

Our Family's Journey with Parkinson Disease - DETERMINATION IS KEY



Christine Eason, daughter of a person with Parkinson's disease, Public Relations consultant, and APDA St. Louis Chapter Board Member.

My Dad remained optimistic and determined to live his life

to the fullest throughout his 15-year 'journey' with Parkinson Disease (PD).

As a family, our dogged determination, strong relationships, and a team approach, made all the difference in maintaining the best quality, for as long as possible. That resolve helped us live through the pain of my father's protracted downward cycle of decline and plateau that is such a cruel hallmark of PD. My sister and me were vigilant, keeping an eye on Mom's physical and mental health as she bravely bore the brunt as our dad's primary caregiver.

My parents were career public school teachers, which likely predisposed them, and inspired my sister and me, to relentlessly gather and evaluate information, ask questions, identify and use available resources and find solutions, if only temporary ones, whenever possible. Mom set the standard for being a fierce advocate for her husband. When my Dad was diagnosed with advanced non-Hodgkins Lymphoma and given three months to live, she researched and found a St. Louis Oncologist willing to treat him. My Dad was in remission within three months and was able to make decades more of amazing family memories.

The following are reflections on our approach, understanding they are not recommendations but rather considerations:

- Find a neurologist who specifically specializes in PD, preferably one who is affiliated with a university or teaching hospital known for PD and movement disorders research. While all neurologists are familiar with PD, not all have the same understanding of symptoms, treatment options, or making changes in treatment plans and adjusting medications. Plus, there may be opportunities to participate in ground breaking research studies that offer safe and controlled treatment options for your loved one.
- Consider getting a second opinion. Even after finding a great neurologist at Washington University, that neurologist encouraged us to get a second opinion. The best doctors recognize they may not know everything there is to know about certain conditions. There are several renowned universities with physicians respected for groundbreaking Parkinson Disease and movement disorders research. One of them is Oregon Health and Science University (OHSU) in Portland. They confirmed Washington University's diagnosis and treatment plan.

DETERMINATION IS KEY – (continued from cover)

- Prepare appointment questions in advance Consider sending questions in advance of any appointments. This expedites the appointment, thoroughly addresses concerns and helps clarify often used medical jargon. If you don't understand – speak up.
- Keep a journal of your loved ones' care Write everything down, including who you talked to, when, and follow up recommendations including support resources, etc.
- Your loved one MUST always have an available advocate — A trip to the hospital, the doctor, etc. must include someone accompanying them, and, ideally, someone accompanying the advocate. There can be a lot to monitor and questions to ask. It's too much for just one person. Another set of ears is very important.
- Establish your support network Everyone surrounding person with PD is part of the network. Get to know them all. For example, we found getting to know the families of other PD individuals presented surprising and helpful opportunities and resources we would have otherwise never knew were available.
- Support the Caregiver Remember they are going through a grieving process and are also overwhelmed with a mountain of responsibilities. Help them delegate, remembering they may not necessarily ask for what they need. Help identify back up support for when they need a break or have other commitments. Consider hiring someone to make regular unannounced visits at a care facility if you are unable to do so.
- Be ready for communication and information confusion at the hospital — There are communications problems even in large hospital systems. Not all hospitals use the same databases or transfer/exchange records. Dad was admitted to an ER after a bad fall, if our family had not been there observing and asking questions, he would have been given another patient's medication (heart medicine) by mistake. This would've undoubtedly killed him. Mix-ups happen even in the most reputable hospitals. Don't be afraid to speak up.

- Not all attending physicians, known as "hospitalists," communicate and cooperate as well as you may assume - again, even within large hospital systems. On another occasion when Dad was admitted to rehab after a bad fall, his hospitalist unilaterally switched his medications and dosing schedule without consulting with his neurologist or with us. It made Dad's recovery that much more difficult. Furthermore, the hospitalist refused to contact the neurologist. This is where patient advocacy becomes critical. Prepare for some uncomfortable conversations and don't back down. You have options such as speak to the hospital administrators or "patient ombudsmen." Don't be afraid to push back.
- Be prepared for some difficult conversations with loved ones who are primary caregivers. They may not necessarily be aware or willing to accept when it is time to move the PD individual out of the home and into assisted living or a skilled nursing facility.
- Parkinson Disease is particularly expensive Life expectancy is not affected by the disease itself. I had a friend whose father lived with Parkinson Disease for well over 30 years. Talk to your banker, lawyer and/or financial planner to make sure all your financial and legal affairs are in order.

