AMERICAN PARKINSON DISEASE ASSOCIATION
GREATER ST. LOUIS CHAPTER
Strength in optimism. Hope in progress.
May/June 2022

BETTER BRAIN HEALTH AND BALANCE

Dr. Beth Templin, PT, DPT, GCS

Dr. Beth Templin is the owner of HouseFit Physical Therapy & Fitness, which specializes in helping aging adults and people living with PD to stay active and independent and enjoy life fully.

We know that intense exercise is one of the best ways to improve and maintain your physical fitness with a Parkinson's diagnosis. Just as important is maintaining good brain health. When you take a deeper look into brain heath, there are several recommendations including: participating in regular physical activity, getting a good night sleep, engaging in mentally stimulating activities, eating a brain healthy diet, managing your health, and staying socially engaged.

Today we're going to focus on two of these recommendations, physical activity and mentally stimulating activities. We know that exercise increases blood flow to the brain, helping to bring in nutrients and carry away wastes, promoting healthy brain tissue. **Physical activity** also stimulates the production of Brain-Derived Neurotrophic Factor (BDNF), which helps support the growth and survival of new brain cells.

Mentally stimulating activities can range from playing brain games to learning new hobbies. By challenging your brain and continuing to learn new information, you strengthen your brain, making it easier to think faster, focus and remember more. When you overlap these two activities and perform cognitive challenges while exercising, you amplify the benefits of both for your brain health.

The combination of moving and thinking at the same time requires more concentration and is known as **dual tasking**. Typically, when you dual task, one or both of the activities suffer, meaning they are not performed as effectively. People living with PD often demonstrate larger gaps in performance compared to older adults living without PD. This can affect activities like walking and lead to increased fall risk or loss of independence. The good news is research shows dual tasking can be improved in people living with PD with practice.

There is an app called **Clock Yourself** that you can install on smart phones or tablets that can help you perform these activities at the same time.

BETTER BRAIN HEALTH AND BALANCE

with Clock Yourself (cont.)

This specific app works on reactive stepping or stepping in different directions randomly. Performing reactive step training has been shown to be an important part of balance training and reducing fall risk. Since people living with Parkinson's are at a higher risk of falls than the normal population, I think it's a perfect activity to practice regularly.
Inside the app are several different dual tasking options from which to choose.

We recommend starting with the **Simple Colours**, which is the easiest level. This activity will start by having you imagine standing in the "middle" of 4 colors. The app will call out a color and the objective is to step on that color with one foot, while the other stays in place. In between each color, you will want to return both feet to the center. The activity will have you stepping in 4 different directions: forward, backward, left and right. You can set the speed of how fast the colors will be called out. I'd recommend starting with 40-50 steps per minute (SPM).

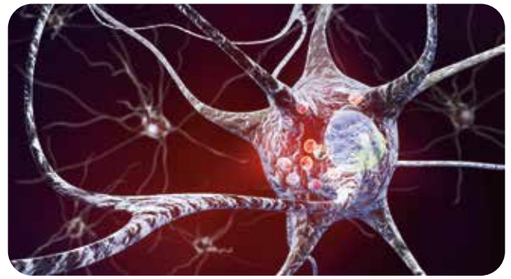
Once this level feels easy, you can choose to increase the physical challenge by increasing speed of steps by increasing the SPM or you can increase the cognitive load by moving onto the next level. The second level is the **Simple Clock**. In this level you will imagine yourself standing in the middle of a clock face. The 12 in front of you, the 6 behind you, the 3 to your right and the 9 to your left and so on for a full clock face. Again, start at a slow speed of 40-50 SPM until you feel confident stepping in all 12 directions. Then continue to increase your speed as you feel comfortable.

When you're ready for a bigger challenge, you can move onto their **Brain Games**. These challenges add another layer of thinking into the mix. For example, months of the year will call out a month like March. You need to figure out that March is the third month of the year and then step towards the 3 on the clock.

We love this app because it can be customized to many different levels of speed of movement, direction of movement and complexity of thinking. It also requires no special equipment or much space to successfully complete the workouts. When you're just starting out 2 minutes may feel exhausting, but as your body gets used to and better at dual tasking, you may be able to increase to 5 minutes/session. Plus, you get the added benefit of working on your balance recovery strategies, while will decrease your fall risk.

