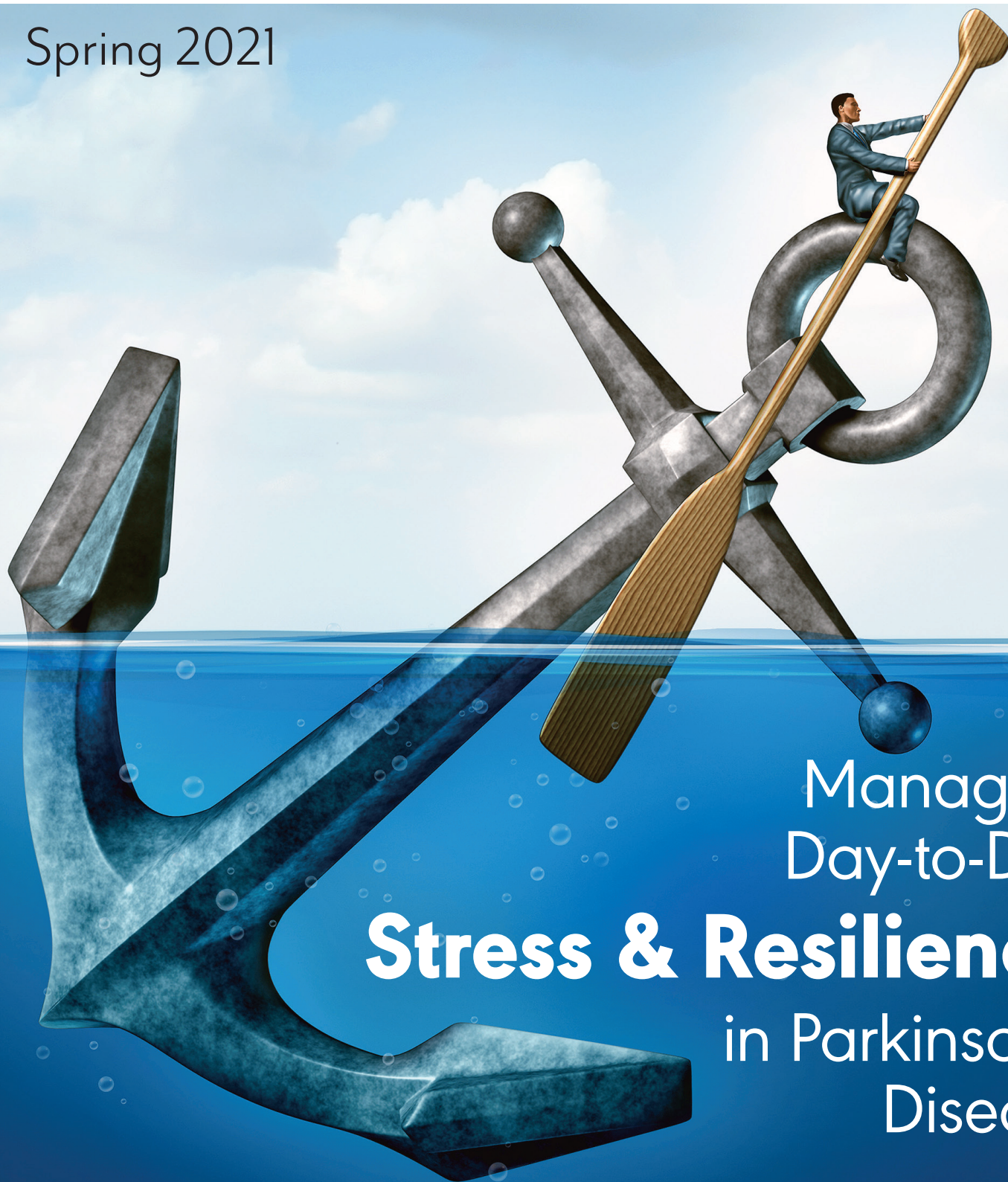


PARKINSON ALLIANCE

Spring 2021



Managing
Day-to-Day
Stress & Resilience
in Parkinson's
Disease

PARKINSON ALLIANCE

Managing Day-to-Day Stress and Resilience in Parkinson's Disease

INTRODUCTION

Day-to-day stressors can take a toll on everyone. Stress pervades our world as we not only face the COVID-19 pandemic, but also as we face the pandemic-related stressors that seem to compound the other life stressors so commonly experienced. For those with Parkinson's Disease (PD), not only are there increased feelings of isolation, economic stressors, and grief or loss, psychological stressors directly related to symptoms of PD can be exacerbated¹. The known progressive decline in motor functioning (gait disturbance, slowed movement, balance problems), and non-motor symptoms (e.g., sleep disturbance, mood disturbance, cognitive changes, autonomic dysfunction) can seem even more debilitating and difficult to manage in our current pandemic. Increased levels of stress during the COVID-19 pandemic may have short-term and long-term consequences for individuals with PD¹. Increased psychological distress can worsen motor symptoms such as tremor, freezing of gait, and dyskinesias, and can reduce the effectiveness of dopaminergic medications²⁻⁴ or reveal or exacerbate rigidity⁵. Furthermore, research has found that increased psychological distress (e.g., depression and anxiety), role limitations (i.e. occupation, family, friendship roles), functional decline and disengagement, and progressive symptoms of PD are highly prevalent and contribute to reduced quality of life⁶⁻¹³. Therefore, in this broader context of managing symptoms of PD while in this pandemic, patients with PD are particularly vulnerable to psychological distress and would benefit from multimodal coping strategies to aid in the adjustment process.

