

A FEW THOUGHTS FOR CAREGIVERS *by Terri Hosto*



Terri Hosto is a licensed clinical social worker and assistant professor in neurology at Washington University School of Medicine. She is a volunteer support group facilitator for the St. Louis APDA. She has dedicated her career to serving older adults and their families, particularly those living with chronic neurological disorders such as Alzheimer disease and Parkinson disease.

Family caregivers are the backbone of care and support for persons living with Parkinson disease (PD). Over time, the tasks of caregiving become increasingly complex and time consuming as the needs of your loved one evolve. Eventually, if left unchecked, the physical and emotional demands can take a toll on your health and well-being also. Caregiver stress is common and may show up in irritability and temper flare-ups, frequent worrying, mood swings, anxiety, depression and feelings of guilt. Physical signs may include headaches, backaches, tight muscles, teeth grinding, upset stomach, poor sleep and fatigue.

There are various stress stoppers that can help protect you from the overwhelming effects of stress, including: **1)** taking a few deep breaths while focusing on your breathing, **2)** sequentially tightening and relaxing all major muscle groups beginning with your feet and moving upward through your body, **3)** visualizing a favorite place or situation that brings you a sense of calm and

(continued on next page)

peace, **4)** going for a walk in nature, **5)** listening to soothing music, or **6)** repeating positive phrases that are meaningful to you (“This too shall pass.” “Things will work out,” “Take one day at a time.”). Different stress stoppers may be helpful in different situations. It takes practice to develop healthy ways of coping with stress.

Early on, your loved one with PD may still be capable of doing things on his or her own. As symptoms progress, however, you may have to discern when and how best to assist your loved one. It is important to allow your loved one to do as much as possible for himself or herself as long as it is deemed safe. Most people wish to stay independent and do not want to ask for help, even when it takes them more time and effort to do things. Sometimes the best way you can help your loved one is by giving encouragement and staying positive (“Do the best you can, it’s okay if it’s not perfect” “Just do what works for right now” “You know how to handle this, you’ve done it before”).

Be mindful of your loved one’s dignity and self-esteem when you intervene with help. Have patience and offer assistance only when needed. Resist the tendency to takeover because you can do things quicker or more easily. If there are true safety concerns, and if you and your loved one with PD cannot agree on when to turn over certain

activities, such as driving, then ask your loved one's doctor for help and guidance.

A calm and predictable environment can alleviate worry and stress for both of you. Regular routines that include exercise, meaningful activities, socialization with others, and periods of rest will help you stay focused on what you can do instead of dwelling things that are out of your control or on the uncertainty of what may lay ahead.

Gather information on services available in your community ahead of time. These may include chore/housekeeping (cooking, cleaning, laundry), personal care (bathing and dressing), and transportation. Check out options for respite care, such as home companions, adult day centers, and short-term residential care. Consider what home modifications might be needed (grab bars, ramps, relocating bedrooms). Learn about housing alternatives and levels of care, like assisted living and skilled nursing. If you or your loved one is a veteran, be sure to look into veterans' services by contacting your local VA caregiver support coordinator. Early on, talk with an attorney about the types of legal documents that may be needed, such as power of attorney, health care proxy and an advanced directive. Keep an open mind about the types of services and support that may be needed.

Discuss options for care and personal preferences before help is needed. This will help to establish a framework for decisions to be made about care choices. Approach conversations about care with an attitude of listening and not telling. Talk to your loved one with PD about what he or she is still comfortable doing. Ask open-ended questions. Do not make assumptions about his or her wants and needs. Listen to how your loved one is feeling, as well as to what his or her stated needs are. Be sure that your needs and concerns as a caregiver are also heard and respected. What you may prefer and what your loved one is willing to accept may be very different. Good communication has a give-and-take nature. Have open and ongoing conversations about each of your interests as needs and circumstances change.

