

## OCCUPATIONAL THERAPY for Parkinson's Disease



*Jamie Archer has a Master's in Occupational Therapy from Washington University where she helps patients with Aging; movement disorders; neurological disorders; stroke, and traumatic brain injury.*

### What is occupational therapy?

Occupational therapists work to break down barriers that limit your ability to do the things you want and need to do every day. We do this by adapting tasks and the environment to help you perform activities more independently. Occupational therapy also provides education in self-management with chronic conditions like PD to address the skills needed to manage your condition on a daily basis.

### Why is occupational therapy recommended for individuals with PD?

The neurologic changes that occur with PD can result in slowed movement, stiff joints, impaired coordination, forgetfulness and trouble concentrating, fatigue or lack of energy, impaired balance, tripping, and falls. All of these symptoms can lead to difficulties with accomplishing everyday tasks.

During a first visit with an OT, an evaluation is typical to determine the areas in which you are experiencing difficulty. This is done through interviewing you and your family and/or care partners. The physical setup of your home and any resources available to you are assessed. You might also be asked to observe you doing some normal daily activities or parts of activities to further assess your abilities. Then, they will typically work with you to make a plan for how to address each

of your personal goals. Occupational therapists also make recommendations and offer strategies that will help you better manage living with PD as you age. Below is a list of common interventions.

- Establishing a daily routine
- Strategies to adapt self-care tasks like eating, grooming, dressing, and bathing
- Strategies to support household management, including medication management and handwriting
- Fatigue management
- Exercise / activity participation
- Fall prevention
- Driving
- Care partner trainingsurrounding person with PD is part of the network.

### Who can benefit from occupational therapy and when?

Anyone who is experiencing difficulty with performing daily activities can benefit from occupational therapy. Occupational therapists can assist individuals with PD at any stage – it's never too early. In fact, we encourage therapy services early in your diagnosis to help you maintain an active lifestyle while adjusting to changes in function caused by PD. Having an occupational therapy assessment several times throughout the course of the disease is not uncommon. Due to the progression of PD and related changes in function overtime, therapists often reassess individuals to assist with adaptations to daily activity. Care partners can also benefit from working with an occupational therapist to determine the safest ways to assist your loved one with the activities they do every day and to address care partner health and well-being.

# THE IMPORTANCE OF ADVANCE PLANNING

It can be daunting when you or a loved one is given a new diagnosis, and you may sense a loss of control. This feeling often reminds me that in ancient Chinese culture, the two Chinese characters for crisis mean “danger” and “opportunity.”

When you are in crisis – as difficult as that may be, there is also a chance to get your affairs in order – both personally and financially. Proposed medical treatments, physician appointments, healthcare costs, and long-term care planning can be overwhelming. They can also be the catalyst to seeking legal advice and settling your affairs to provide peace of mind for yourself, your caregivers, and your loved ones.

Turn your crisis into an opportunity. Creating a comprehensive estate plan is the first step in this process. If you already have an estate plan, meet with an attorney to review your documents to determine if any changes in the law or your situation necessitate updates or revisions. This is the time to meet with an elder law attorney specializing in long-term care planning, who is educated in the difference between ordinary estate and long-term care planning.

Discerning your needs can be overwhelming. To simplify the process, consider compartmentalizing into two parts: planning for your life and, ultimately, for your death.

## PLANNING FOR LIFE

**Lifetime planning - planning for when you are living but unable to manage your affairs. The inability to manage your affairs might be a temporary or permanent condition or disability.**

### Power of Attorney

A Power of Attorney is an essential legal document that allows you to appoint a person and a

successor person to manage your finances, property, and assets. The person making a Power of Attorney is called the “principal.” The person named to act on behalf of the principal is called the “attorney-in-fact” or “agent.” This article will use the term agent with the understanding that agent and attorney-in-fact are interchangeable.

The agent in your Power of Attorney has the legal authority to pay your bills, manage your bank and investment accounts, sign contracts, sell your car or home, and take any other action allowed in the document.