Specific to individuals with PD, scientific literature shows a variety of coping styles and strategies that may help to build a sense of resilience during stressful times. "Resilience" has been defined in a variety of ways, including the ability to bounce back or recover from stress, to adapt to stressful circumstances, and to function above the norm in spite of stress or adversity^{14,15}. A recent study found that actively seeking information and social support were prominent adaptive coping strategies in PD patients¹³. Overall, research has demonstrated that proactive styles of coping tend to contribute to higher perceptions of quality of life and resilience^{7,11,16}. Examples include finding strategies to resolve disease-related problems, seeking social connection and support, seeking information from medical providers, and pro-active stress management such as exercise, meditation, and adaptive cognitive appraisals (flexible and adaptive thought processes^{7,11}). Additionally, spiritual resilience has been shown to mitigate psychological distress in those with PD¹⁰. When considering the vulnerability of PD patients to psychological distress, particularly related to functional decline, understanding factors of resilience and specific coping strategies on physical and mental quality of life is of great importance.

OBJECTIVES

- To learn about the person with Parkinson's experience with current stressors.
- To understand the person with Parkinson's perspective on resilience and coping strategies.
- To provide general comments about and recommendations pertaining to fostering a sense of resilience and engaging in healthy coping behaviors.

METHODS

- Participants were recruited from prior survey participation that was conducted by The Parkinson Alliance (PA), announcements at PD support groups, announcements in medical clinics, and The PA website.
- There were 567 individuals who participated in this survey.
- Participant representation was across the United States, with New Jersey (15%), California (11%), New York (11%), Florida (10%), Texas (8%), Pennsylvania (7%), Arizona (5%), Minnesota (2%), Colorado (2%), Ohio (2%), Tennessee (2%), Michigan (2%), and Massachusetts (1%) having the most participants. There were 18 (3%) international participants.

Questionnaires/Measures:

1. The Parkinson Alliance Demographic and Clinical Questionnaire;
2. Perceived Stress Scale;
3. Brief Resilience Scale;
4. Patient Reported Outcome Measure – Global Health: Physical and Mental Health domains (Short Form)

The Parkinson Alliance Demographic and Clinical Questionnaire:

The self-report questionnaire inquired about basic demographic information (e.g., gender, race/ethnicity; marital status, education) as well as pertinent clinical information pertaining to stress, coping, and quality of life.

Perceived Stress Scale -10¹⁷:

The Perceived Stress Scale (PSS) assesses the degree to which the respondent appraises situations in the previous month to be stressful and is considered an indicator of the global level of stress experienced by a person. Items were designed to tap how unpredictable, uncontrollable, and overloaded participants find their lives. The PSS includes 10 items, and responses are on a 5- point scale (0=Never; 1=Almost Never; 2=Sometimes; 3=Fairly Often; 4=Very Often). A higher score indicates higher levels of perceived stress.

Brief Resilience Scale¹⁸:

The Brief Resilience Scale (BRS) is designed to gain insights into the extent a person perceives him or herself as resilient—having the ability to bounce back or recover from stress or adverse contexts. This ability may be particularly important for people who are already ill or are dealing with ongoing health-related stresses. The BRS is comprised of 6 items: 1. I tend to bounce back quickly after hard times. 2. I have a hard time making it through stressful events. 3. It does not take me long to recover from a stressful event. 4. It is hard for me to snap back when something bad happens. 5. I usually come through difficult times with little trouble. 6. I tend to take a long time to get over set-backs in my life. Participants rate the responses on a 5-point scale (1 = strongly disagree; 2 = disagree; 3 = neutral; 4 = agree; 5 = strongly agree). A higher score indicates higher sense of perceived resilience.

Two-item PROMIS® Global Physical and Mental Health Scales¹⁹:

The PROMIS Global Health (v 1.2) instrument contains one physical and one mental health scale. These scales were developed to be brief generic self-report measures of health, consisting of 2 items in each domain of physical and mental health: Physical health items: 1) In general, how would you rate your physical health? 2) To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? Mental health items: 1) In general, how would you rate your mental health, including your mood and your ability to think? 2) In general, how would you rate your satisfaction with your social activities and relationships? Items are rated on a five-point scale (1=Poor; 2=Fair; 3=Good; 4=Very Good; 5=Excellent). A higher score indicates better [perceived] global health.

Comparisons based on age and disease duration groups:

- **Age:** For the purpose of the survey report, age groups were divided into a **Younger PD group** (< 69 years of age) and an **Older PD group** (> 70 years).
- **Disease Duration:** Research pertaining to individuals with PD has indicated that the average time from symptom onset to development of motor complications was 6 years^{20,21}. Research has divided groups into **Early PD** (< 6 years) and **Advanced PD** (6+ years) to define a valid partition between early and advanced disease states.

Factors to consider when interpreting the results:

- This study used a survey-based methodology. Generalizability of the results may be limited. Sample sizes noted in the sections below may vary somewhat within specific groups (e.g., younger, older, early, advanced, etc.), since some individuals may not have responded to a specific question. Research has found that some individuals with PD, particularly as cognitive difficulties become more apparent, may have reduced insight/awareness into or appreciation of their difficulties, a factor warranting consideration when interpreting self-report questionnaires. Importantly, the subjective report in this survey serves to highlight the “patient’s perspective” about his or her experience with perceived stress, resilience, and quality of life.

RESULTS

- The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1.
 - There were 567 individuals who participated in this survey.
 - The average age of the participant was 72 years, with an average disease duration of 11 years.
 - Just over half of the participants were male.
 - The majority of the participants were Caucasian/White.
 - The majority were married and living with someone.
 - Approximately 60% the participants reported having a college degree or graduate degree.

