

Parkinson's Post

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

Welcome to the Fall 2020 Edition of Parkinson's Post!

Julie Pavelka, MS, APRN-NP

Movement Disorders | Department of Neurological Sciences | Nebraska Medicine
parkinson.network@nebraskamed.com

Fall has officially arrived and daylight savings time has ended. We have experienced some cooler days along with the beautiful color changes of the leaves on the trees. All in preparation for some beautiful snowflakes! I am hopeful you have been able to continue to be active, both physically and cognitively, striving to maintain our new normal while maximizing the quality of our lives. While staying as active as possible, it's essential that we continue to avoid crowded places, close contacts, and confined spaces. Avoid gathering in groups where you are unable to consistently maintain six-feet of distance from others and wear a mask when you're with people outside of your household. Avoid enclosed spaces with poor ventilation.

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 Disease (PD) Support Group; however, all are now virtual to accommodate our PD community.

We have continued our virtual PD Care Partners Support Group and virtual Women with PD Support Group (refer to Upcoming Events in 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 Holidays!

Inside this issue

- Letter to Nebraskans
- New Faculty Spotlight
- Parkinson's disease or Parkinson's syndrome
- Tips for Meal Planning
- PWR vs. BIG: What is the Difference?
- Parkinson's — What do my genes have to do with it?
- What is Dementia?
- Creations by our Parkinson's Community
- Upcoming Events
- Reliable Resources





Fellow Nebraskans

In our lifetime, hospitals in Nebraska have always answered the call to provide high quality healthcare to our patients. We have never had to imagine a time when hospitals could not provide lifesaving care for the patients who come through our doors. We, the healthcare providers of Nebraska, are concerned that this unimaginable time is fast approaching. We are nearing a dangerous period of this pandemic and fear that many more lives will be lost without action from all Nebraskans.

Nebraska currently has one of the fastest-growing outbreaks of COVID-19 in the United States. We continue to add capacity to the hospitals. Currently, at Nebraska Medicine, ten floors are full of COVID-19 patients. We are not able to add more space and will soon not have the manpower to care for more patients. However, this dramatic climb in cases can be slowed. You can help us flatten the curve.

Wearing a mask is an effective way to help stop the spread of COVID-19. The

CDC recently again showed that masks reduce the risk of spread to those around us and protect us from getting the virus. The data on mask use is clear – masks slow the transmission of COVID-19. We call on all Nebraskans to wear a mask anytime they are leaving their home, especially anytime they cannot be socially distanced from others.

We ask all Nebraskans to cut back on any unnecessary trips outside their homes. We need to socially distance to prevent the continued spread of COVID-19. Even people that do not show symptoms can still spread the virus. Social distancing can break this chain of transmission. We need to limit all gatherings to those just within our immediate households. Social distancing has economic impacts in our community and we ask that Nebraskans support local businesses in any way they can through these challenging times.

No single health measure is 100% effective at stopping the spread of COVID-19. They must be used together. That is why we are asking all of you to

take every action possible to limit the spread in the community and to save lives.

Your frontline health care workers are exhausted. We are scared that the hospitals won't have the space and people to meet the ever-growing demand. We are seeing many deaths and will continue to see many more. Nebraskans have always been strong and hardworking people who have never failed to help our neighbors in the most challenging times. We call on Nebraskans to rise up once again to do everything we can for our state's health and safety. We believe in the people of this state. Your actions can save lives. We need you to wear masks, practice social distancing and limit the size of social gatherings. The life you save may be your own. We need you all to help those healthcare workers who dedicate their lives to save yours.

Sincerely,
The Health Care Workers of Nebraska
Medicine and UNMC



New faculty spotlight: Miguel Situ-Kcomt, MD

Miguel Situ-Kcomt, MD, is a new faculty member in the UNMC Department of Neurological Sciences.

Hometown: Lima, Peru

Title and department at UNMC:

Assistant professor at the UNMC Department of Neurological Sciences, Movement Disorders Division

Research/professional interests:

- Medical education
- Parkinson's disease pathophysiology and management
- Peripheral movement disorders

How I fell in love with neurology and movement disorders:

I thought of medicine as the art and science of empathizing with other people, as well as delving into the mechanics of the human machinery. Thus, I found neurology, and by extension movement disorders, as a natural progression of that perception.

Education:

- MD, Universidad Peruana Cayetano Heredia, Lima, Peru
- Residency, neurology, University of Cincinnati
- Fellowship, movement disorders, University of Cincinnati

Memberships:

