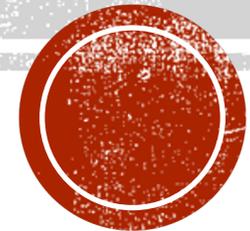


LONELINESS IN PARKINSON DISEASE



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INTEGRATIVE MEDICINE

- Integrating aspects from other health care systems along with western approaches
- Attempts to activate the innate healing process rather than relying on cure-oriented medicine
- The mind and body can be very resilient
- WHO “ Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”
- Holistic, lifestyle oriented approach



NATURE PJ PARKINSON

npj | Parkinson's Disease

www.nature.com/npjparkd

ARTICLE OPEN



Synergy of pandemics-social isolation is associated with worsened Parkinson severity and quality of life

Indu Subramanian^{1,2}, Joshua Farahnik³ and Laurie K. Mischley^{3,4}

Social isolation and its deleterious effects on health increases with age in the general population. People with Parkinson's Disease (PWP) are no exception. Social isolation is a risk factor for worsened health outcomes and increased mortality. Symptoms such as depression and sleep dysfunction are adversely affected by loneliness. There is a paucity of research on social isolation in Parkinson's disease (PD), which is all the more critical now in the setting of social distancing due to COVID-19. The goal of this study was to survey individuals with PD to evaluate whether social isolation is associated with PD symptom severity and quality of life. Only individuals reporting a diagnosis of idiopathic PD were included in this analysis. The primary outcome measures were the Patient-Reported Outcomes in PD (PRO-PD) and questions from PROMIS Global related to social health. PRO-PD scores increased as social performance and social satisfaction scores diminished. Individuals who reported being lonely experienced a 55% greater symptom severity than those who were not lonely ($P < 0.01$). Individuals who documented having a lot of friends had 21% fewer symptoms than those with few or no friends ($P < 0.01$). Social isolation was associated with greater patient-reported PD severity and lower quality of life, although it is unclear whether this is the cause and/or a consequence of the disease. In essence, the Parkinson pandemic and the pandemic of social isolation have been further compounded by the recent COVID-19 pandemic. The results emphasize the need to keep PWP socially connected and prevent loneliness in this time of social distancing. Proactive use of virtual modalities for support groups and social prescribing should be explored.

npj Parkinson's Disease (2020)6:28; <https://doi.org/10.1038/s41531-020-00128-9>





BACKGROUND

- Social isolation has deleterious effects on health
- Basic human need- food, water, shelter
- Increases with age in general population
- Social isolation is a risk factor for worsened health outcomes & increased mortality - worse than smoking half a pack of cigarettes a day or being obese
- In veterans- depression, anxiety, suicide and substance abuse
- Lack of research in Parkinson disease (PD)
- Social distancing due to COVID-19



DEFINITIONS

- Social isolation - “the lack of integration of individuals in their social environment. Living alone, possessing fewer social network ties, and minimal social contact are all markers of social isolation”
- Loneliness- “is an undesirable subjective emotional state in which there is a perception of social isolation, or the felt experience of being lonely”



LONELINESS IN 3 SPHERES

- Intimate, or emotional, loneliness : yearning for a close confidante or emotional partner
- Relational, or social, loneliness: longing for close friendships and social companionship
- Collective loneliness: need for a network or community of people who share one's sense of purpose and interests
- Loneliness can be felt if any one of these dimensions is not satisfied
- possible to be happily married and still feel lonely



LONELINESS IS BAD FOR THE BODY

Stress: Social support buffers stress

-when people lack social support and feel isolated they have increased susceptibility to the effects of stress

Immunity: Loneliness and social network size are both individual predictors of poor immune response,

-worst immune response being in people who are both lonely and lack a social network

Cognition:

-affect cognitive processing ,cause a hypervigilance that predisposes to anxiety

-Lonely individuals tend to visually fixate more on socially threatening stimuli than on pleasant ones

Sleep: disrupt circadian rhythms and lead to more fragmented sleep



REASONS FOR SOCIAL WITHDRAWAL IN PWP

- Motor: immobility, hypophonia, tremor, drooling and dyskinesia
- Non-motor issues: apathy, depression, anxiety and fatigue
- Bowel and bladder control
- Perceived stigma



METHODS

- 2100 patients- 1746 with idiopathic PD enrolled in observational study
- CAM Care in PD, web-based questionnaire
- Baseline data were used for a cross-sectional analysis of individuals reporting a diagnosis of idiopathic PD
- All regression models were adjusted for age, gender, income, and years since diagnosis



METHODS

- PROMIS -quality of life; choice between “Excellent,” “Very good,” “Good,” “Fair,” and “Poor,”: “In general, would you say your quality of life is:...”;
- 1. “In general, how would you rate your satisfaction with your social activities and relationships?”;
- 2. “In general, please rate how well you carry out your usual social activities and roles
- Two true/false statements : “I am lonely” and “I have a lot of friends.”
- The PRO-PD was used for quality of life; shown to correlate with years since diagnosis, Hoehn and Yahr, UPDRS, PDQ-39, and PROMIS Global measure of quality of life (QoL),
- Provides a surrogate marker for PD-continuous, stratifies by symptom