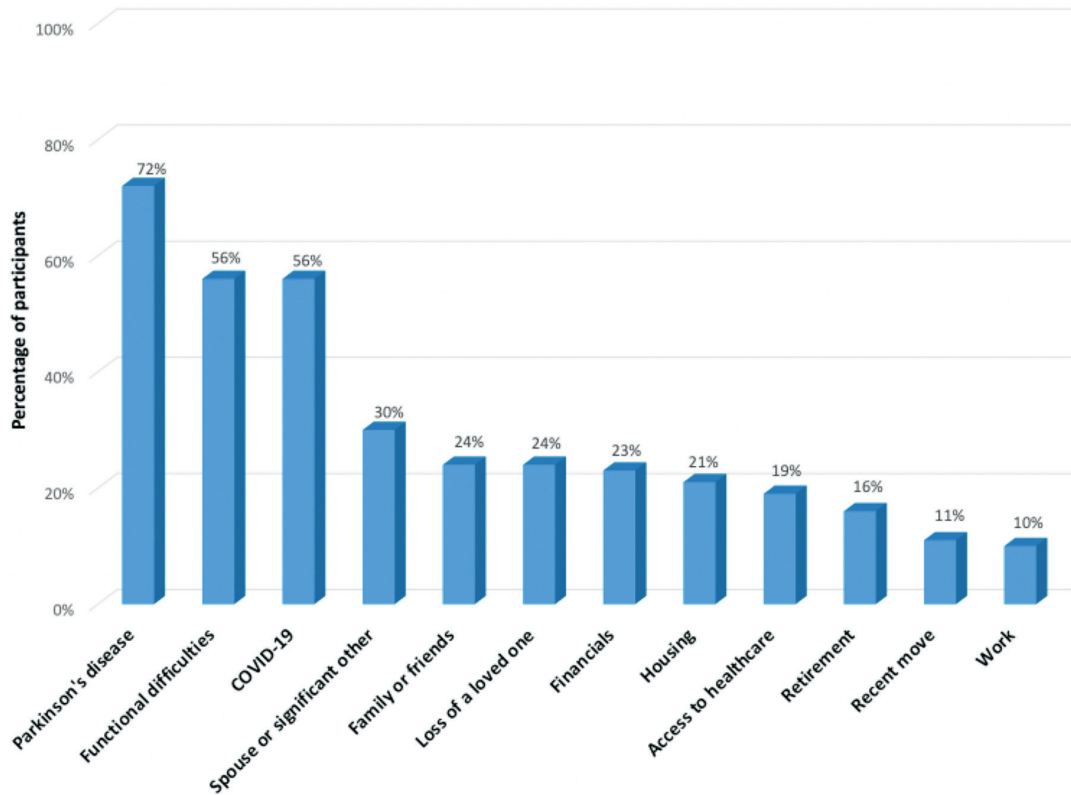
Table 1. Demographics and Clinical Features of the Participants (N=567)

	(Mean, Range, and percentage)
Average Age in Years (range)	72 years (50-100 years)
Duration of PD in Years (range)	11 years (0 to 42 years)
Average Age of PD Diagnosis (range)	61 years (28-94 years)
Male	52%
Female	48%
Married	74%
Lives with Someone	83%
Race	
Caucasian	93%
African American	3%
Other:	4%
Education	
<12 years	3%
High School	11%
Some College or Associate Degree	24%
College	30%
Participants with Deep Brain Stimulation (N=133)	
Average Age at Time of DBS in Years (range)	60 years (36-80 years)
Average Duration since DBS in Years (range)	8 years (0-25 years)
Target: STN	41%
GPi	10%
Not Sure	49%

STRESS:

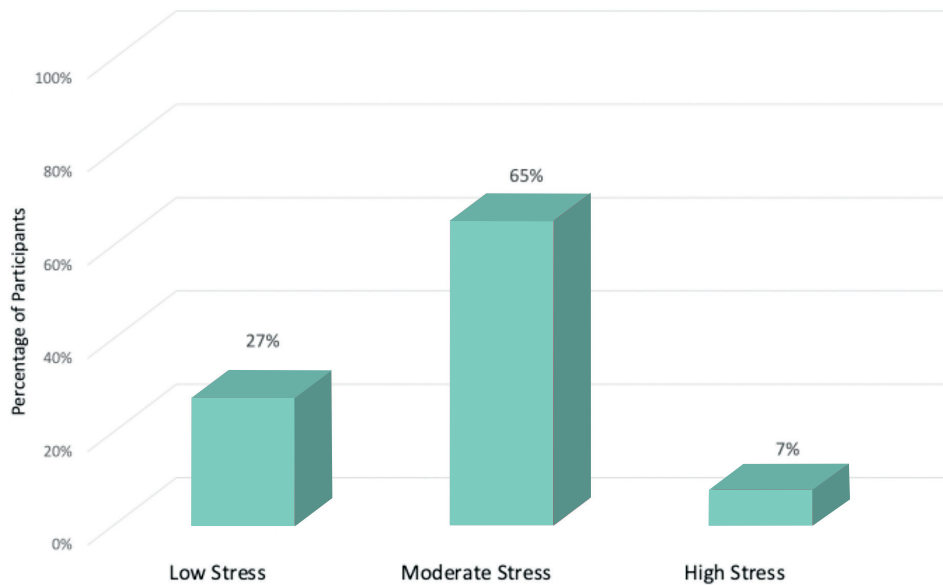
Many stressors were identified for the participants in this survey (See Figure 1). The top three stressors were 1. having Parkinson's disease, 2. experiencing functional difficulties, and 3. COVID-19 related factors, followed by having stressors related to relationships.

Figure 1. Primary stressors rated as causing moderate to severe stress (N=567)



- The majority of the participants perceive their level of stress as moderate in severity. See Figure 2.
- Perceived stress levels were comparable across age and disease duration groups.