### Healthcare Power of Attorney

A Healthcare Power of Attorney is a legal document that gives the agent the authority to make healthcare decisions if the principal becomes disabled or is unable to communicate. A Healthcare Power of Attorney is separate from a Power of Attorney for finances. This is important because a principal may wish to name different agents, and the documents are provided for different purposes.

It is important to discuss your end-of-life wishes with the agents named in your Healthcare Power of Attorney. More information about initiating these discussions is available at these websites: [theconversationproject.org](http://theconversationproject.org) and [nhpco.org/national-healthcare-decisions-day](http://nhpco.org/national-healthcare-decisions-day).



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Contact Tasha Doty  
[tdoty@wustl.edu](mailto:tdoty@wustl.edu)  
 or 785-865-8943

# THE IMPORTANCE OF ADVANCE PLANNING

(continued)

## Durable Power of Attorney

A Durable Power of Attorney is a legal document that states the agent's authority shall not terminate even if the principal becomes disabled or incapacitated. Both financial and healthcare Power of Attorney documents can be durable.

## Revocation

If you change your mind and want to appoint a different agent, you may revoke your Power of Attorney. In Missouri, a written revocation is required.

## PLANNING FOR DEATH

**While unpleasant to think about, death is inevitable and difficult for the ones we leave behind. Planning for your death is a simple way to ease their burden and leaves no room for questions about your wishes.**

## Last Will and Testament

A Last Will and Testament is necessary and included in most, if not all, estate plans. A Testator is a person who executes a Will. A Will allows the Testator to name a Personal Representative, also called Executor, to handle his or her affairs

upon death. The Will also specifies the Testator's wishes as to the distribution of assets. One of the most common misunderstandings about a Will is that having one will keep your estate from going through probate. Proper asset-titling and beneficiary designations are the only ways to avoid probate. A good estate attorney will guide you through that.

## Revocable Living Trust

A Revocable Living Trust is a legal document that allows a person, called a Grantor or Settlor, to instruct how assets are used during a lifetime and distributed upon death. After a trust agreement is prepared, assets are titled to the trust. Trustees are named to manage the assets upon the Grantor's incapacity or death.

A Revocable Living Trust is not a substitute for a Will; however, like a Will, a trust designates to whom your assets will be distributed at your death.

## Guardianship and Conservatorship – the Consequences of Failing to Plan

Without a plan, if you become incapacitated and cannot manage your healthcare decisions and finances, it will be necessary for someone to seek court intervention for guardianship and conservatorship.

Guardianship is a legal process in which a person is determined to be incapacitated and cannot manage decisions about food, shelter, and clothing to such a degree that harm could result. Conservatorship is a legal process where a person is deemed disabled and cannot manage decisions about finances due to a physical or mental disability. In both situations, a guardian and/or a conservator is appointed to make these decisions.

This process can be adversarial, expensive, and emotional for all parties but can be avoided with proper planning. Having Power of Attorney documents as a part of your lifetime planning strategy prevents guardianship or conservatorship





from being imposed on you and simplifies the process for your loved ones to manage your affairs.

**Important Points to Remember:**

1. The right time to consult an estate planning attorney is now.
2. Consider consulting a Certified Elder Law Attorney (CELA), as certified by the National Elder Law Foundation. A CELA is an attorney with specialized education, training, and experience in estate planning, legal aspects of healthcare, long-term care planning, Medicare and Medicaid, and other government benefits.
3. Consult your financial advisor to review your assets and discuss strategies for paying for long-term care.

Planning ahead and communicating your wishes provide peace of mind and prevent current or future crises from overwhelming you and your loved ones. The opportunity to prepare for the unknown is a worthy means of honoring yourself and your family during your life and after your death.