SOCIAL HEALTH PREDICTS QUALITY OF LIFE

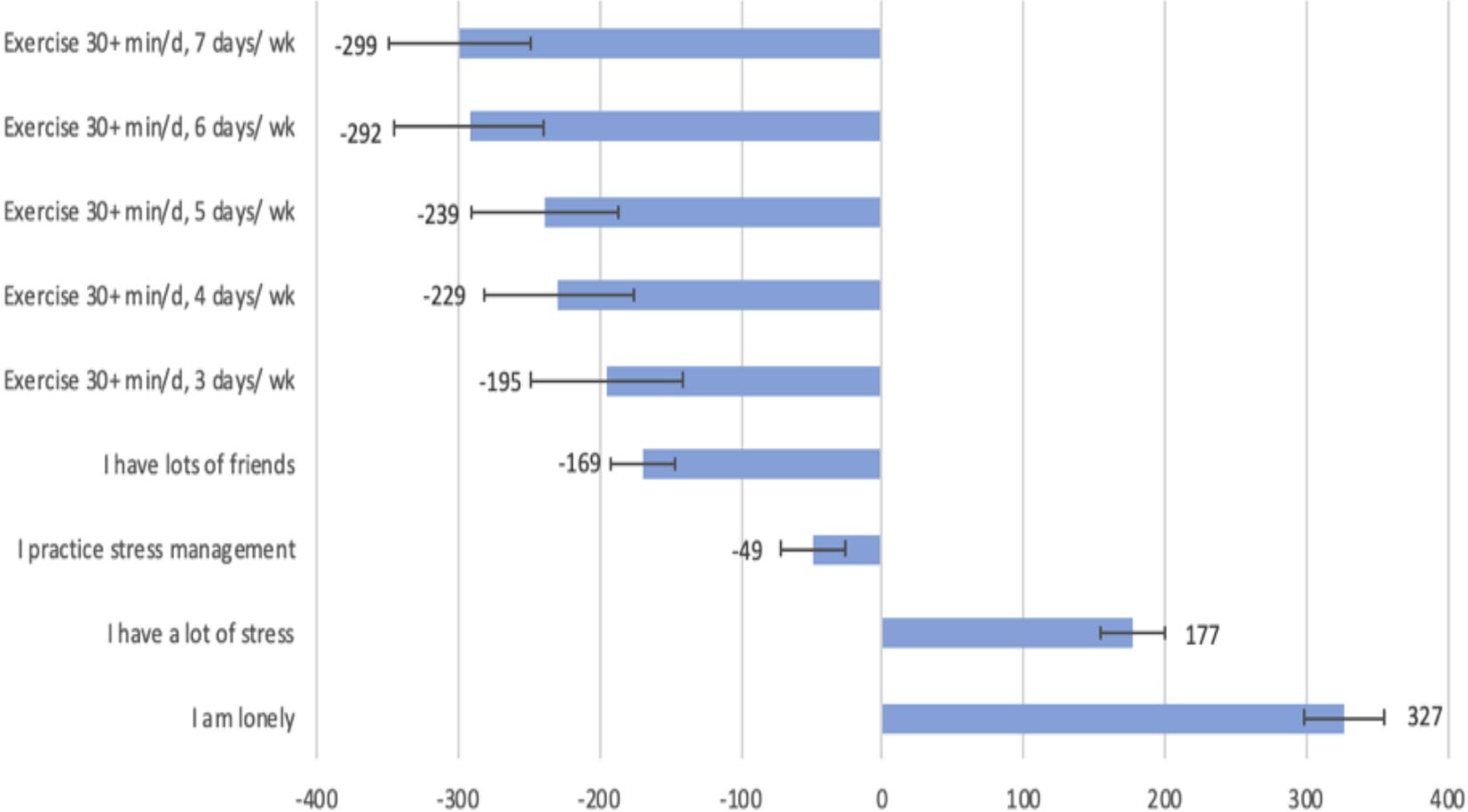
Social Health Predicts Quality of Life More Than Tremor



