



AMERICAN PARKINSON DISEASE ASSOCIATION

MISSOURI CHAPTER NEWSLETTER

May/June
2024

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GARDENING WITH PARKINSON'S DISEASE

A Guide to Gardening with Increased Ease

By Karena Laswell, OTS and Sadie Schultes, OTS

Spring is upon us and our gardens await! Setting yourself up for success, a stretching routine, assistive technology, and smart home modifications may be able to make gardening a more attainable activity for someone living with Parkinson's disease. Assistive technology are devices or products that help people carry out everyday activities with increased independence.



Set Up For Success

For those with Parkinson's disease, preparing to garden requires careful consideration to ensure a safe and enjoyable experience. Individuals with Parkinson's may be more sensitive to heat and are at an increased risk of developing melanoma. Planning outdoor gardening activities before 10 am or after 4 pm to avoid peak sunlight hours when the sun's UV rays are strongest, along with wearing sunscreen and sun protective clothing, can be effective to protect against harmful UV rays and decrease the risk of developing skin cancer.

Hydration is key when participating in outdoor activities that increase risk of dehydration and heat stroke, as well as worsen Parkinson's symptoms. Proper hydration not only supports overall health, but also helps to maintain energy levels during gardening tasks.

Additionally, preparing for any potentially uneven surfaces by utilizing mobility aids such as a walking stick or walker, avoiding gardening when fatigued, and setting up gardens in easy to access areas can enable those with Parkinson's to navigate gardening areas with better balance and stability, as well as reduce risk of falls.

GARDENING WITH PARKINSON'S DISEASE (continued)

Stretching Routine

Stretching before and after gardening can help elongate muscles and prevent injury or soreness. The stretching routine listed below can be completed seated or standing. Seated stretches should be performed if an individual has decreased balance or experiences dizziness with position changes. Be sure to breathe continuously throughout the routine.

1. Seated hamstring stretches

Sit up tall on edge of chair with one leg bent and one leg straight ahead. Gently lean forward at the hips until you feel a stretch in the back of the straight leg. Hold this position for 20 to 30 seconds. Perform 2 to 3 repetitions then switch legs. To get a calf stretch while doing this, point your toes of the straight leg toward the ceiling.

2. Lateral Bends

Start with your back straight with arms relaxed by your sides. Raise your arms above your head and gently lean to one side. Hold for about 15-30 seconds, return to center, and then repeat on the other side.

3. Figure Four Stretch

Start sitting in a chair with back straight and feet hips width apart. Lift one leg off the ground and bend your knee. Place the ankle on the opposite knee to create a number four with your legs. Hold this position for about 15-30 seconds and then switch legs.

4. Chest Opener

Start with your back straight and place hands on hips. Squeeze your shoulder blades together while pressing your chest forward. Hold this position for 15-30 seconds.

5. Arm Circles

Begin by standing or sitting up straight and extend your arms to the side forming a letter "T" with your arms. Circle your arms clockwise and pretend you are drawing a circle in the air. Complete 15 repetitions and then complete in the opposite direction for 15 repetitions.

Assistive Technology

There are many assistive devices available that can allow individuals to maintain gardening activities this spring. A raised flower bed or hanging plant baskets can eliminate the need for crouching down or being on the knees when planting, weeding, and maintaining plants or flowers. If one prefers gardening in the ground, a rolling garden cart or a garden kneeler and seat can help make gardening more comfortable while staying close to the ground. Gardening equipment can be modified to be more accessible for all individuals. A lightweight hose, lightweight watering can, or an automatic sprinkler system could assist in the watering process. Long handled gardening tools or ergonomic gardening tools may ease the process of digging, weeding, or raking. Electric clippers could be an option for an individual that has diminished grip strength. Grippy gloves are also a great solution for increasing grip and stability when utilizing tools. It is important to stay safe when using these tools.

Resources

Most items can be easily purchased online and some items may be available at gardening stores. If you are unsure of which items to purchase, Missouri Assistive Technology (<https://at.mo.gov/>) has a lending library, including many adaptive gardening tools.