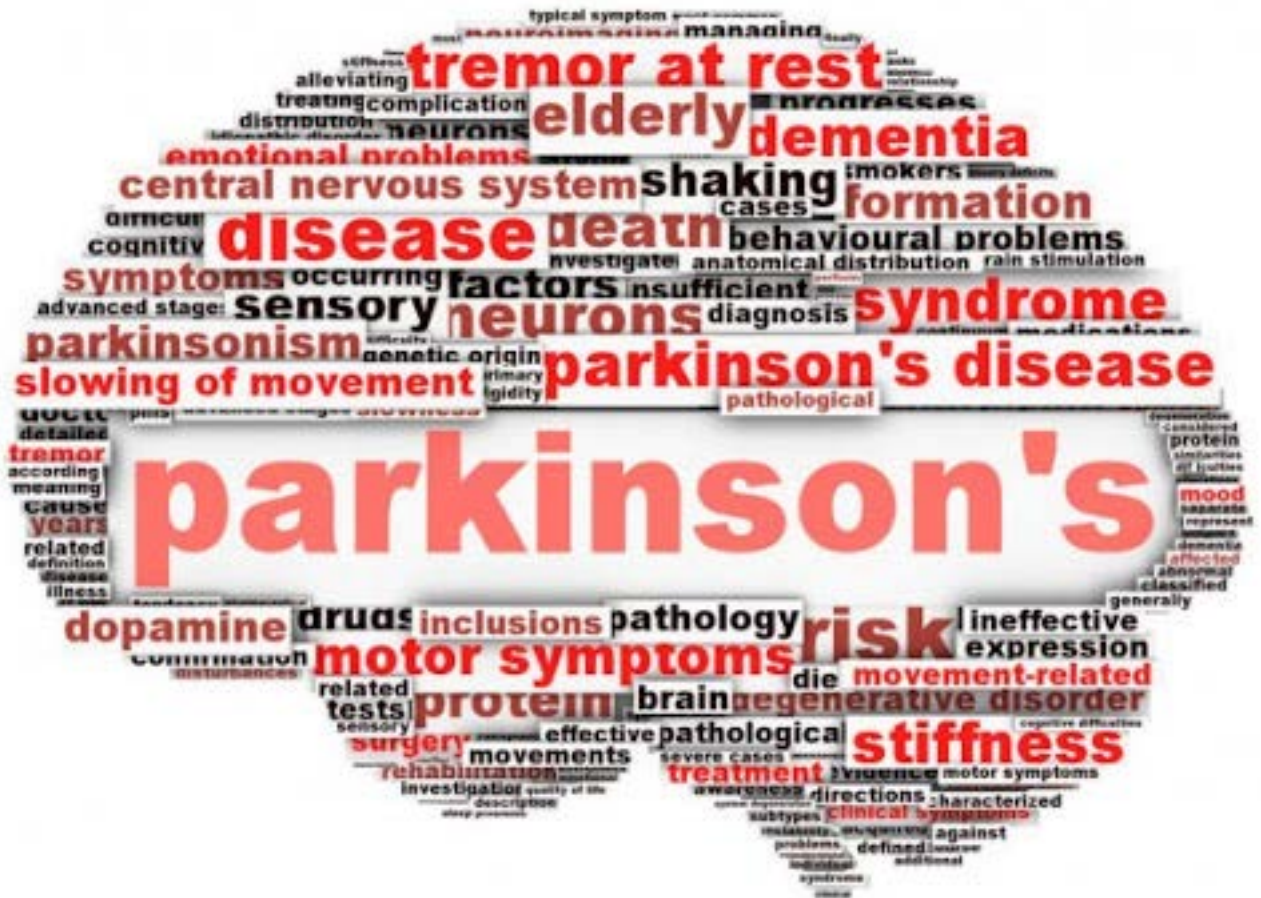
- American Academy of Neurology

Three things people may not know about me:

- I enjoy reading about history.
- I am an avid foodie.
- I recently have taken up the hobby of practicing Kung Fu.



Clinic location: Clarkson Doctors North Tower & Twin Creek
For appointments and referrals: 402-559-8600



Parkinson’s disease or Parkinson’s syndrome? Revisiting our diagnostic approach

Miguel Situ-Kcomt, MD

Assistant Professor | Department of Neurology | University of Nebraska Medical Center

Coming to terms with the initial diagnosis of Parkinson’s disease (PD) is as big of an event as it is dealing with the disease from then on.

This is further deepened by each individual’s experience with the condition, whether they had a close family member, a distant relative, a good friend, their next door neighbor or even having seen it in medical TV shows or read it in books. All of the sudden, they belong to this club of unfortunate people who share the same destiny. Or do they? This is where the topic becomes iffy and will explain why, though they all have “Parkinson’s disease,” and they do respond to this amazing medication called “levodopa,” their journeys will be markedly different.

The key question to ask clinicians is “what is the cause of PD?” To which we will usually answer that it is thought to be the accumulation of insoluble alpha-synuclein and the degeneration of a brain region that produces dopamine. However, that in itself is not a good answer but rather an admittedly superficial scratch of what “the cause” is. As with a detective in a crime scene, the findings of alpha-synuclein aggregation and lack of dopamine are but clues of what may have happened rather than the active process itself. In anatomical terms, these

are scars of something that is assaulting the brain’s physiology. A decade worth of research has steadily focused on targeting alpha-synuclein elimination without great results. Other therapy alternatives attempting to interrupt the mechanism of degeneration have been brought to dead ends. These apparent failures, though, have brought light into something that we may have ignored previously; is it “cause” or “causes?”

