



AMERICAN PARKINSON DISEASE ASSOCIATION

ILLINOIS CHAPTER

September/
October 2023
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WORRY AND CHRONIC ILLNESS

By Katie Willard Virant, MSW, JD, LCSW, as printed in Psychology Today, July 14, 2023

Those of us living with chronic illness tend to experience a great deal of worry over our health. It makes sense: Our bodies have been the site of pain, and we dread re-experiencing the suffering we have already known. As understandable as this is, however, worry harms us. The physiological effects of worry send stress hormones coursing through the body and put the nervous system in a continuously activated state. It's also emotionally painful to be consumed with worry: We're not able to feel safe and connected when we are dwelling on adverse events that haven't yet happened.

Given that worry is such an unpleasant experience, why do so many of us continue to engage in it? Some theories opine that we worry because we want to be prepared for the worst-case scenario, running through all options in our minds. Perhaps this works up to a point—but our worried minds don't stop once we've sorted through the various possible scenarios. Rather, we continue to ruminate, unable to pull ourselves out of imagining the worst.

Other theories note that worry is an attempt to manage uncertainty. Again, though, it doesn't really work. Uncertainty is a part of life, and worrying about what may occur doesn't eliminate the reality that we cannot know the future.

One theory of worry—the contrast avoidance model—posits that we worry in an attempt to avoid the feeling of contrast that occurs when a positive state of being is changed by a negative occurrence. That is, people use worry as a coping strategy “because they prefer to feel chronically



WORRY AND CHRONIC ILLNESS (continued)

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distressed in order to prepare for the worst outcome, rather than to experience a shift from a positive or euthymic state to a negative emotion” (Newman & Llera, 2011). Researchers have found that worry actually does work to cushion the blow of an adverse outcome. However, the cost—staying in distress in order to avoid the awful feeling of downshifting into distress—is high.

If you recognize yourself as someone who worries because you're afraid of feeling the dreadful surprise of receiving bad news, the following prompts may help you to think and feel more deeply about this coping strategy.

- Think of a time when you experienced an adverse event “out of the blue.” What was it like for you to move from a state in which everything was fine to a state in which things were very wrong? Did you feel shocked? Vulnerable? Duped? Stupid? If you can, write about this or talk it through with someone. Something about being surprised by an adverse experience was extraordinarily painful to you—so painful that you are willing to live in distress so as to avoid re-experiencing that feeling of surprise. Try to identify what it is that you're afraid of experiencing again.
- Treat yourself gently. Many people who worry are ashamed of their reliance on this coping strategy. They know they are torturing themselves, but they can't imagine giving up worry. Often, their loved ones roll their eyes at them, saying with exasperation, “Just stop worrying so much!” Acknowledge that your worry does serve a purpose. You are trying to keep yourself safe from being surprised by something terrible happening. Acknowledge, too, the high price you pay in an effort to stay safe.

- Both sides of this equation feel difficult: Living in constant distress is unpleasant, but being vulnerable to the surprise of an adverse experience feels untenable.
- Recognize that managing worry is a process. Recognize, too, that this process is best accomplished in relationships with others. We cling to worry when we feel unsupported. Find support. Every one of us is vulnerable to loss and pain. Developing relationships in which we feel seen and loved in the face of loss is crucial. If this feels challenging, therapy can help.
- Develop a mindfulness practice. Worry catapults us to an unknown future, removing us from the present moment. Find ways to connect to the present moment every day—through movement, through attention to your senses, through breath work.
- Find mantras that resonate with you, helping to calm you when you worry. Examples include: “I can't know the future”; “I will have support and love if something awful happens—I will not be alone”; “I am making up stories in my mind right now”; “All will be well.”
- Believe that you can change. People who have relied on worry all their lives tend to see it as an immutable trait. It's not. It's a coping strategy that you've relied on too heavily, to your detriment. With support—your therapist, your family, your friends—you can develop other coping strategies that don't have to hurt so much.