Do not try to plan for a prolonged period of care and do not make promises about the future. You

can never anticipate every possible need or plan ahead for every detail of care. Focus on the greatest concerns and "must dos" and prioritize your efforts accordingly. Learn to be flexible. This includes being willing to learn new ways of doing things. Find acceptable shortcuts to conserve your energy for what is most important. Include time for yourself.

The duties of caregiving are often given precedence over self-care. As a caregiver you may find that you skip meals, experience lack of sleep, use alcohol or self-medicate to unwind, and put off medical appointments. You owe it to yourself and your loved one to take care of your own health and well-being. A nutritious diet will provide you with fuel to perform caregiving tasks, a good night's sleep will provide rest and restoration, and regular exercise will provide the strength and endurance you need to meet the physical challenges of caregiving.

For your mental health, you must have regular breaks from caregiving. This may require asking other family members or friends to pitch in. Be specific about what you need (three hours off twice a week) and what others can do to help your loved one (make meals, offer companionship). Time off, or respite care, can also be arranged through formal services like adult day centers and homecare agencies. Whether it be a few hours or an entire day, time away from caregiving will help restore and renew you so that you can care for your loved one.

It is important that you establish a support network. Connecting with a caregiver support group can help reduce feelings of loneliness and social isolation. Caregivers who are in similar situations understand what you are going through and can validate your needs. They can provide emotional support and encouragement, as well as strategies for managing caregiving tasks in more efficient and less stressful ways. If you feel overwhelmed, consider talking to a professional counselor. Your support group may be able to provide you with recommendations.

Coping with stress, communicating effectively, becoming informed, adapting to change, accepting help and taking care of oneself are all vital keys for caregivers. **Caregiving takes resourcefulness, perseverance, courage ... and above all an abundance of love.**

LEAVE A LEGACY



At a certain stage in life, we begin to think philosophically. We have crossed various milestones set for ourselves. We think about what we've accomplished – with our families and in our community. We begin to wonder if there is a way we

can make a difference in society when we are no longer able to physically contribute to our interests and passions.

Those of us fortunate enough to have saved through the years to care for family, begin to desire to make additional contributions. I believe we each must follow our heart.

Clearly, as President of our local APDA chapter, I am biased. If I did not believe in this organization so strongly, I would not have devoted so many years to its growth and development to help people with PD. APDA was here for my husband and me when he was first diagnosed, offering us resources and support every step of the way. I found comfort in community, as so many other families do. It is my wish to extend those services to all families on this journey.

Every year I am amazed at the number of people the APDA supports and yet humbled by the enormous need for more of what we offer. We seek to expand services to more patients with Parkinson's, their families, their caregivers and their medical community. There is an urgent need to reach more families. Diagnosis of Parkinson's is expanding at a rapid rate. In Missouri and Illinois, alone, there are over 45,000 families dealing with Parkinson's, who, as you know, would benefit from our services. We need to get the word out to those who have never heard of us. Everyone deserves access to more care.

You can help our organization continue to make a difference. In addition to giving what you can today, join me in adding "American Parkinson Disease Association Greater St. Louis Chapter" in your will. Adding APDA St. Louis Chapter as a bequest will make a huge impact.

Please join me and so many others who decided to dedicate a portion of our will to our important organization. Contact your lawyer or Cathy Krane, our Executive Director with any questions. I thank you for your consideration from the bottom of my heart.

- Gail Glenn



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Thanks to your generosity, the wonderful research challenge grant from the James and Alison Bates Foundation was met!

Your support of this challenge is greatly appreciated. The American Parkinson Disease Association (APDA) proudly invests in the most promising clinicians and scientific projects focused on the discovery of the cause(s) and finding the cure(s) for Parkinson's disease.

DETERMINING WHEN TO GIVE UP THE KEYS



Peggy Barco
OTD/L, SCDCM, CDRS
Washington University Medical School
Program in Occupational Therapy

Driving is one of those important functional activities that allows independence and the ability to stay connected in the community. While very important to one's independence, driving is also a public-safety issue – especially when a medical condition exists. Being aware of the changes that can occur with various medical conditions, how these changes can impact driving safety, and using good judgment regarding one's own driving ability are important in determining when it is time to give up driving.

