

## THERE'S NO PLACE LIKE HOME



Jacque Phillips, RN BSN, is the President and Founder of AccuCare Home Health Care, a private duty in-home health care company. Since 1994, Jacque has been committed to providing the highest quality of care delivered with compassion, integrity and

dedication. In your home. On your terms.

The diagnosis of Parkinson's Disease can be daunting and scary at first. There are questions, "What is going to happen next?", "Will I be able to stay in my home?", or "How will this affect my family?"

The key to quality of life is maintaining independence and dignity as long as possible. As a result, having a clear understanding of available resources and options is highly important.

There is no place like home, which is where most people wish to stay forever. It's familiar, there is a routine, and they know how to navigate their surroundings comfortably. The thought of having to move to a new place can stir up feelings of fear and anxiety.

#### "How will I know when I need help?"

Most often, they need a little help to remain independent. This development is sometimes more gradual and will likely progress into a need for full time assistance. Often, family and or friends pitching in to help in the beginning is all that is needed.

However, the number one indicator of needing extra help in the home is lack of safety. Safely moving throughout the home without constant fear of falling is a warning. The ability to exit the home safely, without assistance, in case of emergency is also an indication that more help may be needed.

#### "How do I get help?"

Usually, a family or friend will reach out to a home care company. Often, their physician or nurse will recognize more assistance is appropriate. They may have recommendations of a private duty company.

It is always a good idea to ask friends, neighbors, medical professionals, or someone who has used home care services, either in the past or currently. Word of mouth is an excellent referral resource. After you get recommendations, it is time to navigate the web site and see what services the company provides. See if the website looks professional, has RN oversight, and a long history in the health care industry.

Next, it is best to call the top three home care companies on your list and ask questions about your needs. Most reputable home care companies will offer to come out and do a free in-home assessment. This will also cover the very important home safety assessment. As the process progresses, they will help you define the care needs as well as develop questions when comparing home care companies.

## THERE'S NO PLACE LIKE HOME - (continued)

#### "What services can I expect?"

The level of services you can expect can vary quite a bit. Many of the private duty home care services are non-medical. This generally means they have no medically trained staff like Nurse Practitioners, RNs, LPNs and even CNAs.



While companion care is okay, it is nice to have medical oversight in the home as needs change. A medically experienced team may notice a change in your medical condition early on. This helps decrease complications and allows for appropriate medical care right away.

They can get from companion care up to a Registered Nurse from 1 to 24 hours a day (many services require a 4-hour minimum). The client and/or family can decide how many hours and how many days a week. Sometimes the family member just needs respite care one or two days a week.

The nurse who performs the assessment can talk this through to determine the appropriate hours, times, and tasks to maintain an independent lifestyle, while supporting friends and family, and partnering with medical professionals in providing a 360-approach in home care.

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## **CURRENT RESEARCH**

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



Maximizing Home Independence, Safety and Access to Healthcare for Older Adults in Missouri Study

Contact Tracey Summerfield <u>SummerfieldT@health.missouri.edu</u> or 573-882-1991

#### Walking and Music Study

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

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#### **Cognitive Stimulation Therapy Group**

Contact Zainab Ali <u>zainab.ali@wustl.edu</u> or YeaJi Kim <u>k.yeaji@wustl.edu</u>

> Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

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

#### Lower Back Pain Study

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

#### Sleep Study

Contact Mengesha Teshome <u>teshomem@wustl.edu</u> or 314-747-8420

# THE LINK BETWEEN CHRONIC ILLNESS AND LONELINESS

## Staying connected for better health.

Used with permission by Katie Willard Virant MSW, JD, LCSW Posted February 15, 2022, on Psychology Today | Reviewed by Ekua Hagan



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.

Loneliness hurts. We humans are wired to survive and thrive in community. When we feel disconnected from others, we ache. This ache is our psyche's warning that all is not well, and we need to find our way back into connection.

Loneliness has been much discussed during this time of the global pandemic. Interruptions to work, school, and social life meant that people couldn't maintain their usual forms of connectedness to others and to the world at large. For many people with chronic illnesses, these interruptions were not new. Paradoxically, many of us felt less lonely during the pandemic, as our experience of disconnection was being named and validated. We weren't the minority during the pandemic—we were in the mainstream.

As the dangers of COVID-19 recede and people resume their regular connections, those of us living with chronic illness know that disease will continue to interrupt our relationships, leaving us vulnerable to loneliness. This post seeks to explore the loneliness associated with chronic illness and offer strategies for mitigation.

#### What Is Loneliness?

Researchers define loneliness as an "unpleasant

experience that occurs when a person's network of social relationships is deficient either qualitatively or quantitatively (Bekhet & Zauszniewski, 2008)." A qualitative deficiency in social relationships occurs when intimacy is lacking. That is, while one may have interactions with people, the interactions do not provide a sense of closeness. A quantitative deficiency refers to a lack of any social interactions, superficial or intimate. So loneliness has both an objective component (the number of social interactions one has) and a subjective component (the quality of depth in social interactions).