Karena Laswell and Sadie Schultes are occupational therapy students completing their doctoral Capstone alongside Dr. Sydney Marshman of Happy at Home Consulting with a focus on aging in place, prevention and management of lifestyle induced illness or injury.



CURRENT RESEARCH

Please visit our website for more information



Memory Intervention for Parkinson Disease Study

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

Music Based Walking Program

Classes in August and September
Please contact Sydney Baudendistel
bsidney@wustl.edu or 314-273-6206

How Deep Brain Stimulation Changes the Function of the Brain's Cortex

Please contact Kaeli-Skye Spight
DeepBrainStimulation@wustl.edu

Please include in your email if you are with or without PD and your age.

Studies of Neuroinflammation in Parkinson's Disease

Please contact Brooke Watkins
nil-PDinflammation@email.wustl.edu or 314-747-3083

Protein and Imaging Biomarkers (PIB) Study

Please contact Kayleigh Oberndorfer
nil-pdpibstudy@email.wustl.edu or 314-362-0420

Protein Aggregation and Neurotransmitter Deficits (PAND) Study

Please contact Emma Carr
nil-PANDstudy@email.wustl.edu or 314-362-7586

Precision-Mapping Study

Please contact Emma Carr
nilprecisionmapping@email.wustl.edu or 314-362-7586

Movement, Speech, and Thinking Study

Please contact Jason Longhurst
jason.longhurst@health.slu.edu or 314-977-8533

Lower Back Pain Study

Please contact Martha Hessler
mjhessler@wustl.edu or 314-286-1478

Improving Diversity in Parkinson's Research and Care Study

Please contact Dominique Woodhouse
woodhouse@wustl.edu or 618-401-2328

Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

Please contact Kevin Holley
kevin.h@wustl.edu or 314-286-1641

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WORKING THROUGH AUTOMATIC THOUGHTS

Thought patterns and chronic illness

By Katie Willard Virant MSW, JD, LCSW

Key Points

- Our brain uses automatic thinking to streamline responses to stimuli.
- Sometimes automatic thinking can be maladaptive, requiring an override.
- We can correct for cognitive biases by working with our mental camera.

The predictive text function on my iPhone lately has been making an error. It reads the word “so” and assumes that I want to write “Sophie.” I’ve corrected it many times, but it sees “so” and stubbornly assumes that I am writing to or about my friend, Sophie.

Our brain offers its own “predictive text” function when it makes assumptions based on our past experiences. Sometimes, this works very well. When we encounter a hot stove burner, for example, we don’t have to write a pros and cons list about whether we should place our hand there. Our brain quickly computes that a hot stove burner is dangerous and should not be touched. Thank you, automatic thinking!

However, just as with our iPhones, there are times when our brain’s attempts to shortcut do not serve us well. This post explores how certain types of automatic thinking can increase distress surrounding chronic illness.

Attentional Bias

When we exhibit attentional bias, we pay selective attention to specific information, failing to place that information in a broader context. Many people living with chronic illness experience a hyper-vigilance around symptoms. We are very attuned to our bodies, noticing every ache and pain. This makes sense, as our brain believes — and rightly so — that we need this information to keep ourselves safe. Attentional

bias comes into play when our brain is so focused on identifying symptoms that it ignores or barely registers health.

Take a moment to focus on a part of your body that is uncomfortable. What’s it like to zoom the camera of your mind’s eye on only that sensation? If your right hip hurts, for example, focus only on the pain you are experiencing in that area. Now zoom the camera out to include your whole body. Does your knee hurt? Your foot? What about the other side of your body? You’re still acknowledging that your right hip has pain, but your brain is now placing the pain in the larger context of your whole body. Pain is part of your experience when you zoom the camera out, not the whole of your experience. When you correct for attentional bias, you receive a different picture of what is happening.



Interpretation Bias

Interpretation bias involves what we do with the information our brain has noticed. In chronic illness, there can be a tendency to interpret signals from the body as illness-related. There also can be a tendency to catastrophize.