We have to remind ourselves that PD was described in 1817, more than two centuries ago and, to this date, our

cont. pg. 5

from pg. 4

diagnosis still remains purely clinical and, once the patient dies, pathological. James Parkinson would point out in the preface of his essay that “mere conjecture takes the place of experiment” in his description of “the Shaking Palsy.” Indeed, pathology findings tell us the end of the tale but do not give us information about what made such end happen, or if it is at all related. We have come to the assumption that this clinical entity called “Parkinson’s disease” had to have a one pathway that brought on the common symptoms. In the latter 20 years, though, more and more studies of trying to flesh out the mechanism of the condition elucidated that there are innumerable factors that may come to a similar conclusion. Genetics, environmental exposure, toxins, foods, other diseases that affect our brain, all of these factors have been included in the enormous corpus of information that entails PD; and this is exempting atypical parkinsonisms, which are another topic by themselves. A growing idea came to mind, what if PD is not a disease but rather a syndrome, that is, a collection of clinical symptoms that can have a range of causes? The failure of several clinical trials for disease-modifying medications had subgroups of patients who improved. Could this mean that we are confronting an impossible enemy? If it is conformed of thousands of different entities that just happen to share the same clinical features, then the dream of a PD panacea is long gone.

This should not be the case. We still have hope, but what we need to do is shift our mindset in the approach of PD. One of the best medical analogies we have to

an example of successful management of a condition that was thought to be “one disease” but is now known to be many is breast cancer. Decades past, we assumed that breast cancer was all the same because it involved the same tissue and region. However, people had different progressions. We now know that breast cancer is dependent on what specific biomarkers the cancerous cells contain, because each marker means the condition will react to a unique combination of medications. This is the mindset that we need to assume with PD. If PD is all the same, then why people do better than others over time? Why is it that though two friends with the same condition, and may exercise with the same intensity all the time, can have different outcomes? The explanation lies in the fact that each PD patient has a different biology and thus deserves an individualized therapy.

Unlike oncology, we have not been able to successfully characterize the possible subtypes of PD because we still think of it as a lone entity despite the evidence pointing to the contrary. It is a necessity for clinicians and patients alike to go back to square one and revise what we know in order to drive research in the appropriate direction. We hope that in the future when our patients are asked about their PD, they can safely say: “I have X type of PD” in which case we can infer that your disease course will be similar to other “type X PD patients” and so you will require “X type treatment.”

References:

1. Espay AJ, Kalia LV, Gan-Or Z, Williams-Gray CH, Bedard PL, et al. Disease modification and biomarker development in Parkinson disease: Revision or reconstruction? *Neurology*. 2020 Mar 17;94(11):481-494. doi: 10.1212/WNL.00000000000009107. Epub 2020 Feb 26. PMID: 32102975; PMCID: PMC7220234.
2. Parkinson J. An essay on the shaking palsy. 1817. *J Neuropsychiatry Clin Neurosci*. 2002 Spring;14(2):223-36; discussion 222. doi: 10.1176/jnp.14.2.223. PMID: 11983801.



What's for Dinner? Tips for Meal Planning

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

Planning meals ahead of time can help you stay on track with your nutrition goals, eat a well-balanced diet, save time and money, and relieve some of the stress with determining what to have to eat each day.

1. Write down a list of meals you like to eat. Keep it on the refrigerator, post it in the kitchen or keep it digitally on a computer or phone. Any meals that create leftovers is a bonus!
2. Start small. Begin by planning out a few meals for the week ahead. Write out what meals you plan to have on what day.
3. Focus on lean proteins (fish, chicken, beans) and lots of fruits and vegetables. Don't forget our other main food groups including whole grains, dairy and healthy fats.
4. Plan a crockpot meal or pot of soup.
5. Use frozen fruits, vegetables and meats. This allows you to take what you need and keep the rest preserved in the freezer.
6. Add variety by changing up the main ingredients. Instead of rice, choose quinoa or barley. Instead of broccoli, choose cauliflower, asparagus or brussels sprouts. Use sweet potatoes or squash instead of white potatoes.
7. Select theme nights — Meatless Monday, Taco Tuesday, Breakfast for Dinner, Grill Out, Fish Friday, etc.
8. Make a grocery list from the meals you select.



Some of my favorite go-to meals include:

- **Stir fry.** Using brown rice, garbanzo beans and vegetables. Use canned garbanzo beans (no salt added if you're watching the sodium) and frozen bags of stir-fry vegetables. Add some of your favorite seasonings – garlic powder, onion powder, paprika and basil go well!
- **Quinoa enchilada casserole.** Using quinoa, black beans, corn, and tomatoes with green chiles. Using canned or frozen beans and vegetables is a time saver! I'll also add in diced green peppers and onions if I have that on hand and then season with chili powder, cumin, garlic powder, salt and pepper. This can be baked in the oven or on the stovetop. Add sour cream (or plain Greek yogurt), avocado and salsa before serving as desired.
- **Grilled fish with roasted potatoes and vegetables.** Dice up potatoes and vegetables of your choosing. Some of my favorites are roasted broccoli, yellow squash, zucchini and Brussels sprouts! The potatoes and vegetables can be tossed in olive oil and salt and pepper and thrown on the same pan in the oven. You could also bake the fish instead of grilling and cook the whole meal all on one tray!

PWR vs. BIG: What is the Difference?