References

- Newman, M.G. & Llera, S.J. (2011). A novel theory of experiential avoidance in generalized anxiety disorder: A review and synthesis of research supporting a contrast avoidance model of worry. *Clinical Psychology Review, 31*(3): 371-382.
- Katie Willard Virant, MSW, JD, LCSW is a psychotherapist practicing in St. Louis. She is a graduate of the Brown School of Social Work at Washington University in St. Louis and of the St. Louis Psychoanalytic Institute's Advanced Psychodynamic Psychotherapy program. She works with adults, adolescents and children on a variety of issues, including loss and grief, life transitions, and living with chronic illness.

NEW AND IMPROVED APDA SYMPTOM TRACKER APP

Helps Track Your Unique Symptoms



APDA SYMPTOM TRACKER

Each person's Parkinson's disease symptoms are different. The more information you and your care team can learn, the more personalized your care can be.

The APDA Symptom Tracker App is an online self evaluation tool of motor and non-motor symptoms, including: **tremors, rigidity, swallowing, anxiety and balance**. It allows you to easily track and identify changes in these symptoms over time. You can print or email results to your healthcare team to make appointments more focused and productive.

The latest update to the APDA Symptom Tracker App includes an interactive medication tracker. Also added are helpful notifications and reminders, push notifications about helpful education programs, and updates on treatments. Now also available in Spanish!



Download the free mobile app today on Google Play or at the Apple App store.



VIRTUAL PROGRAMS & YOUTUBE VIDEOS Allow You to Get the Information and Exercise You Need at Home

APDA offers a large selection of virtual programs. You can watch them from the convenience of your home. Programs include exercise classes from chapters around the country and education programs from the APDA home office as well as from different chapters. Check out these great programs by visiting www.apdaparkinson.org/upcoming-events/. Be sure to pay attention to the time zone!

Also, our sister chapter in Missouri, offers a wide variety of exercise videos on their YouTube Channel, two Zoom exercise classes a week, and three series of quick exercise videos. Visit their website at www.apdaparkinson.org/mo and click on the Exercise Classes button. You can see all their offerings in the Exercise at Home section. You can even exercise your voice and your mind with the Missouri Chapter's videos on their website.



LIVE WELL, YOUR WAY

My Circle helps you age gracefully, wherever, YOU choose to live



Tim Vosse, CPA, MBA, is the founder and CEO of My Circle. Tim has over two decades of experience in creating retirement communities.

Plan Ahead to Stay in Your Home

St. Louisan, Maya Angelou wrote: "The ache for home lives in all of us, the safe place where we can go as we are and not be questioned."

It is always better to be prepared than to be surprised. This is especially true when you think about your own future. Unexpected events like a fall, medical diagnosis, or a change in your support system can impact how you live your life. However, stresses and uncertainties about the future can be put to rest by planning ahead.

By proactively planning for a smooth and safe transition into the later stages of life, you can gain control over your financial, estate, health, and life

decisions. This gives you the support and resources needed to make informed decisions and ensure your voice is heard and your wishes are met.

Below are steps you can take to ensure a comfortable, successful, and safe quality of life as you plan for the future in the home where you want to be:



Housing

Proactively planning for housing changes will decrease potential stress and enhance your overall safety, comfort, and quality of life. If your goal is to stay in your home, consider your needs for physical safety, social-emotional connectedness, and the type of living environment.

Housing updates are small, practical changes compared to downsizing or moving into independent living or retirement communities. Evaluate your living situation and anticipate home updates to accommodate your needs such as: installing ramps,

widening doorways, adding bathroom grab bars, and improving lighting.

Staying up to date on home technology also creates a positive living-at-home experience, allowing you to stay in contact with loved ones and healthcare professionals. Security systems and assistive smart home technology, like Google Home and Amazon Alexa, are helpful options to assist in your safety while living at home.



Health Care

Plan for healthcare expenses by reviewing your healthcare insurance, including Medicare or Medicaid, and consider supplemental insurance plans. If you have long-term care insurance, knowing the benefits, limits and when it can be utilized is crucial. Trusted professionals can assist in this health care planning that will match your wishes and needs.



Financial Planning

Assess your financial situation and meet with a financial advisor to understand your retirement income needs. Consider your health and ideal lifestyle to determine a plan for your savings, insurance, and investments.