As with attentional bias, this makes perfect sense. The brain knows that chronic illness symptoms often mean danger. Unfortunately, for many of us who live with chronic illness, the warning it provides sounds less like, “Just flagging these sensations for you. Do you think they are illness-related?” and more like, “RED ALERT! RED ALERT! THINGS ARE BAD AND THEY’RE ONLY GOING TO GET WORSE!”

Just as we did in addressing attentional bias, let's pull the camera back. Observe the panic from a place outside of your big feelings. Speak gently to the panicked part of yourself, saying, "Boy, you're really afraid. And it's understandable. But you don't have enough information to justify this high level of panic. Can you take a few breaths so we can evaluate what's happening from a calmer place?" Treat yourself with respect and compassion. Once you're able to calm yourself down, evaluate the symptoms you're experiencing with a clearer head. Congratulations — you're learning how to correct for interpretation bias.

Recall Bias

Recall bias involves focusing on particularly painful moments in our past experiences. We may remember vividly the harrowing moments in our illness journey, without also remembering the times when our health was relatively stable. Especially when we experience a bodily sensation that causes concern, our minds immediately may flash to images of our darkest times.

By now, you know the drill: We're going to do some camera work with our mind's eye. Instead of staying with the image of your scariest moment, we're going to play the film forward. Let's imagine that experiencing symptoms causes you to remember yourself lying in a hospital bed. Time didn't stop when you experienced that moment, so you are going to call to mind images of you rehabilitating and coming home from the hospital. Unfreeze the camera and look at the entire memory rather than only its worst parts.



Why Correcting Automatic Thoughts Matters

Correcting automatic thoughts about illness grounds us in a more balanced reality. Keeping our stress levels in check is mentally and physically healthy, benefiting our quality of life. Putting in the work to identify and correct automatic thoughts helps us to rewire our brains, updating problematic thought patterns to more adaptive ones.

References

Savioni, L., and Triberti, S. (2020). Cognitive Biases in Chronic Illness and Their Impact on Patients' Commitment. *Frontiers in psychology*, 11, 579455. <https://doi.org/10.3389/fpsyg.2020.579455>

EXERCISE CLASS SCHEDULE

For more information please refer to www.apdaparkinson.org/mo or call 636.778.3377