Lauren Kesteloot, PT, DPT

Rehabilitation Services Lead | Nebraska Medicine Bellevue Medical Center

Exercise is a physiological tool that promotes brain health, repair adaptation, and behavior recovery from the inside. For people with Parkinson’s disease (PD), exercise is considered medication as it naturally increases the brain’s production of dopamine, a chemical in the brain that assists with movement. The medications prescribed for people with PD only provide symptom relief for dopamine-related motor (movement) symptoms. As depicted in the table below, exercise not only can help improve motor symptoms, but it can also help relieve many of the non-motor symptoms associated with PD. Symptoms from PD that may improve include: cognitive, emotional and autonomic (automatic bodily functions).



PD Symptom Management: Medication versus Exercise

Symptom Type	Medication	Exercise
Motor	<ul style="list-style-type: none"> • Rigidity/Stiffness • Bradykinesia/Slowness • Incoordination 	<ul style="list-style-type: none"> • Rigidity/Stiffness • Bradykinesia/Slowness • Incoordination
Emotional	None	<ul style="list-style-type: none"> • Depression • Anxiety • Apathy
Cognitive	None	<ul style="list-style-type: none"> • Attention • Executive function
Autonomic	None	<ul style="list-style-type: none"> • Sleep • Constipation • Pain

There are many exercise programs available online and in-person designed for people with PD. While community-based exercise programs have proven to be beneficial, prescribed skilled physical therapy assessment and interventions are key to maximizing quality of life and

optimizing functional mobility for people with PD throughout the progression of the disease. Physical and occupational therapy are most beneficial at the time of diagnosis and throughout the disease as PD is a neurodegenerative disorder. The Lee Silverman Voice Training BIG (LSVT

BIG) program and Parkinson’s Wellness Recovery (PWR!) program are the two primary rehabilitation programs specially designed for people with Parkinson’s disease.

So what is the BIG difference?

The LSVT BIG program is a physical therapy component of the LSVT LOUD program, a rehab program developed by a family who had a loved one with PD more than 25 years ago. LSVT BIG trains people with PD to use their body more normally. People living with PD tend to move with smaller and slower movements. They may have more trouble with getting dressed, getting up or moving around. LSVT BIG involves exercises using the whole-body which assist people with PD to learn to “Think BIG!” and move bigger. This program trains fine motor skills (like buttoning a shirt) as well as large motor skills (like walking and balancing). The program is most beneficial at the early or mid-

cont. pg. 7

from pg. 7

stages of the disease. Research indicates that LSVT BIG treatment can assist with increasing walking speed, step length and arm swing with walking. The standard protocol includes one-hour treatment sessions, four times a week, for four weeks. The outcomes of this month-long treatment indicate good results as it is a standardized protocol but long-term benefits have yet to be determined.

How do people with Parkinson's disease emPWR themselves?

Dr. Becky Farley developed the PWR! rehabilitation program after assisting with the development of the LSVT BIG program during her post-doctoral fellowship. Similar to LSVT BIG, the PWR! program is an evidence-based, neuroplasticity-based program focused on large amplitude movements. While this program incorporates a set of exercises, called PWR! Moves, it is highly individualized. PWR! Rehabilitation in itself is more of a concept on how a physical or occupational therapist provides interventions. A PWR! trained therapist designs a comprehensive treatment plan to optimize brain health, learning, and function as well as slow or stop progression of the disease. The

concepts of PWR! can be utilized to provide skilled physical and occupational therapy interventions throughout all stages of the disease although early intervention is key to maximizing functional outcomes and quality of life. One

Primary concept of PWR! is to get better and stay better with exercise. Additionally, the program frequency and duration is variable and based off the individual patient or clinician preference. This program is appropriate to long-term rehabilitation throughout the progression of the disease.

BIG or PWR? Which is better?

LSVT BIG and PWR! could be considered very close cousins. Not only did Dr. Becky Farley have a hand in creating both of these rehabilitation programs, but they are both based of the most current research on using exercise to recalibrate the brain to move and think bigger. They both utilize large, whole-body movements with emphasis on high amplitude (large) movements. The holistic approach of PWR! and LSVT BIG address not only movement issues, but also takes into account non-motor symptoms including emotional changes and cognitive changes.

So which is better, PWR or BIG? Perhaps the answer is both. The LSVT BIG program offers an intense bout of physical therapy to provide for notable gains in functional and movement in a month. The PWR! Program offers more versatility and variable to individualize physical therapy interventions to the patient throughout the disease progression. Regardless, skilled rehabilitation geared towards PD is highly recommended at the time of diagnosis. Early intervention is key, but it is never too late to start.

Parkinson's Wellness Recovery (PWR!) versus LSVT BIG

	PWR	BIG
Evidence-based	Yes	Yes
Neuroplasticity Based	Yes	Yes
Large Amplitude	Yes	Yes
Motto	Exercise for Brain Change	Think BIG!
Duration/Dosage	Individualized	4x/week for 4 weeks

Parkinson's disease — What do my genes have to do with it?

Sarah Doss, MD

Movement Disorder Fellow | Department of Neurological Sciences | University of Nebraska Medical Center

Our genes carry the construction plan for the whole body, so would they also bear the key factors for getting Parkinson's disease (PD)?

Yes and no.

Genes encode our body's proteins and these are indispensable for so many functions of life including dopamine production in nerve cells and the signaling between nerve cells to enable smooth movements. We know that certain changes in the genes, gene mutations, may lead to a faulty protein that can cause these processes to break down. And without functioning dopamine producing cells, the brain cell networks cannot work effectively to keep up movements like an effortless gait.