By reviewing our family's journals and notes, we gladly share our experiences in hopes it may help anyone at any stage in their PD journey better navigate this very overwhelming path.



Sharon Wells, Russell Wells, Christine Eason, and Rebecca Wells-Albers

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Improving Diversity in Parkinson's Research and Care Study

> Contact Dominique woodhouse@wustl.edu or 618-401-2328

Maximizing Home Independence, Safety and Access to Healthcare for Older Adults in Rural Missouri

Contact Tracey Summerfield summerfieldt@health.missouri.edu or 573-882-1991

> Walking and Music Study Contact Martha Hessler <u>mjhessler@wustl.edu</u> or 314-286-1478

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Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3 Contact Martha Hessler <u>mjhessler@wustl.edu</u> or 314-286-1478

> Lower Back Pain Study Contact Martha Hessler <u>mjhessler@wustl.edu</u> or 314-286-1478

Memory Intervention for PD Study

Contact Tasha Doty tdoty@wustl.edu or 785-865-8943

THE RELATIONSHIP WITH STRESS, ANXIETY AND PARKINSON'S DISEASE



How stress and anxiety are related to PD and what you can do about it

People with Parkinson's disease (PD) often notice that their symptoms are worse when they are under stress. Stress, or emotional strain due to difficult circumstances, is an inevitable part of life for everyone, and can be caused for example, by tension with family or employers. Stress is therefore a response to an external situation.

In addition to life stress, people with PD may experience anxiety as part and parcel of their PD itself, caused by chemical imbalances in the brain. Anxiety is a very common non-motor feature of PD and is often accompanied by depression. Anxiety can also fluctuate throughout the day along with dopamine levels, with anxiety experienced most acutely during OFF periods.

Anxiety is fueled by internal forces and can persist when all external causes of stress have been resolved. It is often difficult for a person with PD to separate out stress and anxiety – because practically, they may manifest in indistinguishable ways. Both can cause excessive worry, poor sleep, and inattention, as well as physical symptoms such as rapid heart rate, trouble breathing, sweating and headaches.

Parkinson's symptoms and stress

Although tremor in particular tends to worsen when a person is anxious or under stress, all the symptoms of PD, including slowness, stiffness, and balance problems, can worsen. Symptoms, particularly tremor, can become less responsive to medication. The solution in these situations is not to increase medication but to find ways of reducing stress.

Managing stress and anxiety in PD

Anxiety in PD may need to be treated with medication in order for a person to regain his/ her quality of life. The medications used for anxiety are typically the same medications used for depression in PD and these include selective serotonin reuptake inhibitors (SSRIs) such as sertraline and paroxetine and selective serotonin and norepinephrine reuptake inhibitors (SNRIs) such as venlafaxine. Occasionally, a group of medications called benzodiazepines, (which include diazepam and clonazepam) can be used to treat the anxiety of PD.

Lifestyle modifications

However, not everyone with PD needs medication

to control anxiety and this is a decision to be made in conversation with your doctor. There are numerous life-modifications that may help a person with PD manage stress. These could include:

- Planning ahead and giving yourself enough time to accomplish your tasks
- Using music to create a relaxing environment
- Focusing on maintaining your positive attitude and sense of humor
- Socializing with positive people
- Getting involved in worthy causes
- Attending a support group
- Exercise
- Meditation

Exercise

Exercise has been shown to improve many of the non-motor symptoms of PD, including stress and anxiety. Interestingly, an article published in the journal Movement Disorders, explored the relationship between exercise, stress and PD. The study showed that doing high intensity endurance exercise reduced morning cortisol levels in patients with PD. Cortisol is the body's main stress hormone and although it is crucial to many of the body's functions, levels that are too high or too sustained can cause health problems including anxiety.

Meditation

Meditation is a group of techniques that allow a person to relax the mind and focus inward. Meditation can be used to relieve stress in all types of situations, and has been used in the context of PD as well.