Figure 2. Participant's perception of overall stress levels (N=567)

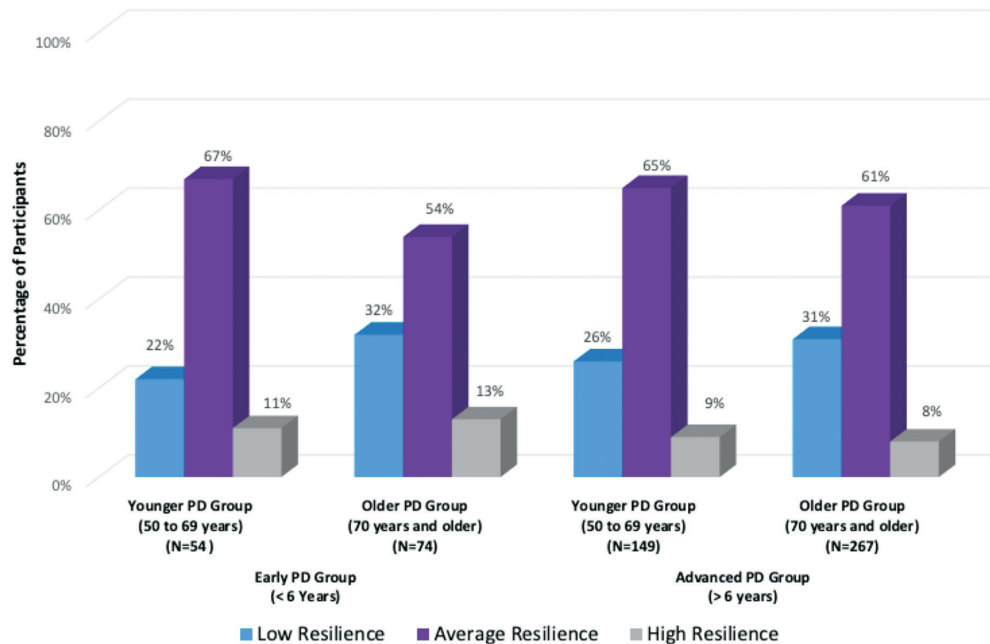


RESILIENCE:

Resilience involves the ability to bounce back or recover from stress, to adapt to stressful circumstances, and to function above the norm in spite of stress or adversity.

- Approximately 60% of the participants in this survey were characterized as having average levels of resilience, while 10% were characterized as having high levels of resilience, and 30% were characterized as having low levels of resilience.
- After matching on disease duration, there was a slight difference of perceived resilience between age groups. The **Younger PD group** (Less than 70 years old) reported modestly greater levels of resilience when compared to the **Older PD group** (70 years of age or older). See Figure 3.
- There was not a significant difference of perceived resilience for the disease duration groups (**Early PD** vs. **Advanced PD**) for age-matched groups. See Figure 3.

Figure 3. Participants level of resilience across disease duration and age matched groups



HEALTH RELATED QUALITY OF LIFE:

Health-related quality of life (HRQOL) refers to perceived physical and mental health.

- Approximately 63% of the participants perceive their **physical health** related quality of life as comparable to the general community, while almost 2% perceive **physical health** to be better than others in the community. In contrast, 36% perceive that their **physical health** is worse than community-based comparison groups.
- Approximately 68% of the participants perceive their **mental health** related quality of life as comparable to the general community, with almost 3% of the participants perceiving their **mental health** to be better than others in the community. In contrast, 29% perceive that their **mental health** is worse than community-based comparison groups.

- Perceived **physical health** appears to get worse as age and disease duration increase. Moreover, when taking into account disease duration and age, the perception of **physical health** was worse for the **Advanced PD group** and the **Older PD group** when compared to the **Younger PD group** and **Early PD group**. See Figure 4.
- After taking into account age and disease duration-matched groups, **mental health** appears to be worse for the **Advanced PD group** when compared to the **Early PD group**. Age did not appear to impact perceived **mental health**. See Figure 5.

Figure 4. PD participants' perception of Physical Health compared to the general community

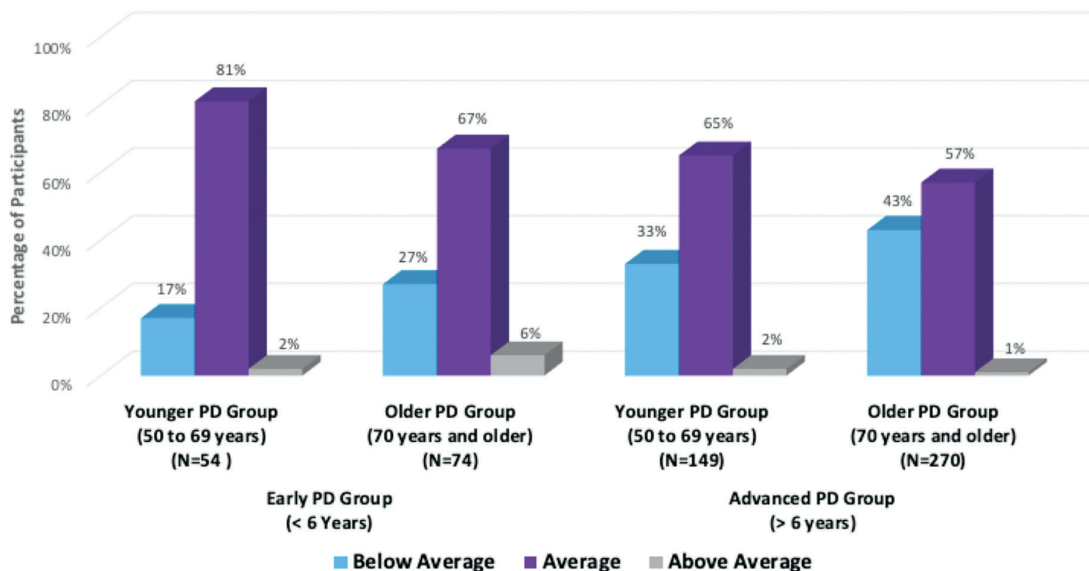
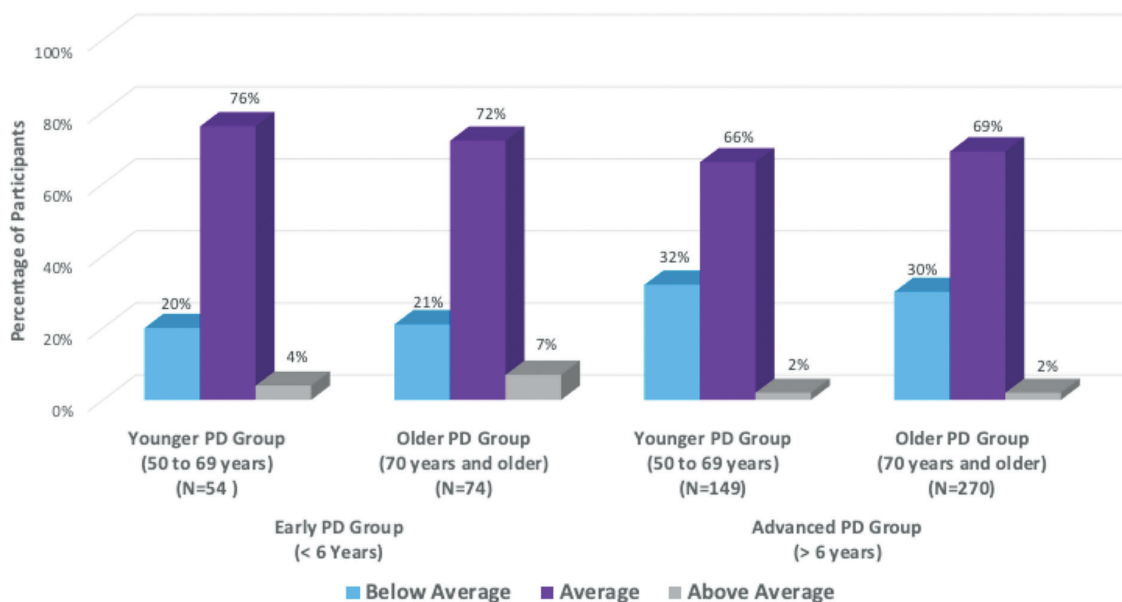