Loneliness predicts increased depression (Kool & Geenen, 2011). Loneliness also perpetuates itself, as the brain of a lonely person changes to view the world as more threatening. Thus, lonely people expect and remember more negative social interactions (Kool & Geenen, 2011).

#### **How Chronic Illness Leads to Loneliness**

Chronic illness interrupts connection by removing opportunities for interaction (Rokach, Lechier-Kimel, & Safarov, 2006). Symptoms and treatment often require withdrawal from the world at large. Pain and fatigue cause chronically ill people to miss out on school, work, and social life—all areas where connection is made and built upon (Macdonald et al., 2018).

Even when people with chronic illness are feeling relatively well, opportunities are foreclosed. The way that our societal structures and education work is not compatible with the unpredictability and uncertainty of chronic disease. Many people with chronic illness who do manage to work or go to school find that social life is non-existent due to the demands placed upon their bodies. "I can go to school and have this illness," one young person told me. "I can't go to school, have this illness, and have enough energy left over to do anything else."

Other aspects of chronic illness also interrupt connection. The fear of other people observing one's symptoms can lead to self-isolation (Carter,

Qualter, & Dix, 2015). "What if I am in public and I have to go to the bathroom?" "What if I have a seizure in front of people?" "What if I lose mobility when I'm with my friends?" "What if I'm with people and I start struggling to breathe?" These are common anxious thoughts for people living with chronic illness, leading them to forego opportunities to connect.

The fear of being found disappointing is another powerful motivator to self-isolate. "I can't move quickly, so I shouldn't go with my friends because I'd just hold everyone back." "I'm not very fun because my illness makes me tired and cranky—nobody wants to be around a Debbie Downer."

Of note, too, is that illness perception—how one views their illness—is affected negatively by loneliness (Tuncay, Fertelli, & Mollaoglu, 2018). The higher the loneliness level, the more negatively the illness is perceived. This is important, as negative illness perception affects mental health and the ability to cope with illness (Tuncay, Fertelli, & Mollaoglu, 2018).

## **Changing Loneliness**

The first step to changing loneliness is to acknowledge that one is lonely. Sometimes, identifying loneliness as an issue is tricky. People with chronic illness may feel that their problem is their illness rather than the loneliness that it creates. They think if they can't fix the illness, then they can't fix the loneliness. This is not true. It may well be more challenging to ameliorate loneliness when one is living with illness, but it is not impossible. And it's very likely that ameliorating loneliness will improve illness perception and overall quality of life.

Loneliness tells us that we've moved out of connection in a way that is not good for us. The antidote is to move back into contact with people. If you're feeling lonely, think about how to increase both the quantity and quality of your interactions.

Regarding the quantity of interactions, how many people do you encounter in a day? What is the nature of those encounters? Something as small as a smile and a "thank you" to your postal carrier counts as an interaction. Try to increase these micro-moments of connection by getting out of the

house or—if that's impossible—getting online.

Regarding the quality of interactions, who are the people with whom you can be vulnerable and close? Can you strengthen those connections with meaningful conversation and experiences? Can you be open about your loneliness and your wish to deepen relationships?

You may believe that you cannot do this, that your illness makes it impossible for you to build and maintain connection. Some of this may feel shame-based ("I am too deficient for anyone to want to connect with me") and some may feel fear-based ("People are going to hurt me"). You'll need support in understanding and changing this, and therapy is exactly the place to do this work.

Connection is a vital part of any treatment plan for chronic illness. If you're not getting enough of it and you don't see a way to change that, it's time to ask for help. You are worthy and wanted. Therapy can help you come back into community, decrease loneliness, and improve your quality of life.

#### References

Bekhet, A.K. & Zauszniewski, J.A. (2008). Loneliness: a concept analysis. Nursing Forum, 43(4): 207-213.

Carter, B., Qualter, P, & Dix, J.A. (2015). Social relationships, loneliness and adolescence: the potential for disruption by chronic illness. Journal of Child Health Care, 19(4): 421-422.

Kool, M.B. & Geenen, R. (2011). Loneliness in patients with rheumatic diseases: the significance of invalidation and lack of social support. The Journal of Psychology: Interdisciplinary and Applied, 146(1-2): 229-241.



