

## HOME MODIFICATIONS FOOD FOR THOUGHT

Moving easily around the home is a priority for people with PD. Modifications to your house or apartment can help keep you safe and enable you to remain in your home longer. Occupational therapists who specialize in home modifications can assess your home environment and your functional needs and make recommendations on which home modifications would be most beneficial for you. Below are some frequently suggested modifications.

### Bathrooms

**Shower and Tub:** Grab bars around the shower or tub to help entering and exiting. Replacing towel bars with grab bars is a great way to remove a false sense of security. If you lose your balance, a towel bar, won't hold you.



Replacing shower doors with a shower curtain removes the step into a shower. The shower floor can be raised to meet the lip of the door jamb, so you are not stepping over the lip, but just stepping up. A shower transfer bench is also a great safety measure for getting in and out of the shower. A handheld shower kit with an extra-long hose makes self-care easier and wearing aqua socks while showering prevents slips on the shower floor.

**Toilet:** Rails can help when lowering yourself but aren't very good for getting up if you don't have arm strength. A long grab bar across from the commode can help you get up. A toilet lift kit could also be helpful. A regular toilet seat is used and raised 3 ½ inches.

### Bedrooms

Is the bed too high? A lower bed, therapeutic bed, or modified bed can make getting in and out of bed easier. A bed rail or floor-to-ceiling safety rail can also help. Motion sensor lighting is a great way to highlight the path to the bathroom in the middle of the night. Consider using door handles instead of doorknobs, as they are easier to open.



### Stairs

If there are stairs in the hallway, banisters on both sides can make a difference, and extra lighting makes steps easier to see, especially lighting directed at the stairs. Stair lifts can also be helpful and can turn corners as well as go up multiple levels, however they can be expensive. Putting a gate at the opening of staircases can keep someone from stumbling and falling down the stairs. The gates can be made to match the handrails. Consider skid resistant surfaces for the stairs.



### Getting Around the House

A well-lit home makes navigating between rooms easier for people with PD. Consider adding touch  
*(continued on page 3)*

# DANCE HAS TRANSFORMATIVE POWER FOR PEOPLE WITH PARKINSON'S



*Eve Fischberg, OTR/L is the founding director of **The Joy of Movement** ([thejoyofmovement.org](http://thejoyofmovement.org)) and teaches dance classes for people with PD and their care partners in Springfield, IL.*

“If you can talk you can sing. If you can move you can dance.” Zimbabwean proverb

We have entered a dance class. Dancers, some seated, some standing, try out newly learned moves with their partners. Lively rhythmic music invites the class to experiment with the new movements—and we hear laughter—this is serious fun. The dancers are all people living with Parkinson disease and their care partners, discovering the joy of moving to music together.

For people living with PD and their care partners, dance can be a great gift, enhancing quality of life, elevating mood, strengthening social connections, and improving functional movement. In 2001, the partnership between the Parkinson's community and the dance community took a giant leap forward when Olie Westheimer, the founder and Executive Director of the Brooklyn Parkinson's Group initiated discussions with the Mark Morris Dance Group, an internationally acclaimed modern dance company that had just opened a new dance center in Brooklyn. As a result of these discussions, Dance for PD<sup>®</sup> arose; it has since grown into an international program, serving people with PD in over 100 communities in nine countries. The program is called Dance for PD<sup>®</sup> because the emphasis of the program is on dance and not on the disease. An extensive training program has been developed, with the aim of certifying instructors in the philosophy, principles and techniques that are the basis of the Dance for PD<sup>®</sup> program. Classes offered by Dance for PD- trained instructors may be found on their website: [danceforparkinsons.org](http://danceforparkinsons.org)

*This website lists the wealth of benefits of dance:*

1. Dance develops flexibility and instills confidence.
2. Dance is first and foremost a stimulating mental activity that connects mind to body.
3. Dance breaks isolation.
4. Dance invokes imagery in the service of graceful movement.
5. Dance focuses attention on eyes, ears, and touch as tools to assist in movement and balance.
6. Dance increases awareness of where all parts of the body are in space.
7. Dance tells stories.
8. Dance sparks creativity.
9. The basis of dance is rhythm.
10. The essence of dance is joy.