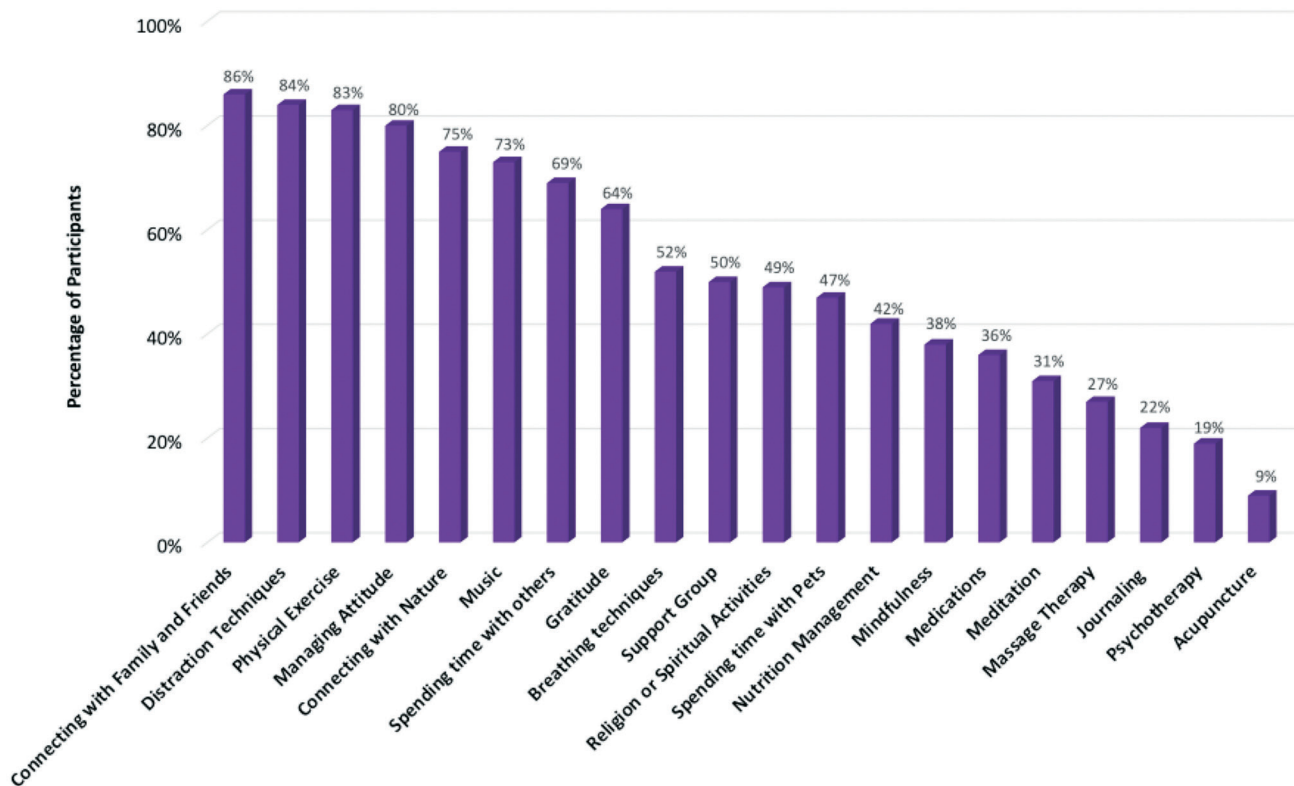
Figure 5. PD participants' perception of Mental Health compared to the general community



COPING TECHNIQUES:

- 62% of the participants in this survey reported that they have *at least* some difficulty coping with stress.
 - Do not cope well: 9%
 - Copes a little bit well: 16%
 - Copes somewhat well: 37%
 - Copes quite a bit well: 31%
 - Copes extremely well: 6%
- 55% of the participants reported that their ability to cope with stress now, when compared to before PD, is worse. In contrast, 29% reported that there is no difference in their ability to cope with stress now as compared to before PD, while 8% reported that they can cope with stress better now when compared to before they had PD.
- The top five most frequently reported coping techniques included connecting with friends and family, use of distraction techniques, engaging in physical exercise, managing attitude, and connecting with nature. The least commonly used coping techniques include acupuncture, psychotherapy, journaling, massage therapy, and meditation (See Figure 6).
- The coping techniques with a strong relationships to perceived resilience included managing attitude, participating in psychotherapy, engaging in spiritual or religious activities, and taking medications.