Estate Planning

Meet with an attorney to create or update your living will, power of attorney, and other necessary legal documents. Identify your healthcare and financial preferences and confirm you have identified your beneficiaries. Determine how you wish to allocate your assets, and you may also want to discuss end-of-life wishes.

By creating legal documents and consulting professionals, you prevent potential disputes among family members regarding your assets, medical treatment, and end-of-life care.



Social Engagement

Plan for a satisfying social life during your senior years. Explore joining groups based on your interests and hobbies. Volunteering and learning programs are other ways to stay social and involved in your community. Staying socially connected is essential, as socialization is linked with your overall cognitive wellness.



Transportation

Explore what your transportation needs are and if modifications need to be made to support your mobility. Options like paratransit services or medical transportation may be necessary to meet your needs.



Assuring Your Control

The most important part of the planning process is letting your wishes be known. By using the steps above, you can identify what your goals are. Professionals, programs, and resources are available to help you navigate these decisions based on your circumstances.

When you communicate your goals, your family and friends can respect, accept, and help you meet them. You can remain in control of your future care needs by planning proactively, helping you reach your ideal healthy, secure, and enjoyable senior life.





APDA VIRTUAL PARKINSON'S ROADMAP for Education and Support Services™ (PRESS™)

Free program, space is limited, and registration is required.

Program Presented Virtually via Zoom

Every Thursday, September 7th – October 26th 2023
10:00am – 11:30am CT

- What's Next After Diagnosis
- Medication Management of Parkinson's
- Importance of Exercise in PD
- Dealing with Physical Symptoms of PD
- Impact of Parkinson's on Daily Coping and Relationships
- Tips for Daily Living
- Caring for Others, Caring for Yourself
- Building Your Healthcare Team

The group is open to any adult who has been diagnosed with Parkinson's disease within the last 5 years, their care partners, and adult family members.

To register or for additional information please contact
Nicole.reidy@uchicagomedicine.org at: 1-773-834-1688
www.apdaparkinson.org

ILLINOIS SUPPORT GROUPS

For more information, please call 773-834-1688 or email nicole.reidy@uchicagomedicine.org

Joining a support group is a great way to connect with others who understand what you are going through, learn about Parkinson disease and ways to cope with the challenges that come with having PD.

Our support groups are for:

People new to PD • People who have had PD a long time • People who are caregivers or relatives of those with PD

Groups are open to anyone who wishes to attend. A group may invite guest speakers, plan an event or just discuss topics of interest to the participants. All support groups are led by a trained facilitator. If you can't find a group in your area, please let us know. All support groups are free of charge.

Alton - Senior Services Plus, Main Building

2nd Wednesday 1:00pm

2nd Tuesday 2:00pm - Care Partners ONLY

Belleville - SW Illinois College's Programs and Services for Older Persons

3rd Monday 1:30pm

3rd Tuesday 11:00am - Care Partners ONLY

Carbondale - Prairie Living at Chautauqua

1st Wednesday 1:00pm

Carlinville - Carlinville Area Hospital

4th Tuesday 11:00am

Champaign - Savoy United Methodist Church

Every Monday 10:00am

Decatur - Westminster Church

3rd Thursday 1:30pm

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 Tuesday 2:00pm

Quincy - Quincy Library

2nd Saturday 10:00am

Virtual via Zoom

1st and 3rd Mondays 12:00pm

4th Tuesday 11:00am (except June, July, August)

1st Wednesday 1:00pm

NEW Virtual Caregiver Support Group and Book Club - Zoom

Thursdays November 2nd – December 21st, (November 22 instead of 23) **10:00am – 11:30am CT**

Deadline for Registration: October 20th or until registration spaces are full

This caregiver support group is an eight-week group in which we will be reading a book specifically designated for adult caregivers who are caring for a loved one with Parkinson Disease or Parkinsonism. Each week we will read and process a chapter specific to ambiguous loss. Ambiguous loss is defined as a loss without certainty, without clarity, and we do not get all of our questions answered. Education will also be provided on ways to cope with multiple losses, adjusting to these losses, and working on strengthening resilience. This program is free, space is limited, and registration is required.

**Please contact Nicole Reidy for more information or to register at
773-834-1688 or nicole.reidy@uchicagomedicine.org**

WAYS TO GIVE TO APDA

Your donations help support research to find a cure for Parkinson's disease as well as local programs to help people live their best life while living with PD.