CURRENT RESEARCH

Please visit our website for more information on each of these studies



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Improvisational Movement Study -
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Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3 -
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Lower Back Pain Study -
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Walking and Music Study -
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GENETICS IN PARKINSON DISEASE

Robert Heuermann, MD/PhD and Scott Norris, MD

Key Points:

- **Approximately 10% of PD cases are linked to a genetic mutation**
- **Those with an associated genetic mutation don't always develop PD symptoms**
- **Genetic testing for PD has potential risks and benefits and should be discussed with your doctor**
- **Genetic research has potential to improve future diagnosis and treatment in PD**

The exact cause of Parkinson disease (PD) remains unknown. Increasing age remains the greatest risk factor for developing PD, more than known environmental or genetic risk factors. Most patients with PD do not have affected family members, so the role of genetics was not obvious until the mid-1990s when an abnormal gene (SNCA) was identified in a large Italian family with dozens of affected members. Since, researchers have identified numerous additional genes associated with PD, thus improving understanding of risks and potential treatments of PD.

Proteins are building blocks in the body, combining to form and allow vital organs (including the brain) to function. A **gene** represents the blueprint for a single protein. A gene **mutation** (or abnormality) may result in defects of the corresponding protein design, thus altering how this protein fits into normal function. The resulting dysfunction represents a genetic disorder. Genetic disorders cause PD with both **dominant** (a 50% risk of acquiring the abnormal gene from an affected parent) and **recessive** (a 25% risk or acquiring the abnormal gene from unaffected parents) inheritance. Abnormal genes are only recognized in about 10% of those with PD. In other words, a genetic disorder only accounts for about one in ten patients with PD. Furthermore, not all individuals with an abnormal gene will develop PD, a phenomenon called **incomplete penetrance**. This means that even patients with an abnormal gene will not always have a clear family history of PD. On one side, very rare genes may carry a high risk of developing PD (examples include SNCA, PARK7, and PRKN). On the other side, more common abnormal genes may only contribute a small risk of developing PD. The frequency of genetic disorders causing PD may be higher (up to 40%) in some populations, including those of Ashkenazi Jewish or North African Berber descent where known abnormal genes may occur in a higher percentage of people.

The most common genetic mutation in PD involves the LRRK2 gene. This mutation only accounts for about 2% of all PD cases. The symptoms of those with LRRK2 mutations appear similar to nongenetic or "idiopathic" forms PD. Other common genetic mutations involve Parkin, PINK1, and DJ-1 genes. These genetic disorders typically cause younger-onset (before age 50) PD with increased tendency for dyskinesia (involuntary wiggling or dance-like movements) as a side-effect of medications.

The decision of whether to pursue genetic testing is highly individualized and best discussed with your doctor. In general, identification of a gene in those with symptoms does not alter treatment options or approach. In those without symptoms, genetic testing is typically discouraged because they may never develop symptoms, even if an abnormal gene is identified. Common reasons to consider genetic testing include presence of PD symptoms when immediate family members (mom, dad or siblings) are affected, or if the onset of symptoms occurs before age 50. Because obtaining the results of genetic testing can be emotional and stressful for some patients and their families, genetic counselors are often helpful when a patient is considering genetic testing. This counselor is particularly important given that the presence of an abnormal gene may make it more difficult to obtain insurance or other benefits given the increased potential risk of developing PD later in life.

Genetic information may additionally be obtained as part of research studies. Depending on the study, these data may or may not be shared with research participants (but are not shared with others outside of the study, including insurance companies). Genetic research is geared toward learning more about genetic risk factors and potential causes of PD, with the ultimate goal of finding improved treatments. Genetic testing requires collection of genetic samples, typically from the saliva, skin, blood, or hair. Methods of collection depend on the research questions being asked and may differ across studies. In general, genetic studies are more helpful with higher numbers of participants given the genetic variability of individual people. Each time a new gene is linked to PD it deepens our understanding of the disease and moves us closer to better diagnosis and treatment.