Figure 6. Percentage of participants use of coping techniques (N=567)



Relationship between Stress, Resilience, Physical and Mental Health, and Demographic Variables

- Greater resilience was significantly related to less stress, ability to carry-out physical activities (less disability), perception of higher levels of physical and mental health, and higher levels of education.
- Resilience was not significantly related to gender, race, marital status, or whether or not one lives alone.

SUMMARY AND DISCUSSION

Stress pervades our world as we not only face the COVID-19 pandemic, but also as we face the pandemic-related stressors that seem to compound the other life stressors so commonly experienced. For those with PD, not only are there increased feelings of isolation, economic stressors, and grief or loss, motor symptoms and psychological stressors directly related to symptoms of PD can be exacerbated¹. Increased levels of stress during the COVID-19 pandemic may have several short-term and long-term consequences for individuals with PD¹. When considering vulnerability of PD patients to psychological distress, particularly related to functional decline, understanding factors of resilience and specific coping strategies on physical and mental quality of life is of great importance.

■ TAKE HOME POINTS FROM THIS SURVEY ■

■ OBJECTIVE 1. To learn about the person with Parkinson's experience with current stressors.

- The top three stressors for the participants in this survey included having Parkinson's disease, experiencing functional difficulties, and experiencing the impact of COVID-19, followed by stressors related to relationships.
- The majority of the participants perceive their level of stress as moderate in severity, with stress related to factors that are perceived as overwhelming, unpredictable, or uncontrollable.
- Perceived stress levels were comparable across age and disease duration groups.

■ OBJECTIVE 2. To understand the person with Parkinson's perspective on resilience and coping strategies.

- Approximately 60% of the participants in this survey were characterized as having average levels of resilience, while 10% were characterized as having high levels of resilience, and 30 percent were characterized as having low levels of resilience.
 - There was a slight difference of perceived resilience between age groups, with the **Younger PD group** reporting modestly higher levels of resilience when compared to the **Older PD group**.
 - Disease duration was not significantly related to perceived resilience, meaning that disease duration did not impact one's perception of resilience.
- Perceived physical health, however, appears to get worse as age and disease duration increase.
- Perceived mental health was adversely impacted by disease duration. Participants with **Advanced PD** reported lower levels of mental health when compared to participants with **Early PD group**. Thus, disease

duration appears to increase vulnerability to reduced mental health, which is consistent with research highlighting increased risk for psychological disturbance with the progression of PD.

- Age did not impact perception of mental health.
- Greater resilience was significantly related to less stress, the ability to carry-out physical activities (less disability), and the perception of higher levels of physical and mental health.
 - Resilience is a protective factor for perceived physical and mental health.
- Over 60% of the participants in this survey reported that they have *at least* some difficulty coping with stress.
- There were numerous coping behaviors reported by the participants. The most frequently reported coping techniques included: connecting with family and friends, distraction techniques, physical exercise, managing attitude, and connecting with nature.
- The coping techniques with a strong relationship to perceived resilience included managing attitude, participating in psychotherapy, engaging in spiritual or religious activities, and taking medications.
 - Coping behaviors known to impact/involve perspective management and adaptive cognitive (thinking) appraisals are known to have significant impact on perceived resilience and physical and mental well-being, and yet, these techniques (e.g., adaptive cognitive appraisals; psychotherapy; spiritual activities) appear to be underutilized, difficult to utilize, or difficult to access. Education about, assisting others in application, increasing access to such techniques may be advantageous for individuals with PD.

■ **OBJECTIVE 3. To provide general comments about and recommendations pertaining to fostering a sense of resilience and engaging in healthy coping behaviors²².**

- **Emotional Validation:**
 - Acknowledge that you are in a situation that brings about feelings of worry, fear, or sadness.
 - Emotional validation increases feelings of security and support.
 - Have self-compassion, understanding that it is okay to experience concern, worry, and fear.
 - Express your concerns to a trusted individual in your life who will listen and express support.
 - Stay connected with family and friends.
- **Managing the unknown and the uncertainty:**
 - Managing where to focus your energy:
 - Identify variables over which you have control.
 - Think about the activities and conversations you have, and how they will positively or negatively impact your mood.
 - Managing your response to the situation:
 - Focus on achievable, short-term goals.
 - Be proactive, problem solve, and create a plan with options.
 - See the possibility of manageable outcomes.
 - Approach the day with a flexible mindset. Symptoms of PD are unpredictable, and its unpredictability will necessitate modifying goals day-to-day, moment-by-moment.
 - Create structure to the times of day or days that you do know what you will be doing ahead of time.

- Budget time for silence and reflection. Deep breathing for several minutes can help channel greater mind-body awareness while lessening stress and anxiety.
- Limit exposure to news/media sources, should such exposure cause distress.
- **Awareness:**
 - Know your emotions, thoughts, and physical well-being (i.e., physical tension; heart rate) in a given moment. Let the awareness influence your steps to self-care.
 - Organize your day to engage in more difficult tasks when you are more likely to be at your best (e.g., optimal “on” times; avoiding demanding tasks when wearing off or during the mid-afternoon when fatigue is most common).
- **Stress management / Managing emotions:**
 - Breath: Take a controlled breath.
 - Create a routine: engage in controlled breathing exercises prior to each meal. Doing so when it is not needed will make it easier to remember to do when it is a stressful situation.
 - Exercise, eat well, and get rest.
 - Expose yourself to positive or inspirational people and information.
 - Engage in mindfulness: Pause and notice one thing you hear, one thing you feel, and one thing you see.
 - Engage in an activity that will make you feel more balanced or positive before ending your day.
 - Make it a routine.
 - Apply stress management techniques such as listening to music, engaging in Tai Chi or Yoga, or seeking education about your situation or condition.
 - Identify something or someone for whom to be grateful. **“In every given moment, we can be grateful,** even though we cannot be grateful for every given moment...Even when we are confronted by something terribly difficult, we can rise to the occasion and respond to the opportunity given to us.” (David Steindl-Rast)
- **Managing your thoughts and interpretations:**
 - “The greatest weapon against our stress is our ability to choose one thought over another.” (William James)
 - “Everything can be taken from a man but one thing: the last of the human freedoms—to choose one’s attitude in any given set of circumstances, to choose one’s own way.” (Viktor Frankl)
 - Notice the negative, stress-inducing thought, and consider another perspective.
 - State positive affirmations, such as “I have demonstrated resolve and resilience before.”
 - Treat yourself with self-compassion, kindness and respect; avoid self-criticism.
 - Identify something or someone for which to be grateful.
 - Let someone know why you appreciate them. Expressions of gratitude are linked to reduced stress and increased happiness.
 - Humor: Find a source of humor, something or someone that will make you smile or laugh.
 - Purpose and Meaning: Identify purpose and meaning in what you are doing.
- **Managing your physical and mental health:**