1. Donate Online
2. Call Us
3. Send Us a Check

Other Ways to Donate:

Join our Monthly Giving Team:

Our Monthly Giving Team is a special group of donors who make a difference through recurring donations. Monthly gifts from team members help pay for education, support and research that enrich lives. A small monthly amount can have a huge impact!

Honor a loved one with a Tribute Gift:

In lieu of a birthday or holiday gift, make a donation to APDA in honor of a beloved friend or family member. Or throw a party to honor someone impacted by PD, and ask guests to make a charitable gift.

Matching Gifts:

Many employers offer programs to match charitable contributions made by their employees. If your employer has such a program, the impact of your gift to APDA may be doubled! Check with your HR Department to see if your company has a matching gift policy.

DIY Fundraising:

Throw a party to honor a loved one impacted by Parkinson's. Plan a bake sale, chili cook-off or yard sale to benefit APDA. Or ask friends to support you in an adventure such running or biking for the fight against Parkinson's disease. Create your campaign online with APDA's support: www.apdaparkinson.org/get-involved/diy-fundraising/

Stock Gifts:

Did you know APDA accepts gifts of publicly traded securities? You can gift stock to APDA, rather than selling it

and donating the proceeds. By doing this, you may receive the federal AND state charitable deduction and avoid paying capital gains tax. Both you and APDA benefit!

IRA Designation:

Make a difference today and save on taxes. It's possible when you support APDA through your IRA. If you are 70½ years old or older, you can give any amount (up to a maximum of \$100,000) per year from your IRA directly to a qualified charity such as APDA without having to pay income taxes on the money. Gifts of any value \$100,000 or less are eligible for this benefit and you can feel good knowing that you are making a difference at APDA. This popular gift option is commonly called the IRA charitable rollover, but you may also see it referred to as a qualified charitable distribution, or QCD for short.

Estate Planning:

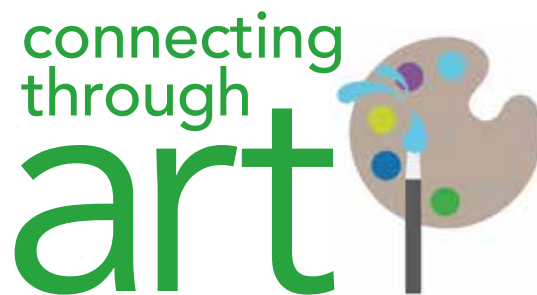
You can name your APDA Chapter as a beneficiary in your will.

Beneficiary Designation:

You may transfer assets to APDA by naming your APDA Chapter as a beneficiary. You can name us as a beneficiary in your life insurance policy, retirement, or pension plan.



VIRTUAL CREATIVE OPPORTUNITY



**Thursday, September 21, 2023
3:00pm – 4:00pm ET**

The program will take place virtually via Zoom.

Connecting Through Art is a creative arts program that offers people with Parkinson's disease the space and ability to express feelings, emotions, and daily concerns through art. It is open to any adult who has been diagnosed with Parkinson's disease and their care partners.

Katrina Casey, Art Therapist, will guide participants through a short mindfulness exercise, a modeling clay activity, and a watercolor session.

The program is free, and art supplies will be provided at no cost to participants.

Registration is required.

To register or for additional information please email Anushka Shiell at
ashiell@apdaparkinson.org



MOVEMENT AND CUEING STRATEGIES TO THAW FREEZING EVENTS IN PARKINSON'S DISEASE

By **Beth Crowner**, Neurological Clinical Specialist at Washington University Physical Therapy

Some individuals with Parkinson's disease (PD) experience freezing of gait (FOG), which results in an inability to take a step or getting "stuck" while walking. This can be frustrating because it slows down walking, resulting in inefficiency. It can also lead to imbalance and falls. It is important to know common triggers for FOG as well as strategies to reduce freezes.