Genes and environment play together

So yes, genetic mutations can have such a deleterious impact on protein function that Parkinson's disease occurs inevitably. This is called a monogenetic disease and is only the case in a very small minority of people suffering from PD. In a larger group of people, there is some influence from a mutation that altered protein function. This is a genetic risk factor. Depending on the mutation this influence can be weak or strong. On the other hand so many other factors happening in life, which we call environmental factors, will play an important role in getting Parkinson's and may explain the whole disease in a large group as well.

This is good news, since it means you can influence your risk and the course of your PD with what you do and it's worth it to try and shape your environment. And a good example of a positive influence is lots of exercise!

The role of genetic changes differs from person to person

To give an example of a monogenetic disease: The SNCA gene encodes for the protein alpha-synuclein which is found in

small clumps in the brains of PD patients. It is thought to have an important role in the chain of events leading to the loss of dopamine producing nerve cells.

Certain large mutations in the SNCA gene are able to cause PD and are passed on in a dominant fashion. This is very rare and such monogenetic Parkinson's disease will be suspected by your physician if the disease starts earlier than usual, like in early adulthood, and if family members in every generation are getting ill. There are many more of these monogenetic forms of PD. All are very rare. In recessive forms of monogenetic PD there can be no other family members affected. Some patients have additional symptoms that raise suspicion for a monogenetic cause.

However, other, smaller mutations in the same SNCA gene only change the alpha-synuclein protein function a little bit. They will not lead down a sure path to PD, but are some of the most common known genetic risk factors for developing PD later in life.

Another example of a more recently discovered common genetic risk factor are mutations in the GBA gene that encodes for a protein with the complicated name glucocerebrosidase, a lysosomal enzyme. Severe recessive mutations in this same gene are known to cause the very rare childhood disorder Gaucher's disease.

What types of genetic testing for PD exist?

There are tests for monogenetic PD. Some only look at the most common mutations, and some look at the whole gene for any mutation. You and your physician may choose to have a certain gene analyzed, or commonly a number of genes known to cause PD, a "gene panel" will be analyzed. Such gene panels also make sense when looking for risk factors.

In rare cases, when you really suspect a genetic cause, but cannot find it, you may decide to have a whole-exome-sequencing or whole-genome-sequencing done. That's an analysis of either all exons (This means all parts of all your genes that are serving to build proteins) or all genes (exons plus introns, the regulatory parts).

What does genetic testing change for me when I have PD?

The diagnosis of PD is made without genetic testing based on your symptoms and sometimes other factors like brain scans. Same goes for the treatment. So what difference does it make?

For people in the risk group of monogenetic PD genetic testing may provide a clear answer to the cause of their Parkinson's. For some people this may provide clarity and peace of mind, it may explain additional symptoms they have and help avoid unnecessary additional tests. Some people feel it makes no difference.

Once you have a result you are able to track the research on your specific form of PD to see if a change in recommendations is coming up.

The analysis of risk factor genes is less common and is done mostly in research studies to learn more about their role in PD. Some patients enjoy being part of such research efforts.

What does genetic testing change for a healthy person when there is PD in the family?

For now genetic testing is mostly recommended for someone with suspicion of monogenetic PD. This person's result can mean a lot to the family as well. If it is positive, other family members may know they are at risk and

cont. pg. 10

from pg. 9

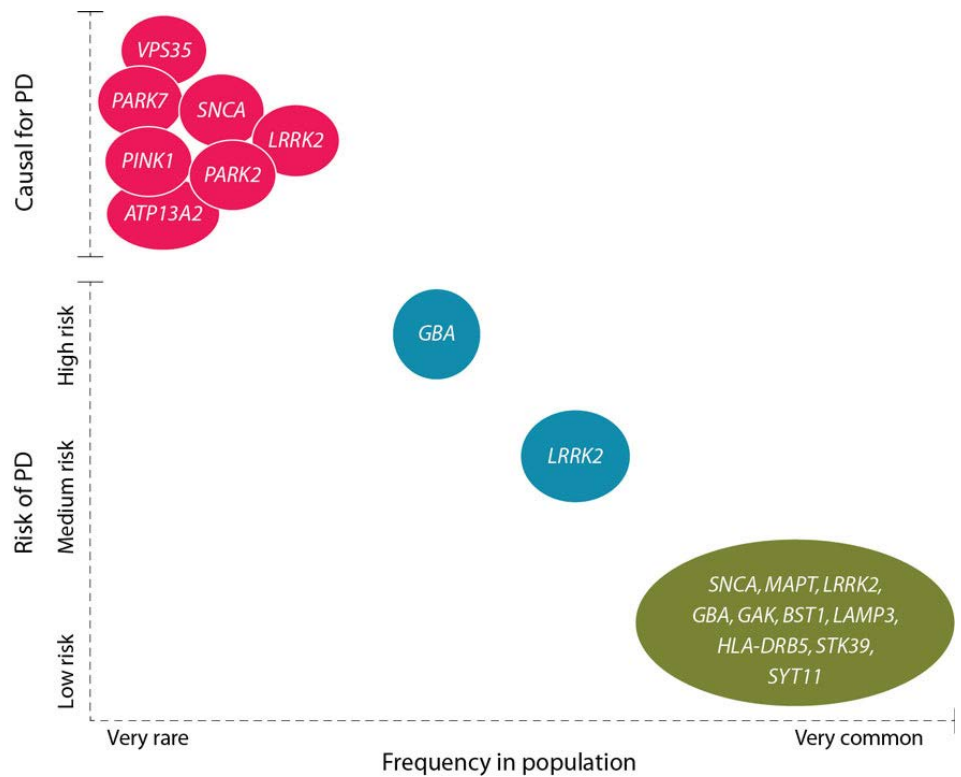
if it is negative the family knows their risk for PD is not substantially increased. Testing healthy family members to predict if they get the disease is called predictive testing. You could consider it if there is a known monogenetic cause of PD in your family. Looking for genetic risk factors of PD in healthy people is generally not recommended, since we do not know enough to provide you with answers about your risk and there is no proven treatment to alter the risk.