Since stress management and resilience are known to be influenced by attitude and psychological health, consider the following points regarding improvement of physical and mental health, particularly as disease duration progresses.

- The direction of causality between resilience, perceived disability, and physical and mental health is difficult to establish for many individuals. The association of PD with psychological distress or disturbance (e.g., depression and anxiety) is well-known, however^{12, 23, 24}, and the treatment of psychological health in PD is often underutilized²⁵. Therefore, in addition to any pharmacological efforts to overcome the motor symptoms of PD, psychological intervention may also be important in improving perceived resilience and well-being.
 - Have a conversation about mental health, such as anxiety and depression (psychological and biological contributions), and related treatments with a specialist in movement disorders (e.g., a neurologist, psychiatrist, neuropsychologist, psychologist who are familiar with PD).
 - Exercise can provide diverse stimulation, social, and emotional interaction, and the physical activity with a variety of brain areas activated, resulting in improved psychological health²⁶.
 - Medications for psychological/psychiatric difficulties may be beneficial (i.e., for depression and anxiety).
 - Since perspective management may be difficult, and since there are many challenges related to coping with PD, cognitive-behavioral psychotherapy (CBT) for individuals with PD (and treatment for family members too, if appropriate) can be an effective treatment for addressing emotional difficulties that are secondary to, if not directly related to (biological changes) Parkinson's disease²⁷. Psychotherapy can assist in validating one's personal experiences, feeling supported, and developing coping strategies to reduce and manage symptoms of depression and anxiety. Such intervention can aid in coping and adjustment to help improve with function, relationships with others, and quality of life.
 - Medications that facilitate psychological well-being, in conjunction with psychotherapy, may be helpful for participants who experience depression and anxiety. However, caution is indicated when it comes to selecting certain medications, as some medications (e.g., benzodiazepines, anticholinergic medications and dopamine agonists) can cause or worsen cognitive and psychological symptoms. It is recommended that use of psychotropic medications be monitored by a specialist in PD.
 - Sleep is an important agent for brain health and physical rejuvenation²⁸. It is often fragmented in PD. Healthy sleep practices include avoid eating 2 hours prior to sleep, limiting screen time (e.g., smart phones, iPads, laptops, TV) at night, going to bed the same time every evening, and eliminating caffeine intake within the recommended 8-hours before going to bed. Melatonin can be effective in treating sleep dysregulation along with other prescription options, which should be reviewed and discussed with your movement disorders specialist.
- Treatment pertaining to the well-being in PD needs to be tailored to an individual's preferences and capabilities. A one size fits all approach is not the best approach. For a review of a broad scope of PD symptoms including and treatment considerations related to motor and non-motor symptoms, one can review previous survey reports on The Parkinson Alliance website that addresses a breadth of symptoms and treatment considerations. [parkinsonalliance.org/research-resources/patient-centered-research](https://www.parkinsonalliance.org/research-resources/patient-centered-research)

— ACKNOWLEDGEMENTS —

There are many contributors to make this research happen. THANK YOU to all who participated. These surveys would not be meaningful without the valuable insights and contributions from the many participants in this survey. I also want to acknowledge my appreciation of the participants who continue to participate in our surveys year-after-year; thank you for your continued support and contributions to our work. I want to extend my appreciation to Jeffrey Wertheimer, Ph.D., ABPP-CN, our Chief Research Consultant and Chief of Neuropsychology Services at Cedars-Sinai Medical Center, Los Angeles, California, who assists in creating the research surveys, analyzing the data, and writing our manuscripts. Thanks goes to Joy Suh, Ph.D., Neuropsychology Fellow at Cedars-Sinai Medical Center, for contributions to the literature review. I would like to thank Ritesh Ramdhani, MD, Regional Director, Deep Brain Stimulation, Northwell Health Eastern Region & Lenox Hill Hospital, New York, for his assistance with reviewing the manuscript.

Additionally, I want to thank Terri Hamran, Director, Information Services, for her assistance with database management, Jennifer McNamara, Administrative Assistant and data entry specialist, and Debra Trisler, Graphic Designer for The Parkinson Alliance, in making this research possible.