Freezing commonly occurs when a person first stands up and can't initiate the first step (start hesitation). FOG also commonly occurs with turning, walking through doorways, changes in flooring surface, or small spaces (crowds, walk-in closets, etc.). Knowing which "triggers" cause a person to freeze is important because strategies can be used before or during these events. Every person with PD that experiences freezing has different freezing severity and triggers. Additionally, each person responds distinctly to different movement strategies to reduce FOG. There are general principles that apply to everyone and person-specific movement strategies that will reduce FOG.

Three general principles that apply to everyone with FOG are **reducing stress during a freezing event, avoiding quick turning, and reducing triggers as much as possible.**

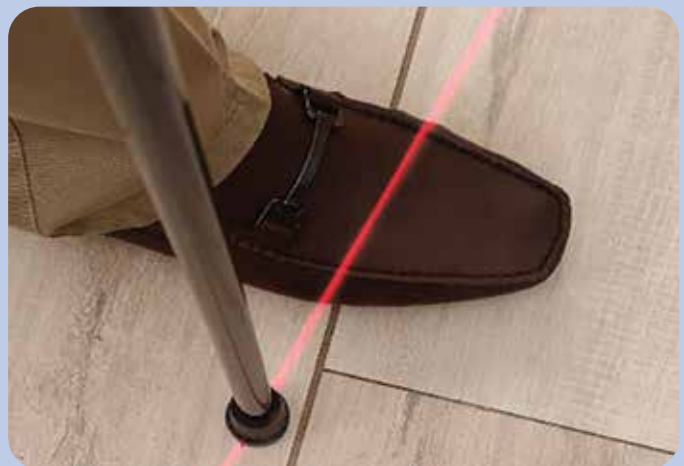
Physical and emotional stress commonly increase all symptoms in PD. People often get upset or anxious when experiencing a freeze. It is important to avoid being stressed, getting upset, or trying to "push through" a FOG event. Doing so will often prolong a freeze or cause greater instability. People should try, as best as possible, to relax and avoid stress during a FOG event.

Turning quickly will often trigger a freeze and often lead to imbalance or falls. When there is space available, a person should make a slow, wide-arc turn. Use of a "clock strategy" is also helpful for turning. This involves a person pretending to be in the middle of an imaginary clock and stepping to different, invisible points on the clock. For example, to complete a 180° clock-wise turn, a person could step with their left leg to 12:00, then 2:00, then 4:00 and then 6:00.

To **reduce triggers**, try to avoid having clutter in the home that causes a person to walk or turn in a narrow space. When walking through a doorway, look at an object in the distance in the next room, and avoid looking at the doorframe. While these general strategies work well for most people with FOG, there are effective movement or cueing strategies that can also be beneficial. However, the effectiveness of the type of cue used varies from person to person.

Types of cueing strategies include visual, auditory, attentional. Visual cues may involve stepping over someone's foot placed in front of the leg that is frozen or stepping on or over lines on the ground. Lines on the ground can be created by putting tape on the floor as a target in areas where freezing occurs. If freezing occurs in a room with tile or linoleum, the lines in the flooring can be used. Visual targets can also be created by a laser-emitted light that creates a line on the ground. The laser can be part of a cane or walker or a device attached to the shoelaces. Auditory cues use a real or imagined beat or rhythm that a person listens to. The beat can be created by using a metronome, listening to music, singing, or counting. Listening to or imagining a steady beat can help with freezing and also reduce the variability in walking pattern in someone with PD. Finally, attentional cues refer to creating BIG movements or taking BIG steps. Attentional cues involve thinking about taking long steps or strides or lifting knees up high while walking. Cueing can be performed prior to a situation that would likely trigger a freeze with a goal of preventing the FOG event. However, if freezing does still occur, the cues are often effective in shortening the duration of a freeze and, hopefully, reducing the frequency that they occur.

Because people respond very differently to each cueing strategy, people with PD are strongly encouraged to work with a physical therapist who has experience working with people with movement disorders to tailor the appropriate strategy to their needs and de-frost their troublesome freezes.



Strength in optimism. Hope in progress.

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**OPTIMISM
WALK** AMERICAN
PARKINSON DISEASE
ASSOCIATION

Thanks to everyone who showed up for a great time at the Naperville Riverwalk Grand Pavilion on June 24. You helped raise over \$30,000 to fund programs and services for people with Parkinson's.

APDA Illinois Chapter

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