Should I get genetic testing?

This is a personal decision and everyone is different in their desire to know or not know about their genetic makeup and to plan their life. Consequences of each potential test result should be carefully considered: what would this knowledge mean for your life and decisions, for your finances including future life insurance policies and how would you feel with the knowledge of having a mutation or not having a mutation. A genetic counselor can help talking through the pros and cons.

How does genetic testing work?

Before testing your physician and you should talk and make sure that all your questions are answered. Genetic counselors are especially trained to do just that, explain the whole process and all consequences for you to make the best decision. Genetic testing requires your written consent for the specific type of test done and cannot just be done like a regular check-up test. Since genetic changes are in every cell of the body the test procedure is simple for an adult: a blood draw or a saliva sample can be sent in. Even though the DNA in your blood or saliva contains a lot more information, only the consented tests will be done. The result will be sent to your physician who will talk with you about it and again answer all your questions. It is up to you who else will know the results, e.g. which family members.



van der Brug MP, Singleton A, Gasser T, Lewis PA. 2015 Parkinson's disease: From human genetics to clinical trials. *Sci Transl Med.* 7(305):205ps20. doi: 10.1126/scitranslmed.aaa8280.

Make sure you talk about the associated costs, which depend on insurance policies. In general they are now much lower than they used to be a few years ago, due to constant improvements in testing procedures.

There are also studies underway that include genetic testing, like the national PD GENERations study for genetic risk factors for PD.

In general, testing procedures change over time so it is best to ask your provider if you are interested.

How would genes change PD therapy?

These are thoughts for the hopeful future. Right now genetic testing guides therapy only in exceptional cases, like in certain deep brain stimulation questions, but generally the therapy is the same, if genetic or not.

So far we do have many medications to treat the symptoms of PD, but all trials for

pills that we hoped would actually slow down or halt the worsening of PD have failed. One thought is now to look at PD as a collection of different diseases based on genetic make-up and analyze potential treatments only in a subgroup with the same genetic mutations, because each subgroup may respond in a different way. Examples are a trial of Ambroxol for GBA gene-associated PD, immunotherapy for SNCA gene-associated PD or promising preclinical studies or LRRK2 inhibitors in LRRK2 associated PD models.

In summary, genetic mutations are rarely completely to blame for PD, but may add to a complex risk profile together with many environmental factors. Modern genetic testing has become more cost effective and when considering it, talking with your physician and a genetic counselor is a great way to get the information you need.

What is Dementia?

Pamela E. May, PhD

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

Dementia is a broad diagnostic category. It is not reflective of a particular disease, in of itself. The term dementia is often misunderstood, and equated to having Alzheimer's disease, which is not always the case.

In brief, dementia is a general term to reflect:

1. A significant decline in thinking skills (beyond the effects of aging alone) and,
2. This decline in thinking significantly interferes with one's ability to perform daily activities independently. These daily activities may include (but are not limited to) driving, managing medications and finances, preparing meals, dressing, and grooming.



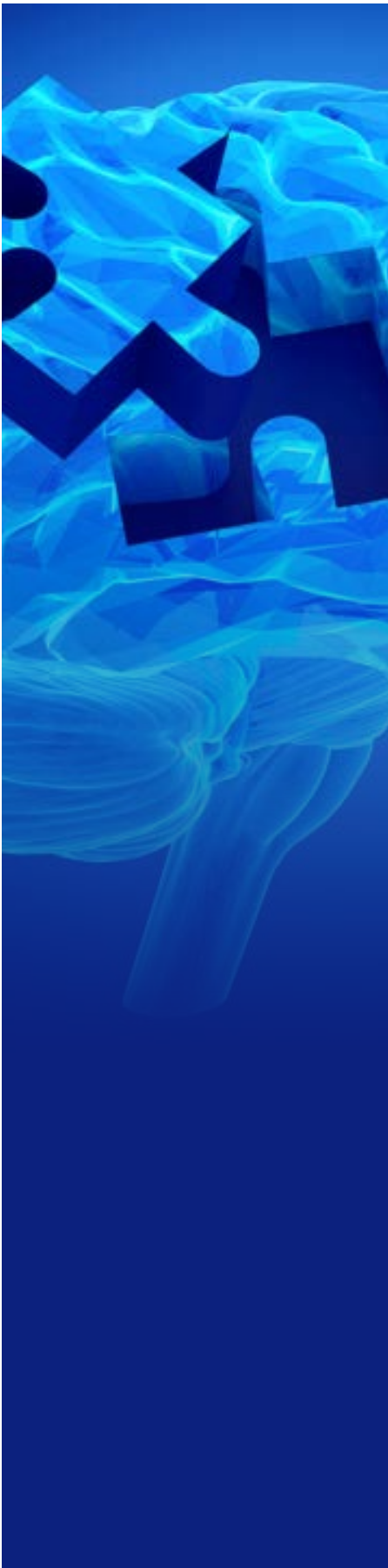
Although dementia is not uncommon in older adults, it is not a part of normal aging. The overall clinical picture is complicated by the fact that there are changes in thinking that go hand-in-hand with normal aging (including declines in mental speed, free recall memory (e.g., how well one can recall information without any cues/reminders), and perceptual reasoning (e.g., solving visual puzzles)) — these changes are not always pathological. Consulting with a primary care provider, undergoing work-up such as a neurological exam and neuroimaging, and/or completing neuropsychological examination can help differentiate what is normal or abnormal with respect to changes in thinking with age.