PD is commonly known as a disease that affects movement and motor function. In addition to the motor symptoms of PD, there can also be vision, cognitive and perceptual changes – especially as the disease progresses. The non-motor symptoms that are most common in PD include: reduction in contrast sensitivity in vision, difficulties in proprioception and difficulties with cognitive functioning. All of these non-motor areas have the potential to greatly decrease driving safety.

1. Decreased contrast sensitivity:

Limited contrast sensitivity affects the ability of an individual with PD to detect visual stimuli in low contrast environments – such as pedestrians in crosswalks on a dark or foggy day. Results of a recent study confirmed that drivers in low contrast conditions with PD displayed less control over their vehicles, had slower responses to hazards and committed more safety errors than those without PD.

2. Decreased proprioception:

Proprioception refers to the sense of knowing where one's body is in space and can decline as part of normal aging, as well as with PD. While evidence on the impact on driving is lacking in this specific area, difficulty positioning the foot correctly on the gas or brake pedal could be a hazard.

3. Difficulties with cognitive functioning:

Evidence is showing that cognitive changes can occur as PD progresses –these changes can include decreased attention, memory, problem solving, planning, visuospatial abilities, and decision making (e.g., executive function). Reports from driving studies indicate that individuals with PD (especially those with cognitive changes) have been found to be less safe drivers – resulting in more driving errors during driving studies. While many persons with PD (especially those in the early stages) remain safe drivers, it is very important to be aware of the possible changes that can occur as the disease progresses. Being aware of changes in cognitive abilities is a positive indicator in remaining a safe driver. For example, if an individual is aware of the cognitive changes, he or she might be more likely to adapt their driving accordingly, such as restricting themselves to daytime driving only, driving only in familiar areas and/or only in less congested times of the day.

How do you know if you need a Comprehensive Driving Evaluation?

Often families and individuals have difficulty assessing driving safety objectively. Indications of driving difficulties can include, but are not limited to, a recent history of accidents/tickets, difficulties maintaining good lane positioning, delayed responses to traffic lights or planning for what lane to get into, difficulty deciding when it is safe to make a turn, relying on non-drivers in the car to help with decision making and getting lost while driving. If you, your family member, or physician are concerned about your driving safety, it is advisable to seek a comprehensive driving evaluation. Some individuals also choose to have “baseline” evaluations from year to year to determine if any of their driving abilities have changed.

What is a Comprehensive Driving Evaluation?

A Comprehensive Driving Evaluation (CDE) is usually provided by an occupational therapist who has a specialty certification in Driving Rehabilitation. A CDE usually takes a few hours and includes clinical testing of visual skills, motor/sensory skills and cognitive functioning related to driving. In addition, the CDE includes an on-road assessment that looks at how the individual actually drives in real traffic conditions. For safety, the on-road assessments are done in a driving evaluation car with a passenger side brake. Once both the clinical and on-road driving assessment are completed, the driving rehabilitation specialist can provide recommendations to the individual, family and physician regarding driving safety.

SPOTLIGHT | Dr. Marina Clements, DPT - Exercise Instructor



“Exercise is the best medicine”. We know this, but let’s admit it--sometimes it can be challenging to get motivated to exercise and even more difficult to establish consistency, which is key in making lasting improvements in your health and fitness. That

is why I make it my personal mission to make exercise something you want to do. Exercise is a celebration of movement and what your body can do. It should be fun, make you feel good, and it should be something you look forward to doing.