Mindfulness is a type of meditation in which a person sustains a focused awareness of thoughts, feelings, bodily sensations and the surrounding environment. There have been a few small clinical trials which investigate whether the practice of mindfulness helps the motor and non-motor symptoms of PD. Although results are mixed, there are some suggestions that mindfulness can decrease stress and increase healthy behaviors in a sustained manner. A randomized controlled trial of mindfulness yoga (which incorporates mindfulness techniques into yoga) in PD as compared to stretching and resistance training, demonstrated that mindfulness yoga improved anxiety more.

Tips and Takeaways

- Anxiety and stress are two different things, but can often manifest themselves in similar ways, making it challenging to tell the difference.
- Anxiety is a common non-motor symptom of PD, and unfortunately, stress and anxiety can worsen motor symptoms of PD.
- A number of lifestyle modifications, including increasing exercise may be very helpful for anxiety
- Cognitive behavioral therapy has been shown to lower anxiety in PD.





APDA St. Louis Chapter Welcomes Two New Staff Members to Serve You

Please give a warm welcome to Kim Sanders, our new Manager of Programs and Community Engagement, and Jennifer "Jen" McNamee, our new Fundraising Event Manager.





Kim Sanders

Jen McNamee

Kim Sanders join the APDA from 8 years working in the medical field with a background in Occupational Therapy. Kim has also been a APDA Support Group leader for the past two years. She looks forward to getting to know you all better.

Jen McNamee spent the last five and a half years at Gateway Hemophilia Association as the Communications and Program Manager. Jen will work with Melissa Skrivan and will manage the Walk, Golf Tournament and other fundraising activities. You'll be hearing from Jen soon!

Parkinson's Hero -Marilyn White

Marilyn White has been the driving force behind Hull of a Race for Parkinson's for 16 years. Back in 2006 Marilyn and her friend, Mable Reed, both of whom had Parkinson's,



were working with a local physical therapist, Lori Riti. Lori encouraged Marilyn and Mable to use their energy to raise money for Parkinson's research by having a race. Hull of a Race was born and named after Marilyn and Mable's hometown with a reflection of the shared humor among these three ladies.

As a runner, Lori was able to guide Marilyn, Mable and their husbands, Sam and Jim, through the first few years of running a 5K/10K race. After Lori moved away, Marilyn and Jim became the co-directors of the race with Marilyn focusing on the collection of donations and the organization of the race, and Jim handling the logistics of the race. As the years passed, volunteers joined "The Pit Crew' of Hull of a Race, but Marilyn continued to do the lion's share of the work. Each year she secured most of the donations for the race because it was almost impossible for anyone to say no to Marilyn's persuasive personality and her persistence. She also continued to handle most of the organizational needs of the race. When Marilyn's health began to fail due to Parkinson's, it was amazing how many people were required to handle the amount of work she had done herself for so many years for Hull of a Race.

Marilyn's work and inspiration has grown Hull of a Race into a professionally timed race on a "Flat and Fast" certified course with choices of a 5K/10K run, a 5K competitive walk and a Fun Run for kids. Over the course of 16 years, Hull of a Race has donated over \$100,000 to the St. Louis Chapter of the American Parkinson's Disease Association. Each of the past two years Hull of a Race sent \$14,000 to the APDA and in 2022 had a record 200 runners participate in the race. None of this would have happened without Marilyn's devotion to Hull of a Race. 2022 was the first year that Marilyn was unable to attend the race due to her Parkinson's. But her spirit was with each of the 25 members of the "Pit Crew". Marilyn will always be the hero of Hull of a Race for Parkinson's.

The APDA is so grateful for Marilyn White and the funding received from Hull of a Race over the last 16 years. We were saddened by the news that Marilyn passed away on October 7 and know her legacy will live on through Hull of a Race.

YOGA AND EXECUTIVE FUNCTIONING



Pamela Todd is a practicing yoga therapist in St. Louis, Missouri, where she teaches several ongoing weekly yoga classes. She received her 200hour yoga teacher training in St. Louis in 2011, her 500-hour yoga therapy training was the Inner

Peace program at the ashram in Mount Madonna, California in 2013. She received her international yoga therapy certification from the International Association of Yoga Therapy (IAYT) in 2017.

You may have heard that yoga helps with flexibility, balance and posture. But it is more than just another way to move.

The practice of yoga has long been studied for stress reduction. There is a strong relationship between stress, aging and the shortening of telomeres, the end caps of our chromosomes, which keep those ends from fraying, scrambling our DNA code. These can be visualized as the plastic tips on shoelaces. If these get too short, the cell dies.