## **WRITING BIG - PART II**







## **Adaptive Equipment**

If you are experiencing tremors, dystonia, or dyskinesia, then you might also be experiencing challenges with writing. A simple adaptation of adding weight to either your writing implement or your wrist can help decrease the amplitude of these unwanted movements (Mo & Priefer, 2021). In addition to weighted utensils, there are also writing utensils specially designed for people with PD, such as the PenAgain. Another adaptation that can improve handwriting skills is a slant board. Slant boards create the optimal writing angle of 20-30 degrees, which assists in forearm stabilization and a slight bend of the wrist to provide a functional writing position (Beck, 2016).

## **Strengthening Exercises**

Strengthening the hands can help maintain independence with activities of daily living (ADL) by reducing tremors, rigidity, and bradykinesia (Wang et al., 2020). It is important to work the small muscles of the hands and fingers to improve fine motor control and hand dexterity, which directly correlates to writing and typing.

#### OT Tips:

#### **In-Hand Manipulation:**

• Hold an object in the palm of your hand, move it

to your fingertips and back to your palm, repeat

 Hold a round object in your hand and rotate it clockwise and counterclockwise

#### **Finger Isolation:**

- Place your palm and fingers flat on a table, lift one finger up at a time, repeat with all fingers
- Make an "O" by touching your thumb to each of your fingers
- Pick up coins from the table using your thumb and one finger to pinch, repeat using each finger

#### **Strengthening:**

- Squeeze an object that has resistance in the palm of your hand
  - O Theraputty:
    - Start with one strength and build your way up as you get stronger
  - O Stress ball or rolled-up socks can work as well
- Place a small rubber band around two fingers at a time and stretch the band
- Finger Exercizer:
  - Start with one strength and build your way up as you get stronger
- Frequency of exercises
  - Repeat these exercises 1-3 times per day for 10-12 repetitions or 3-5 minutes to see results

## **Adaptive Equipment/Technology**

#### OT Tips:

- Adaptive keyboards with enlarged keys help minimize mistakes while typing
- Ergonomic keyboards help with hand and finger positioning to increase function
- Computer features, such as "Dictate", performs speech-to-text which reduces the need to physically type
- Computer apps:
  - WordQ performs word prediction to limit the amount of key strokes
  - SteadyMouse removes shaking motion of curser and decreases accidental clicks to make using a mouse more functional

## **Positioning**

Proper body positioning and seating ergonomics can help improve writing and typing. When sitting at a table to either work on the computer or write, keep in mind the 90-90-90 rule. Your elbows should be bent at 90 degrees and at the same height as the working surface, hips should be at a 90-degree angle with your bottom against the back of the chair, knees should be at a 90 degree angle with space between the chair and the back of your knees, and your feet should be flat on the floor.

#### OT Tips:

## Make sure your chair is comfortable and has proper low back support

- Lumbar Support Pillow (\$34)
  - o Supports upper, middle, and lower back depending on placement
  - o Improves posture
  - o Can be placed on office chair, car seat, couch, etc.
- Take frequent movement breaks (every 20-30 minutes)
- OT's like to say, "Proximal stability for distal mobility"
  - Make sure your back and trunk are well supported so your arms and hands can complete tasks

#### **ABOUT THE AUTHOR:**

Andie Hill is an occupational therapy doctoral student at the University of Mary in Bismarck, North Dakota. She just completed a 14-week capstone project with APDA Northwest where she created a program focused on improving fine motor skills in those with PD. She is from Boise, ID but currently lives in Seattle, WA where she enjoys hiking, mountain biking and playing board games with friends. Andie graduated in April 2022 and we are proudly calling her Dr. Andie Hill.

## VIRTUAL EXERCISE CLASS SCHEDULE

Please visit: <a href="mailto:bit.ly/APDAYouTube">bit.ly/APDAYouTube</a> for Live Stream exercise classes. Contact APDA at 636.778.3377 or <a href="mailto:apdaparkinson.org">apdastlouis@apdaparkinson.org</a> for zoom link

#### YouTube

DAY	TIME	CLASS LEVEL		INSTRUCTOR	
Manday	1:00pm	Movement Training	Level 1 & 2	Marina Clements	
Monday	1:00pm	Interval Training Leve		Jen Berger	
Tuesday	1:00pm	Seated Exercise	Seated Exercise Level 1		
Wednesday	2:00pm	Interval Training	Level 2	Michelle Valenti	
Thursday	2:00pm	Seated Exercise	Level 1	Jen Berger	
Thursday	11:00am	Tai Chi	Level 1 & 2	Craig Miller	
Friday	11:15am	Tai Chi & Meditation	Level 1 & 2	Craig Miller	
	1:00pm	Tai Chi	Level 2	Craig Miller	

#### Zoom

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
Tuesday	9:00am	Seated Exercise	Level 1	
Thursday	2:00pm	Seated Exercise	Level 1	