Through my own health and fitness journey, I found that the only exercise regime I could stick to was attending group exercise classes. I fell in love with Zumba, kickboxing and strength and cardio classes in high school and have continued them ever since! There was a community of people who supported each other and held each other accountable for showing up to class each week. I would always leave happy that I showed up. Exercise suddenly became a scheduled priority on my calendar. Group exercise became one of my passions, and I knew that I wanted to provide environments for others to improve their health and wellness by becoming an exercise class instructor. During my time studying to become a Doctor of

Physical Therapy, I became particularly interested in the world of wellness and prevention. I delved into the research and found droves of articles that highlighted the benefits of group exercise over going at it alone. The general consensus was that group exercise was associated with higher reported quality of life and improved adherence to an exercise program compared to exercising solo. During my clinical education I had the privilege of learning how to apply physical therapy principles and techniques into exercise classes at the American Parkinson’s Disease Association of Greater St. Louis.

I absolutely adore teaching, and it is my hope that everyone finds a mode of exercise that inspires them! Maybe group exercise will be your passion, too! Outside of teaching for the APDA, I enjoy swing dancing, attending live music events, spending time outside, thrifting, and trying new plant-based recipes.

Currently, you can find me teaching: Level 2 Cardio and Strength on Mondays at 10 am live on our YouTube Channel.

Be on the lookout for a new class on the schedule this November!

- Dr. Marina Clements, DPT

COMMUNICATION AND INTIMACY



For many couples, maintaining intimacy throughout their relationship requires open lines of communication and engagement. When one member of a couple has Parkinson's disease (PD), there are additional hurdles with unanticipated changes in the couple's physical, emotional, and sexual interactions. Through broadening their view of intimacy and utilizing health care professionals, couples can maintain and even improve their intimate connection, even while living with PD.

How PD Can Affect Intimacy and Sexuality

The changes brought about by PD can affect a couple's relationship, and it is important to understand the scope of those changes in order to maintain your connection as a couple while living with PD.

The motor symptoms of PD—slowed movements, tremor, and stiffness—can interfere with lovemaking, and reduced facial expression can make nonverbal communication difficult. Men may have difficulty achieving or maintaining an erection, or achieving orgasm, while women may

have vaginal dryness or pain, and orgasm may be difficult as well. Medication side effects may reduce desire.

Beyond these physical effects, when one partner takes on the role of care partner, it can affect the ability of both partners to retain their sexual desire. One or both partners may be more tired, and may experience depression or grief as a result of the illness or contemplating an altered future. All of these increase the difficulty of keeping alive an open, intimate sexual relationship.

Communication is the Key to A Fulfilling Intimate Relationship

Good communication is the most important skill for any relationship, and even more so when living with PD. Many couples often have never needed to develop the skill of talking openly about their sexual relationship and their needs for emotional intimacy. Through developing this skill, couples will be better able to adapt to the changes PD brings, and other changes that happen sexually as we age. Sharing feelings, worries, and requests with your partner—being willing to be vulnerable, and being open to and supportive of your partner's

vulnerability—increases closeness, and makes it clear that you are committed to one another.

Key parts of successful communication with your partner include:

- Be positive: Rather than only telling your partner you are unhappy with your level of physical connection, try telling him or her, “Let’s talk about ways we can be more physically close.”
- Offer ideas, rather than blame or criticism, perhaps saying, “Can we try this?”
- Be brave! Embrace talking about the difficult topics; your partner will probably be grateful you brought them up, even if he or she is uncomfortable at first.
- Seek help from a professional if you need it.

Open Up to New Ideas of Sexual Intimacy and Pleasure

Perhaps the most important advice, beyond developing good communication skills, is to open yourself up to new ideas about what sexual intimacy entails and what can be pleasurable. When sex is thought of as a “buffet,” it can become full of interesting and nourishing possibilities beyond the standard fare you may have become used to. By expanding your definition of “sex,” and letting it evolve to fit you and your partner, you can remain intimate even as PD changes one partner’s physical abilities.

There are many different ways of being intimate. Focusing on pleasurable touch and emotional connection can make sex rewarding regardless of any physical limitations. Find the activities you and your partner enjoy, which may be different from what you are used to.