MISSOURI CLASS SCHEDULE

***NEW | Carondelet YMCA**

Tues/Thurs 11:00am - Exercise for Parkinson's

Chesterfield APDA Office

Tuesday 10:00am - Circuit Training | Level 3

Tuesday 11:00am - Strength and Cardio | Level 2

Tuesday 12:00pm - Dancing through the Decades

Wednesday 10:00am - Movement Training | Level 2

Wednesday 11:00am - Seated Exercise | Level 1

Thursday 11:00am - Tai Chi for Parkinson's

Thursday 12:00pm - Parkinson's Boxing | Level 3

Thursday 1:00pm - Strength and Cardio | Level 2

***NEW |** Thurs 2:00pm - Seated Exercise | Level 1

Friday 11:00am - Tai Chi and Meditation

Chesterfield YMCA

Mon/Wed 12:15pm - Parkinson's Pedalers | Level 2

***NEW | Crestwood - Sports Medicine & Training Ctr.**

Tuesday 9:00am - Exercise for Parkinson's | Level 2

***NEW | Eureka - The Timbers Recreation Center**

Tues/Thurs 1:00pm - Exercise for Parkinson's

Jefferson County YMCA

Mon/Thurs 10:00am - Exercise for Parkinson's

Kirkwood YMCA

Monday 11:45am - Parkinson's Pedalers | Levels 2

Maryland Heights YMCA

Tues/Thurs 11:30am - Exercise for Parkinson's | Level 2

South County YMCA

Tues/Thurs 3:00pm - Exercise for Parkinson's

St. Louis City - Stephen A. Orthwein Center

Thursday 12:00pm - Interval Training | Level 2

St. Peters - BJC

Thursday 10:00am - Strength and Cardio | Level 2

Thursday 11:00am - Seated Exercise | Level 1

Ste. Genevieve Co. Community Center

Wednesday 11:00am - Exercise for Parkinson's | Level 2

***NEW | Warrenton - SSM Day Institute**

1st and 3rd Tuesdays 3:30pm - Exercise for Parkinson's | Levels 1 and 2

Washington YMCA

Mon/Wed 1:00pm - Exercise for Parkinson's

Friday 11:30am - Exercise for Parkinson's

Virtual via Zoom

Tuesday 9:00am - Seated Exercise | Level 1

Thursday 2:00pm - Seated Exercise | Level 1

ILLINOIS CLASS SCHEDULE

***NEW | East Belleville YMCA**

Tues/Thurs 11:00am - Exercise for Parkinson's

***NEW | Downtown Belleville YMCA**

Mon/Wed 11:00am - Exercise for Parkinson's

Breese/Clinton Co. YMCA

Tues/Thurs 12:30pm - Exercise for Parkinson's

Carlinville Area Hospital

Tuesday 10:00am - Exercise for Parkinson's

Decatur YMCA

Mon/Wed/Fri 11:00am - Parkinson's Pedalers

Tues/Thurs 9:00am - Parkinson's on the Move

Edwardsville YMCA

Tues/Thurs 11:00am - Exercise for Parkinson's

Highland - Korte Recreation Center

Mon/Wed/Thurs 11:00am - Cycle and Strength

O'Fallon YMCA

Tues/Thurs 12:00pm - Exercise for Parkinson's

Quincy YMCA

Tues/Fri 10:30am - Fit to Fight PD Boxing

Springfield - Grant Conservatory of Music & Dance

Tues/Thurs 1:30pm - The Joy of Movement

Virtual via Zoom

Wednesday 10:30am - The Joy of Movement

Exercise Level Descriptions:

Level 1: Participants exercise seated or standing with support. Movements are done at a pace and intensity that are appropriate for each participant.

Level 2: Participants must be able to walk and stand up from a chair without assistance. Most exercises are done standing.

Level 3: Higher intensity, faster paced classes where participants perform multiple step exercises and may get on/off the floor.

SUPPORT GROUP SCHEDULE

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

MISSOURI SUPPORT GROUPS

Ballwin - Meramec Bluffs Care Center
4th Tuesday 2:30pm

Cape Girardeau - Cape Girardeau Library
2nd Monday 5:30pm

Chesterfield - APDA Office
2nd Monday 10:30am - Caregivers ONLY
2nd Tuesday 1:00pm - Early in diagnoses
***NEW** | 4th Tuesday 1:00pm - Newly diagnosed

Chesterfield - Friendship Village, Trillium Rm.
3rd Thursday 2:00pm

Florissant - Garden Villas North
1st Tuesday 10:00am

Kansas City - Johnson County Rehab Hospital
2nd Wednesday 4:00pm

Kirkwood - First Presbyterian Church
2nd Monday 1:30pm

Olivette - Private Home Care Co - Hybrid
3rd Tuesday 11:00am

Rolla - Phelps Health Cancer Institute, Conf. Rm. B
3rd Tuesday 2:30pm

South County - Cedarhurst of Tesson Heights
4th Wednesday 10:00am

St. Charles - Kisker Road Library
2nd Tuesday 10:00am - Caregivers ONLY

Ste. Genevieve - Community Center
2nd Wednesday 10:00am

St. Peters - Breeze Park Independent Living
1st Tuesday 1:00pm

Washington - Public Library
2nd Monday 3:00pm

Virtual via Zoom
4th Tuesday 6:30pm - All welcome
3rd Monday 1:00pm - Caregivers ONLY
Every Thursday 6:00pm - Young onset ONLY
***NEW** | 3rd Friday 2:00pm - We Care: South Asian families
***NEW** | 2nd Wednesday 9:00am - Adult Children ONLY

ILLINOIS SUPPORT GROUPS

Alton - SSP Main Bldg., The Meeting Room
2nd Wednesday 1:00pm

Alton - SSP Wellness Center
2nd Tuesday 2:00pm - Caregivers ONLY

**Belleville - Southwestern Illinois College's
Programs & Services for Older Persons**
3rd Monday 1:30pm

Carbondale - Prairie Living at Chautauqua
1st Wednesday 1:00pm

**Carlinville - Carlinville Area Hospital,
MOB Comm Rm.**
4th Tuesday 11:00am

Edwardsville - YMCA Niebur Center
1st Tuesday 2:00pm

Greenville - Bond County Senior Citizens
2nd Tuesday 1:00pm

Highland - St. Joseph Hospital, Sullivan Conf. Rm.
4th Wednesday 2:00pm

Quincy
2nd Saturday 10:00am | Public Library
4th Thursday 1:00pm - small group discussion |
Senior Center