Neuroscientists and clinicians have noted the effects of dance on people with Parkinson's for several decades. Although most of the research on dance and PD has been limited to small populations, the results have been promising. Both motor and non-motor symptoms of Parkinson's appear to respond to participation in adapted dance classes. A meta-analysis of thirteen previously completed studies (Shanahan, 2016) concluded that dance may benefit people with PD by offering greater quality of life and social participation, as well as improved balance, endurance, and functional mobility. More recent studies have found:

- Twice-weekly dance classes improve walking ability and decrease freezing of gait (Harrison, 2020)
- Anxiety and depression decrease, and some cognitive skills and quality of life improve with dance classes two times per week (Kalyani, 2019)
- Weekly dance classes enhance self-efficacy and improve quality of life (McRae, 2017)
- Motor symptom progression is slowed by weekly dance classes over course of three years (Bearss, 2021)

A diversity of dance styles have been studied and found to be helpful for people living with PD, including modern, jazz, tango, folk, hip hop and other dance styles.

(continued from front cover)

lighting or motion- or sound-sensor lighting to prevent bumps and stumbles.

Look for a clear path around the house. You need 28 inches or more for a wheelchair or walker, especially through doorways.

In the living room or den, lift chairs can help someone get up from a chair. A vertical bar can also help raise from a chair. If your room is sunken, you might think about railings or banisters to help make the transition.

### Entryways and Exits

We often enter the house from the garage and many times there are steps. Handrails and assist bars in door jambs can make a difference. Assist bars will normally fit between the door



and storm door. You may think about making the steps a walker platform. These are wider, shorter and deeper about half the height of normal step and allows for a walker to fit on each platform. You can also put a stair lift in the garage, even for 2-3 steps.

Many consider ramps for the front of the house. You will need 12 inches of ramp for every inch of step (e.g. 7 ½ feet per step). Other things to think about on the ramps are a high traction surface and multiple rails so you can't run off the ramp accidentally. Ornamental railings could also be helpful for front door. And don't forget the lighting for easier nighttime entry and exiting.

*We'd like to thank Joel Manesberg, owner, Grab Bar Guys, for providing information for this article.*



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The 2021 APDA Optimism Walk was an outstanding success, raising funds and awareness for the Parkinson's community. The APDA Greater St. Louis Optimism Walk led the nation in fundraising over \$185,000! Team spirit was evident throughout, with many family and friends wearing unique team shirts and proudly displaying walk bibs in honor of the person for whom they walked. The opening ceremony kicked off with APDA Greater St. Louis Chapter, Cathy Krane, sharing her thoughts about the importance of community in living well with Parkinson's disease. We also heard encouraging words from our walk co-chairs, Kathy Schroeder and Sue Butler. They expressed their gratitude to the many individuals who made this event a success, especially this year's honorary chairs, Neil and Pam Lazaroff. Exercise instructors, Jen Berger and Michelle Valenti, then led the crowd in stretches to warm up before the walk began and The Brothers Lazaroff played live music to keep everyone motivated during the walk.

Thanks to the support and generosity of more than 500 walkers, APDA Greater St. Louis Chapter will be able to help many people with Parkinson's, their families and care partners. There was outstanding turnout from Team Rock Steady Boxing St. Louis-Fenton, who had 130 walkers on their team led by their captain, Dot LeGrand. Contributing to our success were several outstanding individuals who raised over \$1,000: Sue and Tom Butler, Lora Downey, Erin Foster Voegtli, Gail and Larry Glenn, Randy Henderson, Christine Klein, Mike and Nancy Klein, Catherine Krane, Jeff and Julie Lazaroff, Neil and Pam Lazaroff, Dan LeGrand, Joe Marchbein, Tom Monahan, Carol Murphy, Lou Ann Nolan, Ann Schmelzle, Doug and Kathy Schroeder, David Schrupf, and Margie Silverblatt. Please thank our generous sponsors and recognize their superb contributions to our community. Our appreciation goes out to:

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# IS ESTATE PLANNING ON YOUR “TO DO” LIST?