3 MYTHS ABOUT CHRONIC ILLNESS AND RESILIENCE

Katie Willard Virant, MSW, JD, LCSW, is a psychotherapist practicing in St. Louis.
kwvtherapy.com

Reprinted with permission from Katie Willard Virant. Posted June 15, 2021 on PsychologyToday.com | Reviewed by Abigail Fagan

In fictionalized accounts of chronic illness, the protagonist inevitably manages hardship with strength, humor, and fabulous hair. She's inspiring to those around her, providing an idealized example of grace under pressure. Audiences point to her in admiration, exclaiming, "That's resilience!"

Well, yes. It's resilience on steroids or maybe just... you know... an attractive and completely unrealistic story. It's my experience that the day-to-day resilience exhibited by people living with chronic illness is a lot less flashy and a lot more gritty. This month's column seeks to demystify the concept of resilience, taking it down from the movie screen and bringing it into real life.

Resilience is a concept that describes our capacity to adapt well to adversity (Buckley, Punkanen & Ogden, 2018). We all need resilience, as life inevitably throws us curve balls. People living with chronic illness need a lot of resilience, as the challenges of dealing with incurable disease can be extreme.

Sometimes, people living with chronic illness express shame that they are not more resilient. They should be braver, more positive, less cranky. They shouldn't feel depressed, angry, or anxious about their situation. I'd like to look at three big myths associated with resilience in an effort to dispel them.

Myths of Resilience

Myth #1: Resilience is a character trait that one either has or lacks.

Not so. Resilience is not a fixed personal attribute (Kralik, van Loon, & Visentin, 2006). Rather, it ebbs and flows in various circumstances and over time. To be resilient—to adapt to adversity—can feel doable in some situations and out-of-reach in others. That's normal. To feel broken, at the end of the line, unable to cope does not mean that you are lacking resilience. Rather, it means that your resilience has become depleted at this particular time.

With chronic illness, we can learn to predict the situations that will deplete resilience. It's worth thinking through what those circumstances are for you. For many of us, extreme pain is an experience that dramatically depletes resilience. Knowing this, it's important to have a plan in place to treat it when it arises. If you're identifying depleting situations and planning for how you will manage them, then you are exhibiting resilience.

Myth #2: Resilience is the responsibility of each individual.

If you're not resilient, there's something the matter with you. Wrong. Resilience is a process that is supported within a social context (Kralik, van Loon, & Visentin, 2006). If you live with chronic illness and feel exhausted, depressed, and fragile, you may experience self-judgment. If only you were tougher, braver, more positive... to which I reply: How can we help you? How can your family help you? How can your workplace help you? How can your friends help you? How can social policy help you? And how can I as your therapist help you?

People develop resilience in the context of social connectedness—first in attachment relationships with caregivers and then in relationships with the wider world. Resilience is compromised when our needs are not being met. If you're feeling vulnerable, please recognize that you can strengthen resilience by reaching out for help.

Myth #3: Resilient people are in a good emotional state.

Not necessarily (Kralik, van Loon, & Visentin, 2006). Resilience is extraordinarily helpful: It helps us survive what feels unbearable. But to be resilient does not mean that we don't have feelings about what we're going through. We can be resilient and fragile at the same time. Sometimes people living with chronic illness can feel unseen due to their resilience. Family, friends, colleagues, and even physicians in charge of their care fail to see the vulnerable feelings that sit alongside the resilience. As one of my clients stated, "I don't want pity from people, but I do want them to recognize how hard this is."

If you're living with chronic illness, find ways to identify, cultivate and protect your resilience. Understand that it will ebb and flow. Understand that you require connections with others to keep resilience alive. And understand that resilience co-exists with vulnerability.

Reflecting on Your Own Resilience

As you think about your own experiences, reflect upon the following questions:

- In what ways do I demonstrate resilience? (Think of all the "small" things you do to care for yourself daily. Do you take your medication? Participate in an activity you enjoy? Speak kindly to yourself? These are examples of resilience.)
- When does my resilience feel depleted, and how can I manage that? (Do you feel less resilient when you overwork, for example? If so, are there ways to cut back to ensure that you are not so fatigued?)
- Who are my connections who can accept all of my feelings about my illness? If I'm feeling vulnerable, who can help me with this? (If you're coming up short, please think about calling a therapist. We are connection-builders and can help you cultivate a network.)

References

Buckley, T., Punkanen, M., & Ogden, P. (2018). The role of the body in fostering resilience: a Sensorimotor Psychotherapy perspective. Body, Movement and Dance in Psychotherapy, 13(4).