But is there more to yoga than just stress reduction? Let's look at some of the current research that suggests gentle yoga can improve executive function in the brain, which is important for those living with Parkinson's Disease (PD).

Executive function and self-regulation skills are the mental processes that enable us to plan, focus attention, remember instructions, and juggle multiple tasks successfully. Up to 93% of PD patients can have cognitive symptoms, including problems in executive functions such as working memory, planning, and visuospatial attention. Yoga can help with all these conditions.

In 2015 an eight-week randomized controlled study at the University of Calgary in Canada, showed that both weekly yoga or group therapy maintained the telomere length where an educational seminar could not. In India in 2017, a twelve-week study concluded that a yoga- and meditation-based lifestyle intervention held the potential for delaying aging at the cellular level.

In 2016, Dr. Helen Lavrestsky, Professor at UCLA Semel Institute for Neuroscience and Human Behavior, observed 81 participants, 55 or older with mild memory complaints. They were randomly selected to perform either 2 weeks of memory enhancement training (MET) or yoga weekly and chanting daily. The participants were followed for six months. In this comparison, the clear winner was yoga/chanting for both memory and mood. This was followed up with a study published this year, concluding that yoga and chanting prevents gray matter atrophy in the brain in women at risk for Altzheimer's.

What does all this mean for you? APDA offers free yoga, which I am honored to teach. Together we explore similar yoga practices used in the above studies, which focuses on breath and movement appropriate for adults with physical limitations. In these classes I am slowly introducing simple chanting routines. o, join us while we learn breathing techniques, stretch, move gently to gain more flexibility, hold poses for balance and age more gracefully.



Contact individual location to register. For more information please call 636.778.3377 or apdastlouis@apdaparkinson.org

MISSOURI CLASS SCHEDULE						
LOCATION	DAY	TIME	LEADER	LEVEL	CLASS	
	Tuesday	10:00am	Jen Berger	Level 2	Circuit Training	
	Tuesday	11:00am	Jen Berger	LEVEL	Strength and Cardio	
	Tuesday	1:00pm	Pamela Todd	Level 1 & 2	Yoga	
	Wednesday	10:00am	Michelle Valenti	Level 2	Intro to Exercise	
Chesterfield	Wednesday	11:00am	Michelle Valenti	Level 1	Seated Exercise	
ADPA Office	Wednesday	1:00pm	Marina Clements	Levels 1 & 2	Movement Training	
	Thursday	11:00am	Craig Miller	Levels 1 & 2	Tai Chi	
	Thursday	1:00pm	Michelle Valenti	Level 2	Strength and Cardio	
	Friday	10:00am	Craig Miller	Levels 1 & 2	Tai Chi and Meditation	
	Friday	11:15am	Craig Miller	Level 1 & 2	Tai Chi	
Chesterfield YMCA	Mon/Wed	12:30pm	Michelle Valenti	All Levels	Parkinson's Pedalers	
Kirkwood YMCA	Monday	11:30am	Frank Tucci	Levels 1 & 2	Parkinson's Exercise	
Maryland Heights YMCA	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's	
St. Louis City	Thursday	12:00pm	Annie Morrow	Level 1	Interval Training	
Stephen A Orthwein Ctr.	Friday	2:00pm	Mike	Levels 1 & 2	Fit and Fun	
St. Datara D.IC	Thursday	10:00am	Vicky Frazier	Level 2	Strength and Cardio	
St. Peters, BJC	Thursday	11:00am	Vicky Frazier	Level 1	Strength and Cardio	
Ste. Genevieve	Thursday	11:00	Becky Baumann	Level 2	Parkinson's Exercise	
Sunset Hills	Friday	1:00pm	Marina Clements	Level 2	Movement Training	
Washington YMCA	Mon/Wed	1:00pm		Level 1	Parkinson's Exercise	
ZOOM	Tuesday	9:00am	Jen Berger	Level 1	Seated Exercise	
ZOOM	Thursday	2:00pm	Michelle Valenti	Level 1	Seated Exercise	