There are some practical steps to take to help a couple cope with PD-related challenges and ensure they are connecting physically. Make physical intimacy a priority. Look for ways to have it, and adjust your routines to make it more likely. Establish a “bridging time” for yourself if you need it before sex, during which you relax, get in touch with your body, and connect with your

own sexual energy. Time your medications to fit with your intended time for sex. Be in positions that are comfortable, and try new positions or use pillows for support. Be open to trying new things. Sex should be fun and meaningful, and with care and attention, it can continue to be despite the challenges of PD.

Get the Help You Need

Talk to your doctor about your sexual concerns. Your doctor may not bring up sexuality, but is likely to be able to offer you help in coping with PD-related challenges. You might try asking your doctor, “Can I talk to you about the changes in our sexual life, or my sexual experience?” or “What are the sexual side effects of the medications I am on?” Medications for Parkinson’s disease may affect sexuality, and some may cause hypersexuality; adjusting medications can often help. You may be experiencing depression, which reduces sexual desire. Depression should be treated for many reasons, including its effect on libido.

Finding a Therapist

A sex therapist or sexologist is trained in helping couples improve their sexual and intimate relationships. If there are no professionals in your area, use of technology such as Skype or Facetime may allow you to meet with someone in the comfort of your home.

For more information, you can visit the following websites:

- American Association of Sexuality Educators, Counselors and Therapists www.aasect.org
- The American College of Sexologists International www.americancollegeofsexologists.org

Recommended Reading

- *Naked at Our Age: Talking Out Loud About Senior Sex* by Joan Price. 2011, Seal Press
- *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness*, 2nd edition, by Miriam Kauffman. 2007, Cleis Press
- *Parkinson’s Diva: A Woman’s Guide to Parkinson’s Disease*, by Maria De Leon. 2015, thewordverve inc.

VIRTUAL EXERCISE CLASS SCHEDULE

Please visit: bit.ly/APDAYoutube for Live Stream exercise classes.
Contact APDA at 636.778.3377 or apdastlouis@apdaparkinson.org for zoom link

YouTube - Live Stream

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
Monday	10:00am	Strength & Cardio	Level 2	Marina Clements
Monday	1:00pm	Interval Training	Level 2	Jen Berger
Tuesday	1:00pm	Seated Exercise	Level 1	Michelle Valenti
Wednesday	1:00pm	Interval Training	Level 2	Michelle Valenti
Thursday	1:00pm	Seated Exercise	Level 1	Jen Berger
Friday	10:00am	Tai Chi	Level 1	Craig Miller
Friday	11:15am	Tai Chi	Level 2	Craig Miller

Zoom - Live

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
Tuesday	9:00am	Seated Exercise	Level 1	Jen Berger
Tuesday	10:00am	Strength & Cardio	Level 2	Jen Berger
Thursday	10:00am	Strength & Cardio	Level 2	Vicky Frazier
Thursday	11:00am	Seated Exercise	Level 1	Vicky Frazier
Friday	10:00am	Strength & Cardio	Level 2	Michelle Valenti
Friday	11:00am	Seated Exercise	Level 1	Michelle Valenti

IN-PERSON EXERCISE CLASS SCHEDULE

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

MISSOURI CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS/MEETING SITE
Cape Girardeau	Mon/Wed/Fri	9:00am		Level 1	Boxing Christian Boxing Academy
Chesterfield	Mon/Wed	12:30pm	Michelle Valenti	Level 2	Parkinson's Pedalers Chesterfield Family YMCA
Maryland Heights	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's Edward Jones YMCA
Sunset Hills	Friday	1:00pm	Marina Clements	Level 2	Movement Training Friendship Village - Sunset Hills