Kralik, D., van Loon, A., & Visentin, K. (2006). Resilience in the chronic illness experience. Educational Action Research, 14(2), 187-201.

EXERCISE CLASS SCHEDULE

IN-PERSON EXERCISE CLASS SCHEDULE

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

MISSOURI CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS/MEETING SITE
Cape Girardeau	Mon/Wed/Fri	9:00am		Level 1	Boxing
Chesterfield	Tuesday	10:00am	Jen Berger	Level 2	Circuit Training
	Tuesday	11:00am	Jen Berger	Level 2	Strength and Cardio
	Wednesday	10:00am	Michelle Valenti	Level 2	Intro to Exercise
	Wednesday	11:00am	Michelle Valenti	Level 1	Seated Exercise
	Wednesday	1:00pm	Marina Clements	Level 1 & 2	Movement Training
	Thursday	11:00am	Craig Miller	Level 1 & 2	Tai Chi
	Thursday	1:00pm	Michelle Valenti	Level 2	Strength and Cardio
	Friday	10:00am	Craig Miller	Level 1 & 2	Tai Chi and Meditation
	Friday	11:15am	Craig Miller	Level 1 & 2	Tai Chi
	Mon/Wed	12:30pm	Mchelle Valenti	All Levels	Parkinsons Pedalers
Kirkwood	Friday	10:30am	Frank Tucci	Level 1 & 2	Parkinson's Exercise
Maryland Heights	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's
Ste. Genevieve	Thursday	11:00	Becky Baumann	Level 1	Parkinson's Exercise
St. Louis City	Tuesday	12:00pm	Annie Morrow	Level 1	Interval Training
	Friday	2:00pm	Mike	Level 1 & 2	Fit and Fun
Sunset Hills	Friday	1:00pm	Marina Clements	Level 2	Movement Training
Washington	Mon/Wed	1:00pm		Level 1	Parkinson's Exercise

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LOCATION	DAY	TIME	LEADER	LEVEL	CLASS
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		All	Fit to Fite PD Boxing
	Friday	10:30am		All	Stretching
Springfield	Tues/Thurs	1:30pm	Eva Fischberg	All	The Joy of Movement

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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	1st Monday	5:30pm	Jayanti Ray	VIRTUAL
Carthage	3rd Monday	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
Ozark	4th Monday	10:00am		Sharlin Health & Neuro
Rolla	3rd Tuesday	2:30pm	Julie Riggs	Phelps Health Delbert Day Cancer Inst
South County	4th Wednesday	10:30am	Kimberly Sanders	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. 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 Monday	1:30pm	Jodi Gardner	SW Illinois College's Programs and Services for Older Persons
Carbondale	1st Wednesday	1:00pm	Gayla Lockwood	VIRTUAL
Champaign	Monday	10:00am	Carol Clark	Savoy United Methodist Church
Decatur	3rd Thursday	1:30pm	John Kileen	Westminister Presbyterian Church
Edwardsville	1st Tuesday	2:00pm	Pam Pinegar/Sarah Hoelscher	Edwardsville YMCA
Greenville	2nd Tuesday	1:00pm	Robbie Mueth	Bond County Senior Citizens
Highland	4th Tuesday	2:00pm	Kayla Deerhake	Sullivan Conference Room at St. Joseph Hospital
Jacksonville	1st Wednesday	1:00pm	Jim & Fran Ringle	VIRTUAL
Quincy	2nd Saturday	10:00am	Terri & Dave May	Quincy Public Library

apda AMERICAN PARKINSON DISEASE ASSOCIATION
GREATER ST. LOUIS CHAPTER

Strength in optimism. Hope in progress.

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Thank You!

A big shout out to A-Mrazek Moving Systems and Adonis IT Asset Recovery and Recycling for all your help with the move to our new offices.

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Swinging Into Action for the

APDA 24th Annual APDA Golf Classic

The APDA Golf Classic will be held on **Tuesday, June 21, 2022** at **Norwood Hills Country Club** to support Parkinson's disease research, local programs, and services for our Parkinson's community.

Tickets are $1,200 per foursome ($300/player) and sponsorship opportunities are available. Please contact Melissa Skrivan at **636-778-3378** or **mskrivan@apdaparkinson.org** for more information.

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
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