*Ms. Brigid Fernandez is a Certified Elder Law Attorney as certified by the National Elder Law Foundation.\* Brigid graduated from Saint Louis University School of Law. In addition to her law degree, Brigid is a Licensed Clinical Social Worker and worked*

*for many years as a Medical Social Worker before obtaining her law degree. Brigid pursued her law degree to continue and enhance her advocacy for older adults and persons with disabilities. She is also a Certified Civil Mediator and an accredited attorney with the Veterans Administration. Brigid is a member of The Missouri Bar, the Estate, Trust & Elder Law committee, the National Elder Law Foundation, and the National Academy of Elder Law Attorneys. \*Neither the Missouri Supreme Court nor The Missouri Bar reviews or approves certification organizations or specialist designations.*

**M. Brigid Fernandez, LCSW, CELA  
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FOR MORE INFORMATION:

Call: **636-778-3377** or go to:  
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## IN-PERSON EXERCISE CLASS SCHEDULE

Contact individual location to register. For more information please call 636.778.3377 or [apdastlouis@apdaparkinson.org](mailto:apdastlouis@apdaparkinson.org)

### MISSOURI CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS
Chesterfield ADPA Office	Tuesday	10:00am	Jen Berger	Level 3	Circuit Training
	Tuesday	11:00am	Jen Berger	Level 2	Strength and Cardio
	Tuesday	1:00pm	Pamela Todd	Level 1	Yoga
	Wednesday	10:00am	Michelle Valenti	Level 2	Strength and Balance
	Wednesday	11:00am	Michelle Valenti	Level 1	Seated Exercise
	Wednesday	1:00pm	Marina Clements	Level 2	Movement Training
	Thursday	11:00am	Craig Miller	Level 2	Tai Chi
	Thursday	1:00pm	Michelle Valenti	Level 2	Strength and Cardio
	Friday	10:00am	Craig Miller	Level 1	Tai Chi and Meditation
	Friday	11:15am	Craig Miller	Level 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 Stephen A Orthwein Ctr.	Thursday	12:00pm	Annie Morrow	Level 1	Interval Training
	Friday	2:00pm	Mike Scheller	Levels 1 & 2	Fit and Fun
St. Peters, BJC	Thursday	TBD	Vicky Frazier	Level 2	Strength and Cardio
	Thursday	11:00am	Vicky Frazier	Level 1 & 2	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.	All Levels	Pedalers Cycling
	Monday	1:00pm	Jenny Redden		Seated Yoga
	Tues/Thurs	1:00pm	Lindsey R. Jenny Redden		Functional Chair Fitness
	Wednesday	1:00pm	Jessica B.		Strength & Balance
	Friday	1:00pm	Lindsey 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 Ctr.	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 First Presb. Church	Tues/Thurs	1:30pm	Eva Fischberg	All	The Joy of Movement
VIRTUAL	Wednesday	10:30am			