ILLINOIS CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS/MEETING SITE
Champaign YMCA	Monday	1:00pm	Jenny Redden	All Levels	Pedalers Cycling
	Monday	1:00pm	Jessica R.		Seated Yoga
	Tuesday	1:00pm	Lyndsay R.		Functional Chair Fitness
	Wednesday	1:00pm	Jessica B.		Strength & Balance
	Thursday	1:00pm	Jenny Redden		Functional Chair Fitness
Decatur	Tues/Thurs	9:00am	Michelle Patterson	Level 1	Parkinson's on the Move Decatur Family YMCA
O'Fallon YMCA	Tuesday	12:00pm	Victoria White	Level 1	Exercise for Parkinson's
	Thursday	1:00pm	Stefanie McLaughlin	Level 1	Exercise for Parkinson's
Springfield	Tues/Thurs	1:30pm	Eva Fischberg	Level 2	The Joy of Movement First Presbyterian Church

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 1 Meramec Bluffs Dr. - Veterans Rm.
Cape Girardeau	1st Monday	5:30pm	Desma Reno & Jayanti Ray	VIRTUAL
Carthage	Last Tuesday	2:00pm	Tericia Mixon	Fair Acres Family YMCA 2600 Grand Avenue
Chesterfield	1st & 3rd Tuesday	11:00am	Carrie Burgraff	VIRTUAL
Frontenac	2nd Monday	10:30am	Lynda Wiens & Jay Bender	Salem United Methodist Church 1200 S. Lindbergh
Kirkwood	4th Tuesday	6:30pm	Terri Hosto	VIRTUAL
Sappington	4th Wednesday	10:30am		Cedarhurst Tesson Heights 12335 W. Bend Drive
Ste. Genevieve	2nd Wednesday	10:00am	Teddy Ross	Ste. Genevieve Co. Community Center 21390 MO-32
St. Louis Caregivers	3rd Monday	1:00pm	Kathy Schroeder	VIRTUAL
St. Peters	1st Tuesday	1:00pm	Jodi Peterson	Spencer Road Library #243 427 Spencer Road
Washington	2nd Monday	6:00pm	Carol Weber	Washington Public Library 410 Lafayette S.
YOPD	Every Thursday	6:00pm	Karen Frank & Mike Mylenbusch	VIRTUAL

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Belleville	TBD	TBD	Jodi Gardner	Belleville Health & Sports Center 1001 S. 74th Street
Carbondale	1st Wednesday	1:00pm	Gayla Lockwood	VIRTUAL
Champaign	Monday	10:00am	Carol Clark	Savoy United Methodist Church 3002 W. Old Church Road
Decatur	3rd Thursday	1:30pm	John Kileen	Westminister Presbyterian Church 1360 W. Main Street
Edwardsville	1st Tuesday	2:00pm	Pam Pinegar	Edwardsville YMCA Niebur Center - 1200 Esic Dr.
Highland	4th Tuesday	2:00pm	Kayla Deerhake	VIRTUAL
Quincy	2nd Saturday	10:00am	Terri & Dave May	Quincy Public Library 526 Jersey Street
Jacksonville	1st Wednesday	1:00pm	Jim & Fran Ringle	VIRTUAL

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PARKINSON DISEASE
ASSOCIATION

GREATER ST. LOUIS CHAPTER

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Exciting News!

Check out all the
new exercise classes
on page 10 & 11!

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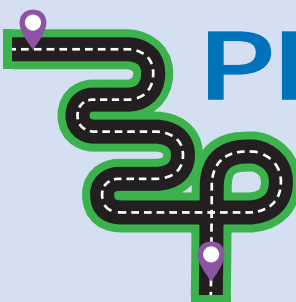
SAVE THESE DATES IN 2022!



Midwest
**Parkinson
Congress**

April 7th, 2022

The banner features a night view of the Gateway Arch in St. Louis, Missouri, with city lights reflecting on the water.



PRESSTM

Parkinson's
Roadmap for
Education
and Support
Services

Saturdays, Jan. 15 - Mar. 12, 2022

The logo consists of a green winding road with a dashed white line, starting from a purple location pin at the top left and ending at another purple location pin at the bottom right.

APDA Community Resource Center

1415 Elbridge Payne Rd, Ste 150 | Chesterfield, MO 63017

Hours: 8:00 a.m. - 4:00 p.m. M-F

636.778.3377

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