



AMERICAN PARKINSON DISEASE ASSOCIATION

MISSOURI CHAPTER NEWSLETTER

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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 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.

CURRENT RESEARCH

Please visit our website for more information



Protein and Imaging Biomarkers (PIB) Study

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

Protein Aggregation and Neurotransmitter Deficits (PAND) Study

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

Precision-Mapping Study

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

Movement, Speech, and Thinking Study

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

Lower Back Pain Study

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

Improving Diversity in Parkinson's Research and Care Study

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

Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

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

Memory Intervention for PD Study

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



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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 health care 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 health care expenses by reviewing your health care 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 health care 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.



EXERCISE CLASS SCHEDULE

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

MISSOURI CLASS SCHEDULE

Chesterfield ADPA 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 | Levels 1 & 2
Thursday 12:00pm - Parkinson's Boxing | Level 3
Thursday 1:00pm - Strength and Cardio | Level 2
Friday 11:00am - Tai Chi and Meditation | Level 1

Chesterfield YMCA

Mon/Wed 12:30pm - Parkinson's Pedalers | Level 2

Jefferson County YMCA

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

Kirkwood YMCA

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

Maryland Heights YMCA

Tuesday 1:30pm - Exercise for Parkinson's | Level 2

St. Louis County YMCA

Tues/Thurs 3:30pm - Exercise for Parkinson's | Levels 1 & 2

St. Louis City - Stephen A. Orthwein Center

Thursday 12:00pm - Interval Training | Level 2

St. Peters - BJC

Thursday 11:00am - Strength and Cardio | Levels 1 & 2

Ste. Genevieve County - Community Center

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

Sunset Hills - Friendship Village

Thursday 1:00pm - Movement Training | Level 2

Washington YMCA

Mon/Wed/Fri 1:00pm - Exercise for Parkinson's | Levels 1 & 2

Virtual via Zoom

Tuesday 9:00am - Seated Exercise | Level 1
Thursday 2:00pm - Seated Exercise | Level 1

ILLINOIS CLASS SCHEDULE

Breese/Clinton County YMCA

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

Champaign YMCA

Monday 1:00pm - Strength and Balance
Tuesday 1:00pm - Functional Chair Fitness
Wednesday 1:00pm - Seated Yoga
Thursday 1:00pm - Parkinson's Fitness
Friday 1:00pm - Functional Chair Fitness

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 - Strength and Cardio

Springfield - First Presbyterian Church

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

Virtual via Zoom

Wednesday 10:30am - The Joy of Movement

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

Chesterfield - ADPA Office

2nd Monday 10:30am - Caregivers ONLY

2nd 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

NEW! Kirkwood - First Presbyterian Church

2nd Monday 2:00pm

Olivette - Private Home Care - 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

Ste. Genevieve - Community Center

2nd Wednesday 10:00am

St. Peters - Spencer Road Library

1st Tuesday 1:00pm

Washington - Public Library

2nd Monday 3:00pm

VIRTUAL

4th Tuesday 6:30pm - All Welcome

3rd Monday 1:00pm - Caregivers ONLY

Every Thursday 6:00pm - Young onset ONLY

ILLINOIS SUPPORT GROUPS

Alton - SSP Main Bldg., The Meeting Rm.

2nd Wednesday 1:00pm

Alton - SSP Wellness Center

2nd Tuesday 2:00pm - Caregivers ONLY

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

3rd Monday 1:30pm

Belleville - Health and Sport Center

3rd Tuesday 11:00am - Caregivers ONLY

Carbondale - Prairie Living at Chautauqua

1st Wednesday 1:00pm

Carlinville - Carlinville Area Hospital, MOB Comm Rm.

4th Tuesday 11:00am

Champaign - Savoy United Methodist Church

Every Monday 10:00am

Decatur - Westminister Presbyterian 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 Public Library

2nd Saturday 10:00am

Virtual via Zoom - Jacksonville

1st Wednesday 1:00pm

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.



COGNITIVE STIMULATION THERAPY



Are you a person living with Parkinson's who is having trouble with memory and thinking?

If so, you may qualify for a free cognitive stimulation therapy program.

CST is a brief, evidence-based treatment for people with mild to moderate dementia. The group is limited to 8 people and runs twice a week for 7 weeks.

**Tuesdays and Thursdays, Oct 3rd - Nov 16th
from 3:00-4:00pm**

APDA office: 16100 Chesterfield Parkway West, Suite 125.

Participants must be pre-screened to participate.

FOR MORE INFORMATION

Contact Amanda or Kim at 636-778-3377 or email: apdamo@apdaparkinson.org

Were you recently diagnosed with Parkinson's disease?

Check out these resources:

PD Essentials — free 1-hour sessions for you and your care partner to get your questions answered, address your concerns, and connect you to resources. Call or sign up on website.

Newly Diagnosed Packet — receive a packet of information, available by email or mail, about diagnosis, symptom management, treatments, medications, and more. Call or sign up on website.

www.apdaparkinson.org/mo

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**AMERICAN
PARKINSON DISEASE
ASSOCIATION**

Logan University Athletic Field
1851 Schoettler Road | Chesterfield, MO 63017

October 7, 2023
Checkin begins: 9:00 am Walk begins: 10:00 am

Register at
www.apdaparkinson.org/mo



Scan Me

*New this year: We've added a sister walk at
Edwardsville Township Park on the same day!*



APDA Missouri Chapter

16100 Chesterfield Parkway W, Ste. 125 | Chesterfield, MO 63017
Office Hours: 9:00 a.m. - 4:00 p.m. Tuesday-Friday | Staff available by phone on Mondays
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