There are different types or causes of dementia. Not all dementias are alike

in their course, as some are classified as progressive (i.e., worsens over time) while others are stepwise (i.e., abrupt declines following sequential neurological insults) or static (as can occur after a traumatic brain injury). **Alzheimer's disease (AD)** is the most common type of dementia and it is progressive. One cardinal symptom of AD is difficulty recalling recent events. The onset of the disease is usually in one's mid to late 60s, although it can occur earlier or later. While having a family history of AD increases risk for developing this disease, it does not mean that one will certainly develop the disease themselves. **Lewy body dementia (LBD)** is the second most common progressive cause of dementia, and is typically characterized by development of significant thinking changes (including, but not limited

to: forgetfulness, concentration and multitasking difficulties, and episodes of confusion) within one year of developing movement symptoms (including, but not limited to: tremor, stiffness, and slowness). Visual hallucinations, changes in alertness, and sleep problems are also common in LBD. Age of onset for LBD is typically around age 50 and older, although it can start earlier. **Parkinson's disease (PD) dementia** is another form of progressive dementia. Having PD does not necessarily mean that one will certainly develop dementia later on in their disease course; however, having PD increases risk for developing dementia (compared to individuals who do not have PD). About 30% of patients with PD have dementia. The course of the dementia

cont. pg. 12



from pg. 11

process in PD is variable, as individuals may experience subtle to gradual decline, followed by more rapid decline later on in their disease course. It can be difficult to predict the exact nature of this course in advance. In PD dementia, there can be a broad range of thinking difficulties affecting attention, multitasking, memory, language, and visuospatial skills. These difficulties gradually develop over time (with insidious onset), usually years after developing motor symptoms and prior to one being classified as having dementia. As such, these thinking changes do not appear abruptly. In addition to thinking difficulties in Parkinson's disease, it is not uncommon for behavioral/psychiatric symptoms to become apparent (or more apparent), such as hallucinations, delusions, depression, apathy, and/or anxiety. For one to be diagnosed with PD dementia, the thinking changes must be significant enough to impair daily functions. This association can be difficult to tease out in the context of PD, as there are changes in motor functions that can also contribute to reduce daily functioning. As such, a thorough, detailed evaluation of one's thinking skills and daily functions is necessary to help understand if a diagnosis of dementia is warranted.

In addition to the above, individuals may develop dementia due to vascular causes (e.g., stroke). **Vascular dementia** may occur in a stepwise fashion (symptoms worsen immediately after each vascular incident, such as stroke, and may remain more or less stable until there is another vascular incident). **Frontotemporal dementia** is less common than AD or LBD, yet is another progressive dementia that often leads to changes in personality, behavior, language, and/or motor functions, with onset typically occurring in one's 50s to 60s.

Of note, there are other forms of dementia not discussed here, and there are conditions that **mimic dementia symptoms** (and are reversible!). For example, medication side effects, nutritional deficiencies, and hormonal imbalance can mimic dementia symptoms. Others may experience abrupt (yet usually temporary) changes in their thinking or behavior due to **delirium** (for example, in the case of a urinary tract infection). Due to the many factors that may contribute to a presentation that is suggestive of dementia, a thorough work-up may be in order.

The treatment of dementia is dependent on the underlying cause. While dementias such as AD, LBD, Parkinson's disease dementia, and frontotemporal dementia do not have a cure, there can be medications that may help reduce symptoms or protect the brain. Regardless of the cause of the dementia, continuing to lead an active, healthy lifestyle, including engaging in physical exercises (that are safe for the person), eating a healthy diet, getting enough sleep, and maintaining a good social network have protective effects on the brain.

If a loved one is suspected to have dementia, it is important to discuss these concerns with a medical provider, consider whether they are safe to complete daily activities (such as driving), and consider planning for the future, such as designating a power of attorney for healthcare and completing a living will. It is recommended to seek medical attention earlier than later, as early diagnosis can aid future planning, guide treatment, and help keep loved ones safe.