*Things to Consider and Discuss Before Meeting with Your Attorney*



*Stephanie Copp Martinez is an attorney and the founder of The Estate Planner LLC, a law firm devoted to helping people protect themselves, their loved ones and their legacy through customized Estate and Elder Law Plans that meet each client’s unique needs.*

Our time on this beautiful blue planet we call home is terminal – for all of us. Planning for what happens if we become incapacitated and at our death is an essential part of protecting ourselves, our loved ones and our legacy. Planning ahead is a gift to those we love – giving them space and time to grieve instead of frantically trying to determine what we wanted and how best to wind up our affairs.

If estate planning is on your “to do” list (and I think it should be on everyone’s “to do” list), here are a few things to consider and discuss before meeting with an estate planning attorney. A couple of things to keep in mind as you read this. These decisions do not need to be made before you see an attorney, this is just to get you started thinking. In other words, don’t let this article be the reason for procrastination. And, even if you’re not ready to see an attorney, many of these discussions are important to have anyway.

## **Who Do You Want Helping?**

One of the hardest but most important decision to make is who should be the helpers. These helpers all have legal names – financial power of attorney, healthcare power of attorney, trustee, personal representative or executor – but essentially, they’re the people helping do what you would have done if you were able. To choose the right helpers, it’s important to ask the following questions.

Who do you trust to make financial decisions for you if you cannot and to wind up your affairs after your death? Who do you trust to make healthcare

decisions for you? For the financial helper, at a minimum, you need someone who is honest, fair, and has some knowledge of personal finance and who is comfortable working with financial institutions. For the healthcare helper, you need someone who understands and will follow your healthcare wishes, who can make themselves available with minimal notice and who will advocate on your behalf.

People choose relatives, close friends and sometimes corporate fiduciaries to fill these roles. Many people choose someone different to serve as financial and healthcare helper, as the skills required differ.

## **What Are Your Healthcare Decisions?**

Healthcare decisions are incredibly important and each individual’s desires can vary dramatically. Discussing the kind of care you want with loved ones is critical. Do not assume you and your loved ones are “on the same page” without a discussion. Here are some of the questions you should consider. Do you want your attending physician to withhold or withdraw medical procedures that would merely prolong the dying process but are not necessary to provide comfort or pain relief? What type of procedures would you be willing to forego – nutrition, hydration, surgery, CPR, ventilator, chemo, diagnostic tests? Would you want to be released from the hospital to die naturally at home? These are not easy discussions to have – but having the hard discussion ahead of time eases the burden for loved ones in the moment when they must make a difficult decision on your behalf.

## **Your Assets – What Do You Have?**

Understanding your financial situation is also a key component of any estate plan. What assets do you have and how do your loved ones access them? Here’s a list of potential assets to consider: bank accounts, investment accounts, IRAs/401ks,

529s, life insurance, health insurance, long-term care insurance, real estate, pension government bonds, stock certificates, safety deposit box, cars, boats or trailers. What about virtual assets? Do you have a Facebook account, emails, photos on your phone? Are you holding any virtual currencies or other virtual assets? How are your assets held – jointly with spouse, in your name only, jointly with someone else? Is there a beneficiary designation and if so, who is designated?

### **Distributions?**

On your death, how do you want your assets distributed? Do you want everything to go to your spouse, or shared between your spouse and your children? Are there charities you support? Do you have friends or other relatives to whom you want your assets distributed? Do you have loved ones who are minors or who need help managing an inheritance?

Considering these tough topics and tackling these difficult discussions can seem daunting. Planning ahead and preparing now, however, is much better than forcing loved ones to struggle with these tough issues when we are no longer able to guide and assist them. Planning ahead truly is a gift.

Check out The Conversation Project's Starter Guide. This is a great resource designed to help people talk about what they want at the end of life. You can print out and use when having the conversations with your loved ones.