# SUPPORT GROUP SCHEDULE

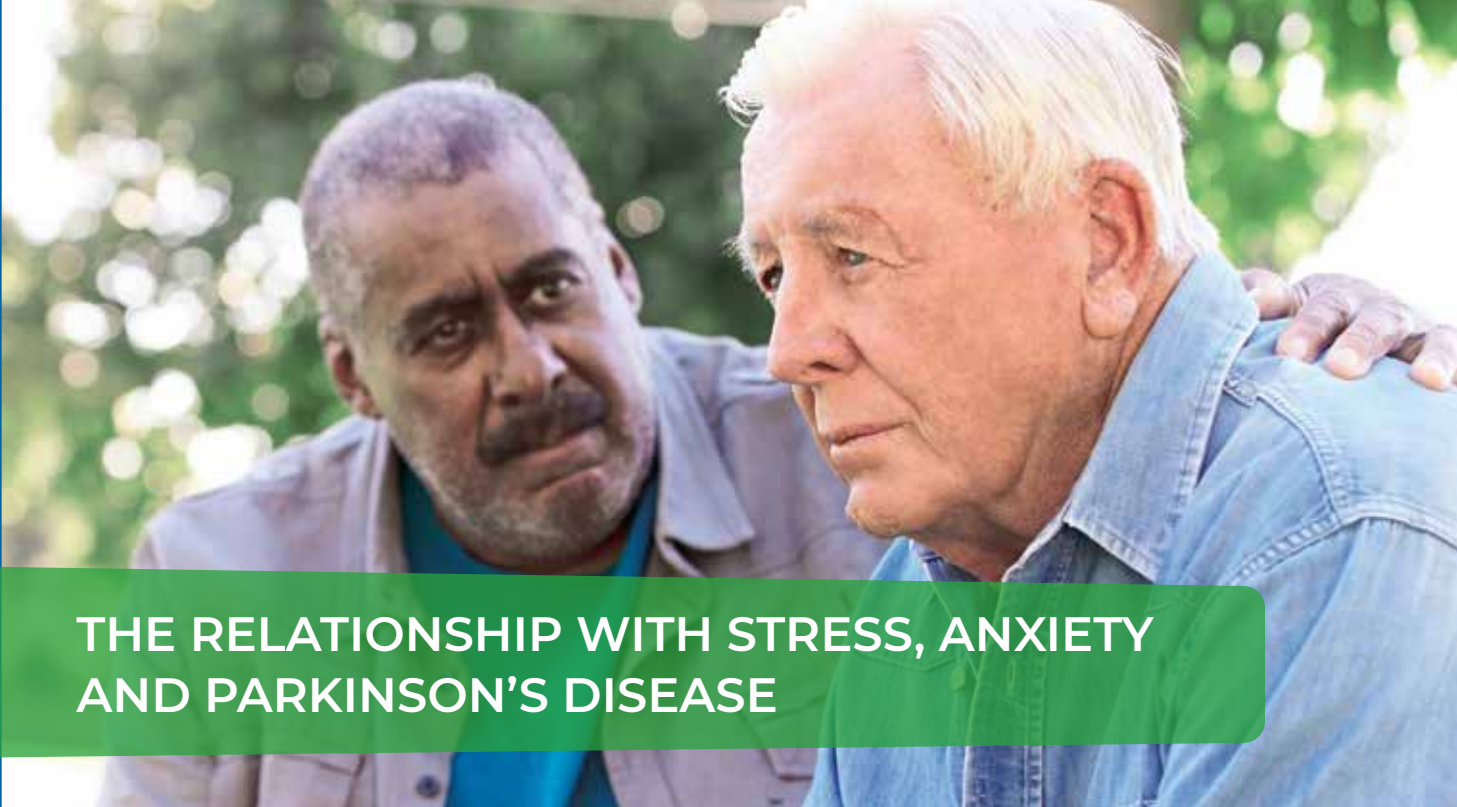
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## MISSOURI SUPPORT GROUPS

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	Prairie Living at Chautauqua
Champaign	Monday	10:00am	Carol Clark/ Dave McWilliams	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



## THE RELATIONSHIP WITH STRESS, ANXIETY AND PARKINSON'S DISEASE

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

#### 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. **In the last issue we explored Managing Stress and Anxiety, Lifestyle Modifications, Exercise, and Meditation. Here, we will explore Psychotherapy and Other Complimentary Therapies.**

#### Psychotherapy

Although the previous ideas can go a long way to control stress and anxiety, you may need additional help (short of medication) to control anxiety. Psychotherapy can be a very effective treatment for PD-related anxiety. One of the most frequently used psychotherapy techniques for stress and anxiety in PD is cognitive behavioral therapy (CBT).

CBT is a type of psychological treatment which focuses on practically changing a thought process

or behavior. It is not concerned about the root cause of a symptom but rather focuses more on the practical here and now.

The basic premise behind CBT is that a person's subjective reaction to an experience can determine how much of an impact the experience will have on that person. The same experience can have vastly different impacts on two different people. CBT aims to harness this variability and provides interventions to train the body to react to an experience differently than it normally would.

