ideas; we can encourage caring for ourselves so we will be able to "give;" we can love and support each other — whether far or near!

One of the sweetest things I've heard from a care partner was how she felt when she took care of her husband. She said, "that was my gift to him." As a care partner, I am thankful for the support

My Journey with Duopa

by Barry Branson

I never would have imagined this journey in my younger years. I was always a little heavy because I loved to eat. I was a picky eater who didn't like most vegetables. I got away with the extra weight because I played football, wrestled, and lifted weights. I was injured a few times, but nothing serious. I had turned into a NERD and was taught technology every day. I could take picture of somebody and proceed to move the head to a different body in less than five minutes. In 2012 I noticed that my hand was having problems with the mouse. After carpal tunnel surgery for the second time, I knew my life would be different. Next my right hand tucked in beside my waist and would stay there all day. I began to talk softly and my notes on the whiteboard got smaller the I wrote. I was in denial when I first heard the word Parkinson's, and then came the depression. I was told at least it wasn't amyotrophic lateral sclerosis (ALS). My old doctor gave me more pills and they would work for a while. One day I asked my new doctor what my limit was. I had learned that my new doctor was a movement disorder specialist. We began

groups; I am thankful for Rich. I am sad he has this diagnosis, but I am thankful he has a good outlook. I am thankful for all the wonderful people we have gotten to know; I am thankful for the medical advances that have been and continue to be made. I am hopeful for a cure!

Today, let us strive to be the best we can be! Let us be a generous "giver" of whatever gifts our loved one needs! Let us be gracious receivers!

Let us celebrate the small victories in life!

to talk about options we still had. Deep brain stimulation (DBS) scared me, even though I had heard positive results came from this procedure. I couldn't shake the picture (cartoons maybe?) of a surgeon with my scalp laid wide open and he had a soldering iron attaching wires to my brain. I thought I could smell flesh burning. I went to Google and began to search for answers because that was what NERDs do. My doctors listened to my research, then separated the fact from the fiction. Duopa was the name of a gel that came out of the pump and a mentor was assigned to me. One of the major things that helped my decision was that if the pump didn't work out, we could reverse the whole procedure. I had heard about the difficulty getting a DBS through TSA at the airport. My Duopa mentor would call a talk with me, as well as address my wife's concerns. The whole installation procedure happened without a problem. My trainers and nurses had prepared me well and I wanted to learn more about Duopa. After having such excellent trainers and mentors, I was proud when they asked me to become a mentor. Later they

flew my wife and I to Chicago for some meetings and I got to interview one of the scientists who does research for Duopa. It was really interesting learning from one of the top scientists in their company and expanded my future expectations.

Thirty years ago, when I worked in the business world, part of my job was giving speeches about careers, which I enjoyed. Today I give speeches on Zoom to support groups, and mentor people who may be considering using a pump. It is rewarding to show people that they are NOT alone, and usually there are many resources we don't know about. I guess I have come full circle. Building a care team with a diverse group of talents is essential to living a good life. This includes medical, mental, physical, listeners, and whomever you think you need on your team. It is easy to get discouraged or depressed. Think of an alternative plan and call yourself "a McGyver". NEVER, NEVER, NEVER give up!



2021 Skate-a-thon for Parkinson's to Take Place During Parkinson's Awareness Month

Parkinson's Nebraska is preparing for its annual Skate-a-thon for Parkinson's fundraiser.

2 p.m. Friday, April 30 to 2 p.m. Saturday, May 1

The 24-hour family-friendly event will celebrate the close of Parkinson's Awareness Month at a new venue at the Ralston Arena (7003 Q St.). This year also marks the first annual virtual skate-a-thon event, a 24-hour virtual event that will be available across the state of Nebraska. Both events will take place from 2 p.m. on Friday, April 30 to 2 p.m. on Saturday, May 1.

"This year's event is very exciting for Parkinson's Nebraska. Not only are we able to hold the Skate-a-thon during Parkinson's Awareness Month, but this is the first year the event is going statewide," said Amber Winter, the executive director for Parkinson's Nebraska. "Over the past two years, we have been focused on outreach and strengthening programs in rural communities, so we are grateful to be able to continue that momentum and engagement with the Virtual Skate-a-thon Event."

There are many ways to get involved both on and off the ice. Skaters will enjoy unlimited ice skating, on-ice activities, games, music, and prizes. There will also be off-ice activities this year including Parkinson's program demos, food, and entertainment. The virtual skate-a-thon event will include a 24-hour live stream of the ice rink, online Parkinson's programs,

Parkinson's trivia, speakers and more. Registration for the in-person and virtual event registration is available online for at the Parkinson's Nebraska website www.parkinsonsnebraska.org. Sponsorship and volunteer opportunities are also available.

This year marks the 13th annual Skate-a-thon Parkinson's. The event is held in memory of its founder, Colleen Wuebben, who flooded her backyard to make an ice rink and raise money to fund Parkinson's exercise classes in Omaha. This year the event is especially meaningful as it takes place at the end of April, Parkinson's Awareness Month, a month dedicated to spreading awareness about Parkinson's disease and available resources. The money raised at this event will support the mission of Parkinson's Nebraska.

Parkinson's Nebraska is dedicated to improving the lives of Nebraskans with Parkinson's and their families. The organization supports communities across Nebraska by connecting them to resources, collaborating with local leaders to develop and fund specialized programs, and community outreach to spread awareness. Parkinson's Nebraska is proud that all money stays in Nebraska to meet the unique and ever-changing needs of people living with Parkinson's across the state.



To learn more about how you can impact the Parkinson's Nebraska, please contact Amber at amber@parkinsonsnebraska.org or 402.715.4707 or visit www.parkinsonsnebraska.org



Moving Day Omaha

We're excited to announce that the Moving Day Omaha walk will be back in person this year on Saturday, June 12 at Stinson Park! Adjustments to the event will be made to ensure we can safely come together and move for PD.

What is Moving Day?

Moving Day is an inspiring and empowering annual walk event that unites people in the community living with PD, their care partners, and loved ones to fight Parkinson's Disease. Moving Day is more than just a walk. It is a celebration of movement – proven to help manage Parkinson's symptoms. Funds raised through Moving Day will help improve care for those with PD, advance research initiatives, and help to provide free educational resources to those living with PD & their caregivers.

Gather your friends, family members, caregivers, work colleagues and community groups and join us on Saturday, June 12 at Stinson Park to walk, move, and raise funds to fight PD. Together, we will provide hope and support for the PD community.

What will Moving Day look like this spring?

Moving Day Omaha will be held in person on Saturday, June 12 at Stinson Park. However, the event will be adjusted to allow for social distancing and other safety precautions. There will be staggered walk times with socially distanced PD exercises. Teams will also have the option to participate online at Virtual Moving Day on Saturday, May 22. We know everyone has unique concerns and needs, so we invite you to help us beat Parkinson's in whichever way makes you feel comfortable and most safe.



Register at
www.MovingDayOmaha.org



If you have questions,
please contact
Elizabeth Rhodus at
913.416.4122 or
erhodus@parkinson.org.



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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

PD Well

www.pdwell.com

To obtain access to our UNMC/Nebraska Medicine 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:

unmc.edu/neurologicalsciences/news/parkinsons-post-newsletter