<https://theconversationproject.org/wp-content/uploads/2020/12/ConversationStarterGuide.pdf>

### **Current Research** *Please visit our website for more information on each of these studies*

**Cognitive Stimulation Therapy Group** - Contact Zainab Ali [zainab.ali@wustl.edu](mailto:zainab.ali@wustl.edu) or YeaJi Kim [k.yeaji@wustl.edu](mailto:k.yeaji@wustl.edu)

**Improvisational Movement Study**, Contact Julie Chen [c.julie@wustl.edu](mailto:c.julie@wustl.edu) or Alex Tan [a.m.tan@wustl.edu](mailto:a.m.tan@wustl.edu)

**Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3** - Contact Martha Hessler [mjhessler@wustl.edu](mailto:mjhessler@wustl.edu) or 314-286-1478

**Lower Back Pain Study** - Contact Martha Hessler [mjhessler@wustl.edu](mailto:mjhessler@wustl.edu) or 314-286-1478

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## LOW BACK PAIN



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Do you have aches and pains? You are not alone. Muscle and joint pains are common as we age. Pain is a protective sensation to help you prevent further serious injury to your body. For example, the pain one might get from burning their hand on a stove tells them to: 1) pull their hand off the stove and 2) avoid doing that again in the future. Normally, pain from a specific injury subsides over time and eventually goes away completely. However, there are cases in which pain persists following, or even in the absence of, injury or damage to a body tissue. This long-lasting pain, commonly referred to as chronic pain, is considered abnormal.

Despite chronic pain being abnormal, it is very common among middle-aged and older adults throughout the world. Chronic pain affects more than one billion people worldwide. Interestingly, people with PD are very likely to

report experiencing pain. This is not solely related to age because people with PD report pain more frequently than their age-matched peers who do not have PD. Pain may start before, around the time of, or after the diagnosis of PD. In one study, people with early PD rated pain as one of their three most bothersome symptoms.

There are many types of pain in PD. The most common type of pain is musculoskeletal pain, which is pain in or around the muscles and joints. The low back is the most common site of pain in people with PD, though pain is also common in the neck, shoulders, and knees. Up to 74% of people with PD report having low back pain. This is important because low back pain is one of the leading causes of disability worldwide. Despite the fact that low back pain is highly prevalent among people with PD, it is often under-recognized and under-treated by healthcare professionals.

If you have low back pain or any other type of pain and it impacts your ability to move, exercise, or perform daily activities, you should discuss this with your physician. They may recommend over-the-counter or prescription pain medication. Further, they may refer you to a physical therapist. Physical therapists are trained to evaluate and

treat people with pain. It is important that you work with your physician to find a physical therapist who frequently sees people with PD. This is because there are unique aspects of PD that must be considered when developing treatment plans to reduce pain. As a physical therapist and clinician-scientist at Washington University, I am particularly interested in better understanding low back pain in people with PD.

Our preliminary work in people with PD indicates low back pain affects the ability to stand for extended periods of time, walk long distances, and lift heavy objects. Further, our findings suggest low back pain may impact sleep in people with PD. Greater low back pain severity was associated with reduced quality of life and physical activity level. This work convinced us to continue studying low back pain in people with PD with the ultimate goal of finding effective treatments for reducing low back pain. To reach this ultimate goal, we must first identify potential treatment targets.

To do this, we are studying which factors might be most closely linked to low back pain in PD. The factors fall into three general buckets: 1)

movement, 2) sensory, and 3) psychologic. Movement-related factors like posture, flexibility, and strength may be related to back pain in PD. Regarding sensory factors, PD itself, particularly the loss of dopamine, may make people with PD more sensitive to pain. Finally, psychologic factors like depression or anxiety, also common in PD, may worsen low back pain. This work will help us understand how to design future treatments. For example, if we find that muscle stiffness is strongly related to low back pain, we might design a study focused on stretching stiff muscles to determine its effect on pain.

*In summary, much work needs to be done better understand low back pain in PD. If you have low back pain, there are several important things to document. First, write down when your symptoms are best and worst. Are there certain movements that make it better or worse? Does exercise help? Also, note whether your back pain changes if your anti-PD medication is working effectively compared to when it is not. These things are important to discuss with your physician, who can help you identify the best path for managing low back pain.*

## VIRTUAL EXERCISE CLASS SCHEDULE

Please visit: [bit.ly/APDAYouTube](https://bit.ly/APDAYouTube) for Live Stream exercise classes.