DO-IT-YOURSELF (DIY) FUNDRAISING



Across the country, people are coming together to join in a common goal to do all we can to help everyone impacted by Parkinson's disease (PD) live life to the fullest. There are no limits to the ways that you can get involved and support the American Parkinson Disease Association (APDA) Missouri Chapter, and our online fundraising tools make registration, ticketing, and fundraising easier than ever. Join us as we spread hope, optimism, and a positive vision for the future.

How do YOU want to DIY fund raise?

Here are some great ways to get you started! Go to <https://www.apdaparkinson.org/get-involved/diy-fundraising/> and click "Create My Own Campaign" to set-up your own personal DIY activity. Fundraising can be FUN!

Create Your Own Campaign

You don't have to sweat to raise funds for APDA. You can turn any activity into a fundraising opportunity. No matter what activity you choose, planning and promoting a fundraising event in your community is a terrific way to raise important funds and awareness for APDA. Your event can be anything from a yard sale or karaoke competition to a bowl-a-thon or dinner dance — the possibilities are endless! Setting up a fundraising page is easy – try it now!

Celebrate a Birthday/Anniversary

Many people turn their birthday or anniversary into an APDA fundraiser. Simply create a personal fundraising page and tie it to a birthday or anniversary celebration, or a special holiday, and invite friends, family, and colleagues to donate in lieu of gifts. Let them know that a gift to APDA is on your wish list! **The best gift can be a donation that supports a cause you care so much about!**

Participate in an Existing Event

Running a half-marathon? Participating in a bike race? Turn your next event into a personal fundraiser for a

cause you care about! With our online tools, you can easily create a fundraising page to let your friends, family and colleagues know that you're about to take on a challenge and using it as an opportunity to raise money for support, education, and research for those affected by Parkinson's disease.

You can turn anything into a fundraiser for APDA! Marie V. raised funds through her Spartan race adventures to honor the memory of her grandfather who had PD.

Pay Tribute to a Loved One

Celebrate someone special in your life by creating a fundraising campaign in their honor or memory. It is a wonderful way to pay tribute to someone who has had an impact on your life, and it gives others an opportunity to make a meaningful contribution in their name. Set up your fundraising page to let people know why this is important to you and then ask family and friends to show their support with a donation.

Whether you are living with PD, know someone who is, or just want to support a good cause – creating a DIY Fundraiser is a fantastic way to make a difference for those impacted by Parkinson's disease. Get started today!



HELPFUL MEALTIME ADAPTIVE AIDS FOR PEOPLE LIVING WITH PD

Amanda Landsbaum, MS, OTR/L

Mealtimes can be challenging for some people living with Parkinson Disease due to symptoms of tremor, hand stiffness, or dyskinesia (involuntary movements). The following are some adaptive aids available that can help, depending on the symptom.

Hand stiffness - Built up utensils

People experiencing hand stiffness, weakness, and even arthritis can benefit from utensils that have a larger grip. Grip styles range from soft, non-slip, or firm. Many styles can also bend to allow for a preferred angle. Most sets range from \$15-20.



(Foam handle)



(Non-slip grip))



(Bendable example)

Tremor - Weighted utensils

A heavier, weighted utensil can help decrease the amount of tremor experienced, making eating easier. There are different styles, and some that look like traditional utensils. Most sets range from \$30-45.



(Weighted, bendable)



(Weighted, non-bendable)

Dyskinesia or tremor - Stabilizing Utensils

Stabilizing utensils contain sensors that detect the force and direction of tremors or dyskinesias and adjust to counteract the movement. They are not typically recommended because they will not solve all the issues and are very expensive, however they are an option. Prices range from \$250-400.



(fork & spoon attachments can be switched)

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