Carol Walton
President and CEO
The Parkinson Alliance

REFERENCES:

1. Helmich, R. C., & Bloem, B. R. (2020). The Impact of the COVID-19 Pandemic on Parkinson's Disease: Hidden Sorrows and Emerging Opportunities. *Journal of Parkinson's disease*, 10(2), 351–354. <https://doi.org/10.3233/JPD-202038>
2. Macht M, Kaussner Y, Möller JC, Stiasny-Kolster K, Eggert KM, Krüger H-P, Ellgring H. (2007). Predictors of freezing in Parkinson's disease: A survey of 6,620 patients. *Mov Disord* 22, 953–956.
3. Zach H, Dirkx MF, Pasman JW, Bloem BR, Helmich RC (2017) Cognitive stress reduces the effect of Levodopa on Parkinson's resting tremor. *CNS Neurosci Ther* 23, 209–215.
4. Zach H, Dirkx M, Pasman JW, Bloem BR, Helmich RC (2017) The patient's perspective: The effect of levodopa on Parkinson symptoms. *Parkinsonism Relat Disord* 35, 48–54.
5. Djamshidian, A. & Lees, A. J. (2014). Can stress trigger Parkinson's disease? *J Neurol Neurosurg Psychiatr* 85, 878–881.
6. Aarsland, D., Marsh, L., & Schrag, A. (2009). Neuropsychiatric symptoms in Parkinson's disease. *Movement Disorders*, 24(15), 2175-2186. <https://doi.org/10.002/mds.22589>
7. Bucks, R.S., Cruise, K.E., Skinner, T. C., Loftus, A. M., Barker, R. A., & Thomas, M. G. (2010). Coping processes and health-related quality of life in Parkinson's disease. *International Journal of Geriatric Psychiatry*, 26, 247-255. <https://doi.org/10.1002/gps.2520>
8. Dissanayaka, N.N.W., Sellbach, A., Silburn, P.A., O'Sullivan, J.D., Marsh, R., & Mellick, G.D. (2011). Factors associated with depression in Parkinson's disease. *Journal of Affective Disorders*, 132, 82-88. <https://doi.org/10.1016/j.jad.2011.01.021>
9. Kuopio, A., Marttila, R. J., Helenius, H., Toivonen, M., & Rinne, U.K. (2001). The quality of life in Parkinson's disease. *Movement Disorders*, 15(2). <https://doi.org/10.1002/1531-8257>
10. Kwok, J.Y.Y., Choi, E.P.H., Chau, P.H., Wong, J.Y.H., Fong, D.Y.T., & Auyeung, M. (2020). Effects of spiritual resilience on psychological distress and health-related quality of life in Chinese people with Parkinson's disease. *Quality of Life Research*, 29, 3065-3073. <https://doi.org/10.1007/s11136-020-02562-x>
11. Liebermann, J.D., Witte, O.W., & Prell, T. (2020). *BMJ Open*. <https://doi.org/10.1136/bmjopen-2020-036870>
12. Montel, S., Bonnet, A., & Bungener, C. (2009). Quality of life in relation to mood, coping strategies, and dyskinesia in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, 22(2). <https://doi.org/10.1177/0891988708328219>
13. Nilsson, M.H., Oswald, F., Palmqvist, S., & Slaug, B. (2020). Coping styles among people with Parkinson's disease: A three-year follow-up study. *Behavioral Sciences*, 10. <https://doi.org/10.3390/bs10120190>
14. Carver, C. S. (1998). Resilience and thriving: Issues, models, and linkages. *Journal of Social Issues*, 54, 245–266.
15. Tusaie, K., & Dyer, J. (2004). Resilience: A historical review of the construct. *Holistic Nursing Practice*, 18, 3–8.
16. The Parkinson Alliance. (February 15, 2021). Differential Impact of Coping Styles on Quality of Life for Individuals with Parkinson's Disease with and without DBS. https://www.parkinsonalliance.org/UserFiles/File/Coping_report07.pdf
17. Cohen, S. & Williamson, G. M. (1988). Perceived stress in a probability sample of the United States. In S. Spacapan & S. Oskamp (Eds.), *The Social Psychology of Health*, Claremont Symposium on Applied Social Psychology (pp. 31-67). Newbury Park, CA: Sage.
18. Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. *International journal of behavioral medicine*, 15(3), 194-200.
19. Hays RD, Schalet BD, Spritzer KL, Cella D. Two-item PROMIS® global physical and mental health scales. *J Patient Rep Outcomes*. 2017;1(1):2.
20. Politis, M., Wu, K., Molloy, S., G Bain, P., Chaudhuri, K., & Piccini, P. (2010). Parkinson's disease symptoms: the patient's perspective. *Movement Disorders*, 25(11), 1646-1651.
21. Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2003). Young-versus older-onset Parkinson's disease: impact of disease and psychosocial consequences. *Movement disorders: official journal of the Movement Disorder Society*, 18(11), 1250-1256.
22. Wertheimer, J. & Maxwell, K. (2020). Strategies for Coping During COVID-19. Cedars-Sinai Medical Center, Coping Resources.
23. Leentjens, A., Dujardin, K., Marsh, L., Martinez-Martin, P., Richard, I.H., Starkstein, S.E. (2012). Anxiety and motor fluctuations in Parkinson's disease: A cross-sectional observational study. *Parkinsonism and Related Disorders*, 18: 1084-1088
24. Menza M.A., Sage, J., Marshall, E., Cody, R., Duvoisin, R. (1990). Mood changes and "on-off" phenomena in Parkinson's disease. *Movement Disorders*, 5:148-51.
25. Livingston, G., Watkin, V., Milne, B. et al., (1997). The natural history of depression and the anxiety disorders in older people; The Islington community study. *J. Affect Disord*; 46, 255-62.
26. Jin, Z., Wang, L., Liu, S., Zhu, L., Loprinzi, P.D., Fan, X. (2019). The impact of mind-body exercises on motor function, depressive symptoms, and quality of life in Parkinson's disease: A systematic review and meta-analysis. *International Journal of Environmental Research and Public Health*, 17(31)
27. Dobkin, R. D., Menza, M., & Bienfait, K. L. (2008). CBT for the treatment of depression in Parkinson's disease: a promising nonpharmacological approach. *Expert Review of Neurotherapeutics*, 8(1), 27-35.
28. Irwin, M. (2015). Why sleep is important for health: A psychoneuroimmunology perspective. *Annual Review of Psychology*, 66(1), 143-172.

The Parkinson Alliance

Post Office Box 308 • Kingston, New Jersey 08528-0308
Phone: 1.800.579.8440 or 609.688.0870 • Fax: 609.688.0875

www.parkinsonalliance.org

a 501(c)(3) non-profit corporation