## 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
Cape Girardeau	Mon/Wed/Fri	9:00am		Level 1	Boxing
	Tuesday	10:00am	Jen Berger	Level 2	Circuit Training
	Tuesday	11:00am	Jen Berger	Level 2	Strength and Cardio
	Tuesday	1:00pm	Pamela Todd	Level 1	Yoga
	Wednesday	10:00am	Michelle Valenti	Level 2	Intro to Exercise
Chesterfield	Wednesday	11:00am	Michelle Valenti	Level 1	Seated Exercise
ADPA Office	Wednesday	1:00pm	Marina Clements	Levels 1 & 2	Movement Training
	Thursday	11:00am	Craig Miller	Levels 1 & 2	Tai Chi
	Thursday	1:00pm	Michelle Valenti	Level 2	Strength and Cardio
	Friday	10:00am	Craig Miller	Levels 1 & 2	Tai Chi and Meditation
	Friday	11:15am	Craig Miller	Level 2	Tai Chi
Chesterfield YMCA	Mon/Wed	12:30pm	Michelle Valenti	All Levels	Parkinson's Pedalers
Kirkwood YMCA	Monday	11:30am	Frank Tucci	Levels 1 & 2	Parkinson's Exercise
Maryland Heights YMCA	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's
Ste. Genevieve	Thursday	11:00	Becky Baumann	Level 2	Parkinson's Exercise
St. Louis City Stephen A Orthwein Ctr.	Thursday	12:00pm	Annie Morrow	Level 1	Interval Training
	Friday	2:00pm	Mike	Levels 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

#### **ILLINOIS CLASS SCHEDULE**

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS
	Monday	1:00pm	Jessica B.		Pedalers Cycling
	Monday	1:00pm	Jenny Redden	All Levels	Seated Yoga
Champaign YMCA	Tues/Thurs	1:00pm	Lindsay R. Jenny Redden		Functional Chair Fitness
	Wednesday	1:00pm	Jessica B.		Strength & Balance
	Friday	1:00pm	Lindsay R.		Standing Functional Fitness
Decatur YMCA	Tues/Thurs	9:00am		All	Pedaling for Parkinson's
Edwardsville YMCA	Tues/Thurs	11:00am		All	Exercise for Parkinson's
Highland Korte Rec Center	M/W/Th	11:00am		All	Cycle and Strength
O'Fallon VMCA	Tuesday	12:00pm	Victoria White	All	Exercise for Parkinson's
O'Fallon YMCA	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

## SUPPORT GROUP SCHEDULE

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

#### **MISSOURI SUPPORT GROUPS**

LOCATION	DAY	TIME	LEADER	MEETING SITE
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	2nd Monday	5:30pm	Jayanti Ray	Cape Girardeau Library
Carthage	3rd Monday	11:30am	Tericia Mixon	Fair Acres Family YMCA
Chesterfield	1st & 3rd Tuesday	11:00am	Carrie Burgraff	VIRTUAL
Chesterfield Caregivers	2nd Monday	10:30am	Lynda Wiens & Jay Bender	APDA
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
Carinafield	2nd Saturday	11:00am	Cassi Locke	The Bodysmith
Springfield	3rd Tuesday	6:00pm		Kingsway UMC
Ste. Genevieve	2nd Wednesday	10:00am	Teddy Ross	Ste. Gen. Co. Mem Hospital
St. Louis Caregivers	3rd Monday	1:00pm	Kathy Schroeder	VIRTUAL
St. Peters	1st Tuesday	1:00pm	Jodi Peterson	Spencer Road Library
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
Alton	2nd Wednesday	1:00pm	Dustin Heiser	SSP Main Bldg, The Meeting Rm
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

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Carmen & Martin Blaylock Rhonda & Daniel Cole Barry Kessler Amy & Larry Lentin Terese & Bob Mitchusson Rotonda Foundation Kathy & Doug Schroeder Glen Slay Ann Schmelzle

# The Benefits of being in a Support Group

- · Social connections with people who get it
- Support circle with many resource
- · Reduce stress, anxiety, and depression
- · Learn ways to manage symptoms
- Learn coping skills and relaxation strategies
- Express feelings and worries in safe place



GREATER ST. LOUIS CHAPTER

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## APDA is looking for new Support Group Leaders

- Do you have PD or are you a care partner of someone with PD?
- Do you want to share with and learn coping skills for PD?
- Are you in an area of St. Louis, Missouri or southern Illinois where there isn't currently a group?
- Do you already have a group and want more resources for your group by joining APDA?
- Do you live in 63021, 63011, 63105, 63124, 63031, 63136, 63135, 63042, 63121, 63139, 63143, 63128?

Call Marilyn Wilson for more information (636)-681-3209



## **APDA Greater St. Louis Chapter**

16100 Chesterfield Parkway W, Ste. 125 | Chesterfield, MO 63017 Hours: 8:00 a.m. - 4:00 p.m. M-F 636.778.3377

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