Contact APDA at 636.778.3377 or [apdastlouis@apdaparkinson.org](mailto: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

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/MEETING SITE
Cape Girardeau	Mon/Wed/Fri	9:00am		Level 1	Boxing Christian Boxing Academy
Chesterfield	Mon/Wed	12:30pm	Michelle Valenti	All Levels	Parkinson's Pedalers Chesterfield Family YMCA
Kirkwood	Starting in-person 2022			Level 1	Parkinson's Exercise Kirkwood Family YMCA
Maryland Heights	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's Edward Jones YMCA
Ste. Genevieve	Thursday	11:00	Becky Baumann	Level 1	Parkinson's Exercise Ste. Gen Community Center
Sunset Hills	Friday	1:00pm	Marina Clements	Level 2	Movement Training Friendship Village - Sunset Hills
Washington	Starting in-person 2022 (Mon/Wed 1:00)			Level 1	Parkinson's Exercise Four Rivers YMCA
Wildwood	Starting in-person 2022			Level 1	Cardio & Strength Wildwood Family YMCA

### ILLINOIS CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS
Breese YMCA	Starting in-person 2022			All	Exercise for Parkinson's
Champaign YMCA	Monday	1:00pm	Jessica B.	All Levels	Pedalers Cycling
	Monday	1:00pm	Jenny Redden		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 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	Monday	12:00pm	Cathy Schluckebier	All	Fit to Fite PD Boxing
	Friday	10:30am	Cathy Schluckebier	All	Fit to Fite PD Boxing
Springfield	Tues/Thurs	1:30pm	Eva Fischberg	All	The Joy of Movement First Presbyterian Church

# SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email [apdastlouis@apdaparkinson.org](mailto:apdastlouis@apdaparkinson.org)

## MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Ballwin	4th Tuesday	2:30pm	Chaplain Carla Schmidt	Meramec Bluffs Care Center
Cape Girardeau	1st Monday	5:30pm	Jayanti Ray	VIRTUAL
Carthage	Last Tuesday	2:00pm	Tericia Mixon	Fair Acres Family YMCA
Chesterfield	1st & 3rd Tuesday	11:00am	Carrie Burgraff	VIRTUAL
Frontenac	2nd Monday	10:30am	Lynda Wiens & Jay Bender	Salem United Methodist Church
Joplin	Monday	3:30pm	Lori Marble & Aaron Lewis	VIRTUAL
Kirkwood	4th Tuesday	6:30pm	Terri Hosto	VIRTUAL
Rolla	3rd Tuesday	2:30pm	Julie Riggs	Phelps Health Delbert Day Cancer Inst
South County	4th Wednesday	10:30am	Kimberly Sanders	VIRTUAL
Ste. Genevieve	2nd Wednesday	10:00am	Teddy Ross	Ste. Gen. Co. Community Center
St. Louis Caregivers	3rd Monday	1:00pm	Kathy Schroeder	VIRTUAL
St. Peters	1st Tuesday	1:00pm	Jodi Peterson	Spencer Road Library #243
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
Belleville	3rd Tuesday	11:00am	Jodi Gardner	Belleville Health & Sports Center
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	1:30pm	Robbie Mueth	1001 East Harris Ave.
Highland	4th Tuesday	2:00pm	Kayla Deerhake	VIRTUAL
Jacksonville	1st Wednesday	1:00pm	Jim & Fran Ringle	VIRTUAL
Quincy	2nd Saturday	10:00am	Terri & Dave May	Quincy Public Library



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## Exciting News!

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inside on Lower  
Back Pain, Home  
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Estate Planning

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### SAVE THESE DATES IN 2022!



### WE'RE MOVING!



In March, 2022, the APDA St. Louis Chapter will be moving offices. Our new home will be at 16100 Chesterfield Parkway W. It is just across Clarkson from where we are now located.

We are maintaining our offices and multipurpose room plus we will be

adding meeting space. We will have our own entrance and parking, with plenty of handicap spaces.

The space is being built specifically for our use. We are excited to move and look forward to your visits in the future!

### APDA Greater St. Louis Chapter

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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