Upcoming Events

UNMC/Nebraska Medicine 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/uZEIfu6srjwuovUY26q79yT6nk3BJr2IUg>

Speakers:

November 20

Miguel Situ-Kcomt, MD
Assistant Professor
Neurological Sciences
Movement Disorders Division

December 18

Jenna (Paseka) Wuebker, MS, RD,
LMNT
Nutrition Therapist
Neurological Sciences
Nebraska Medicine

January 15, 2021

Erin Smith, MD
Movement Disorder Fellow
UNMC/Nebraska Medicine

UNMC/Nebraska Medicine 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=Q1N6Y0dUUVZwaG5PV0dLOVpkZi9uZz09>

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=NWhYR0N1RlVDb0g4SXZZN1QwRXR0Zz09>

Creations by our Parkinson's Community

by T. Christopher Choate

It was a Wednesday. The day after Christmas, 2018. Breakfast in New York City. Her kind eyes and stone face were betrayed by her deep breaths and a single tear from her left eye. I'd known her for 25 years by then... lived with her and slept by her side more than half my life. I knew what was going on inside her chest. I could feel her struggle to stay strong, remain calm, steadfast and steady... while her heart broke. My words fell on the table next to a half-eaten bagel and the remaining strawberries, as our world changed forever. December 26, 2018 was the day I told my wife I'd been diagnosed with Parkinson's disease. At the Grand Hyatt Hotel, on 42nd Street.

I'd held the secret for too long. It was no secret, she knew. If not what and why, she'd known something...for a while. I'd been running from the truth for 6 months. In the middle of that magical vacation in Manhattan, I stopped running. I was 45 years old, she was 47.

A few weeks later, diagnosis confirmed, we stood a couple of thousand miles away from the sunlit corner of that café in New York... in the bathroom of our home in Colorado. Face to face, hand in hand, falling words replaced by falling tears. I could never ask; she never made me. She recited our wedding vows — and took up the fight against an enemy

neither one of us can defeat. And she made it clear that I'd damn well better do the same. In the years since, the bravest woman I've ever known has never given up.

I'm a narcotics detective; my wife is a college professor. We are the proud parents of a United States Army soldier and a high school student. Our lives had no place for Parkinson's disease. It changed us — until we found room. The symptoms are mine; the disease is ours. I have no choice; they do. They choose me. This fight. All of it.

I have good days and days that set me back a bit. I'm grateful for them all and the perspective they bring. I'm coming to the end of my career in law enforcement, which is a harder task than I'd imagined. I've found the white noise in my life muted a little. Priorities and passions are a little louder now. I'm excited for the chance to support my wife in the prime of her career...and grow old with her. I have front row tickets for our kids' arrival at adulthood. I'm planning on being the grandfather I never had, someday. I'm excited about who I am and the things my disease has taught me to appreciate.

I'm a little scared of where Parkinson's disease and I are headed. I get frustrated...tired. I'm still not at peace

with the disease my body has thrust upon my family. I feel some guilt. And I think that's ok. In our house we often say, "Never out of the fight," "Keep moving forward," and most importantly, "I love you."

My name is Christopher Choate. I live in Durango, Colorado. I'm Dr. Jill Choate's husband, PFC Sam Choate's father, and Claire Choate's daddy. I'm a cop, I love to travel, I'm a pretty good cook, and a very passionate mediocre boxer. I'm a patient at the Nebraska Medicine Comprehensive Multidisciplinary Parkinson's Clinic in Omaha, Nebraska. During my first appointment, Dr. Bertoni put his hand on my knee and said, "You have a choice as to how this goes. Your attitude will determine everything from here on out." Parkinson's disease is no fun. But hidden in its' riddle are gifts. The white noise has faded. The good stuff is taking its place. I have a disease for which there is no cure. One that I'll die with. But first...I'm going to live with it.



by Dave Fowler
(Care Partner with Carolyn
Johnsen)

About two years ago, I began referring to myself as a Care Partner, rather than a Caregiver. It seemed to fit much better the life my wife and I have together, as we look back on all the wonderful trips we've taken — Ireland, England, France, Italy, many places in the U.S. — and now travel through the unique and difficult voyage called Parkinson's Plus.

Just as in our pre-retirement trips, for each thing we do together, there are personal side trips. Through Rocksteady Boxing, I met a new friend who persuaded me to join with two RSB participants in a course on Torch Singing, something I'd never have done on my own. After working together in Ruth Davidson Hahn's Dance for Parkinson's, we've seen live musicals and watched many musical videos with dance scenes with a completely new understanding of choreography.

We've studied together the theory and practice behind *Big and Loud*, *Speak Out*, and the information presented in our Support Group and the Statewide Conferences. And now... no safari or river cruise could be as different from our past home life as the challenges of being quarantined in an assisted living residence during the global pandemic. We need each other's support — in different ways, to be sure — but we are in all senses of the word, Partners.



by Julie Stueve

I am a caregiver of Ron Stueve who is my husband and is in an advanced stage of Parkinson's. I have been painting for 58 years. This is one of my more recent whimsical paintings. Painting is a very good outlet for me as a caregiver. It is a great anxiety releaser and gives me time to get away from caregiving without leaving our home.

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 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:

www.unmc.edu/neurologicalsciences/news/newsletters