CBT has been used for a variety of conditions including anxiety disorders (of all types, not just associated with PD) eating disorders and chronic pain, among many others. Interventions used for anxiety could include patient education, self-soothing, deep breathing, progressive muscle relaxation, cognitive restructuring, and graduated exposure to decrease and eliminate avoidance behaviors and promote problem-solving.

There have been numerous studies that have looked at the **effects of CBT for anxiety in PD** and these have been nicely summarized in this article.



### Here is an example of how CBT might work for someone with PD:

Let's say a person with PD is anxious about going out to a restaurant due to fear that he will spill or embarrass himself.

CBT may use graduated exposure to help him overcome his anxiety, in which the person with PD simulates a restaurant meal with increasingly more anxiety-provoking situations until he is ready for the ultimate exposure of actually going out to dinner at the restaurant. Those exposures will work towards a number of goals.

1. One goal is to change the person's cognitive belief that he will always spill and embarrass himself at a restaurant. Using the exposure, he will see that he is able to be at a restaurant and not spill.
2. The next goal is to change the cognitive belief that if he spills, he will definitely be embarrassed. During the exposure, he will realize that even if he does spill, most likely nobody will notice or care.
3. The final goal is to change the cognitive belief that he must avoid embarrassment at all cost. The exposure will help him to understand that if he does spill and someone notices and cares, he can use the relaxation techniques that he is taught, to handle the embarrassment and enjoy the evening out regardless.

### Other complementary therapies for anxiety in PD

Complementary therapies are a growing group of treatments which may improve the symptoms of PD without medication. I have written past blogs on two complementary therapy approaches for several symptoms of PD – **art therapy** and **music therapy**.

Various complementary therapy modalities have been developed that may lower stress and anxiety in PD. These include yoga, massage, the Alexander technique, neurofeedback (described below) and others. Some of these therapies have been studied in small trials with data suggesting that they may be helpful for the anxiety of PD. Others have not yet been studied, although anecdotally, people with PD may feel that they are very useful in combatting anxiety. In general, this group of

therapies may be effective for the anxiety of PD but needs to be studied more rigorously.

### Tips and Takeaways

- Various other complementary therapies may also successfully lower anxiety in PD, although current research is limited and more needs to be done.
- Be sure to talk to your doctor if you are experiencing stress and/or anxiety. It is important for him/her to understand all of the symptoms you are experiencing in order to best help you improve your quality of life.

### REBECCA GILBERT

#### APDA Vice President and Chief Scientific Officer

Dr. Gilbert received her MD degree at Weill Medical College of Cornell University in New York and her PhD in Cell Biology and Genetics at the Weill Graduate School of Medical Sciences. She then pursued Neurology Residency training as well as Movement Disorders Fellowship training at Columbia Presbyterian Medical Center. Prior to coming to APDA, she was an Associate Professor of Neurology at NYU Langone Medical Center. In this role, she saw movement disorder patients, initiated and directed the NYU Movement Disorders Fellowship, participated in clinical trials and other research initiatives for PD and lectured widely on the disease.



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## Welcome

**APDA St. Louis Chapter Welcomes  
New Program Director**

We are so excited to have Amanda  
Landsbaum rejoin the APDA  
team. Amanda is an Occupational

Therapist with over 20 years of experience working in  
the community with people to promote their health and  
wellness. Fifteen of those years have been involved with  
the Parkinson's community providing education and  
support through various programs. She is thrilled to be  
back at the APDA as the Program Director and is ready  
to serve the needs of our constituents with high quality,  
accessible programming.

Midwest  
Parkinson  
Congress

Save the date: April 20, 2023

New location: Renaissance St. Louis Airport Hotel  
1:00 pm to 4:30 pm

## APDA Greater St. Louis Chapter

16100 Chesterfield Parkway W, Ste. 125 | Chesterfield, MO 63017

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

636.778.3377

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