ILLINOIS CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS	
Champaign YMCA	Monday	1:00pm	Jessica B.		Pedalers Cycling	
	Monday	1:00pm	Jenny Redden		Seated Yoga	
	Tues/Thurs	1:00pm	Lindsay R. Jenny Redden	All Levels	Functional Chair Fitness	
	Wednesday	1:00pm	Jessica B.		Strength & Balance	
	Friday	1:00pm	Lindsay R.		Standing Functional Fitness	
Decatur YMCA	Tues/Thurs	9:00am	Michelle Patterson	All	Pedaling for Parkinson's	
Edwardsville YMCA	Tues/Thurs	11:00am	Mary Tebbe Lara Collmann	All	Exercise for Parkinson's	
Highland Korte Rec Center	M/W/Th	11:00am	Hilary Held	All	Cycle and Strength	
O'Fallon YMCA	Tuesday	12:00pm	Victoria White	All	Exercise for Parkinson's	
	Thursday	1:00pm	Stefanie McLaughlin	All	Exercise for Parkinson's	
Quincy YMCA	Tues/Fri	10:30am		All	Fit to Fight PD Boxing	
	Friday	10:30am		All	Stretching	
Springfield	Tues/Thurs	1:30pm	Eva Fischberg	All	The Joy of Movement	

SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email apdastlouis@apdaparkinson.org

MISSOURI SUPPORT GROUPS					
LOCATION	DAY	TIME	LEADER	MEETING SITE	
Ballwin	4th Tuesday	2:30pm	Chaplain Carla Schmidt	Meramec Bluffs Care Center	
Branson	1st Thursday	12:00pm		Stone Co Health Dept., Ste 11	
Cape Girardeau	2nd Monday	5:30pm	Jayanti Ray	Cape Girardeau Library	
Carthage	3rd Monday	11:30am	Tericia Mixon	Fair Acres Family YMCA	
Chesterfield	1st & 3rd Tuesday	11:00am	Carrie Burgraff	VIRTUAL	
Chesterfield Caregivers	2nd Monday	10:30am	Lynda Wiens & Jay Bender	APDA	
Joplin	Every Monday	3:30pm	Lori Marble & Aaron Lewis	VIRTUAL	
Kirkwood	4th Tuesday	6:30pm	Terri Hosto	VIRTUAL	
Ozark	4th Monday	10:00am		Sharlin Health & Neuro	
Rolla	3rd Tuesday	2:30pm	Julie Riggs	Phelps Health Cancer Inst. Room B	
South County	4th Wednesday	10:30am	Melissa Mann	VIRTUAL	
Springfield	2nd Saturday	11:00am	Cassi Locke	The Bodysmith	
	3rd Tuesday	6:00pm		Kingsway UMC	
Ste. Genevieve	2nd Wednesday	10:00am	Teddy Ross	Ste. Gen. Co. Mem Hospital	
St. Louis Caregivers	3rd Monday	1:00pm	Kathy Schroeder	VIRTUAL	
St. Peters	1st Tuesday	1:00pm	Jodi Peterson	Spencer Road Library	
Washington	2nd Monday	6:00pm	Carol Weber	Washington Public Library	
YOPD	Every Thursday	6:00pm	Karen Frank & Mike Mylenbusch	VIRTUAL	

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Alton	2nd Wednesday	1:00pm	Dustin Heiser	SSP Main Bldg, The Meeting Rm
Belleville	3rd Monday	1:30pm	Jodi Gardner	SW Illinois College's Programs and Services for Older Persons
	3rd Tuesday	11:00am	Jodi Gardner	Caregivers ONLY Belleville Health and Sport Center (1001 S. 74th St.)
Carbondale	1st Wednesday	1:00pm	Gayla Lockwood	VIRTUAL
Champaign	Monday	10:00am	Carol Clark	Savoy United Methodist Church
Decatur	3rd Thursday	1:30pm	John Kileen	Westminister Presbyterian Church
Edwardsville	1st Tuesday	2:00pm	Pam Pinegar/Sarah Hoelscher	Edwardsville YMCA
Greenville	2nd Tuesday	1:00pm	Robbie Mueth	Bond County Senior Citizens
Highland	4th Tuesday	2:00pm	Kayla Deerhake	Sullivan Conference Room at St. Joseph Hospital
Jacksonville	1st Wednesday	1:00pm	Jim & Fran Ringle	VIRTUAL
Quincy	2nd Saturday	10:00am	Terri & Dave May	Quincy Public Library

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