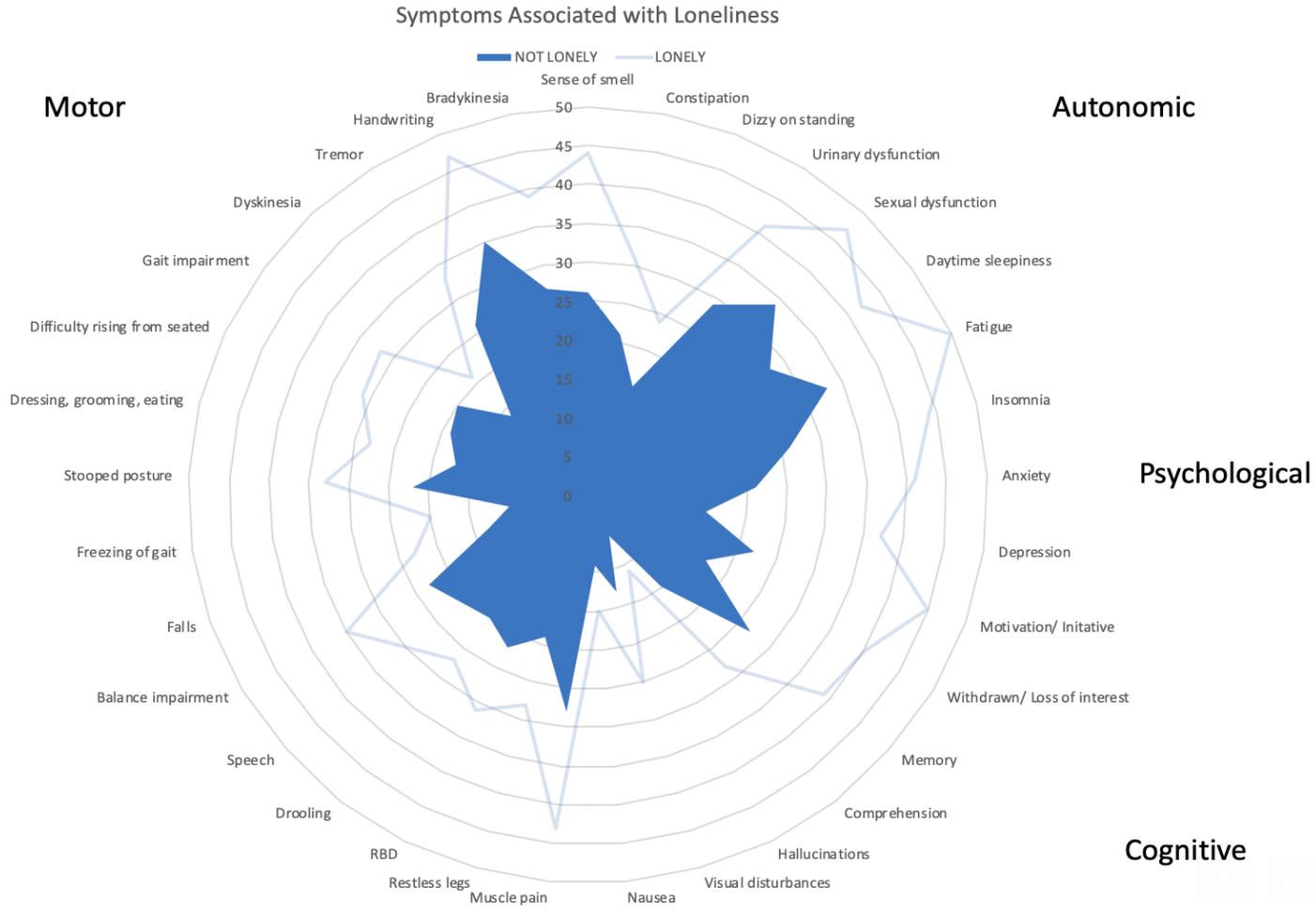
Overall, individuals identifying as being lonely reported consistently greater PD symptom severity. Although tremor is a cardinal symptom of PD and highly visible, feeling socially withdrawn is more closely correlated to overall quality of life than tremor.



THE IMPACT OF LONELINESS



SYMPTOM SEVERITY: LONELY VS NON-LONELY PATIENTS



DISCUSSION: SYNERGY OF PANDEMICS

- **1. Increase in PD Cases globally**
- **2. Loneliness Pandemic**
- **3. COVID-19**



extra

THE BURDEN OF COVID-19 FOR PEOPLE WITH PARKINSON'S



The corona crisis has upset people's routines. This is challenging for everyone. And even more so for people with Parkinson's



Social isolation



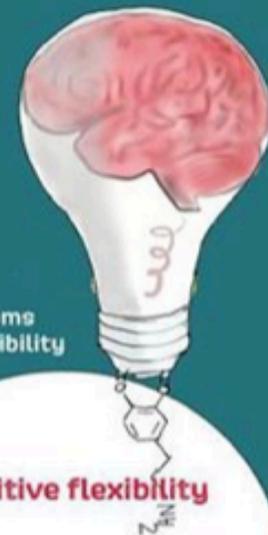
Stress



Physical inactivity



Worsening symptoms
Less cognitive flexibility



Cognitive flexibility

Cognitive flexibility is necessary to adapt in times of crises. It is powered by dopamine of which people with Parkinson's have less than other people. Stress diminishes dopamine levels and a feeling of being in control even further.

Researchers are curious how the Corona pandemic will show in the data which are now being collected by following patients in time. Data are collected with wearable sensors and analysis of biomarkers in bodily fluids. Analysis may give us hints about resilience in Parkinson's



Socialising online

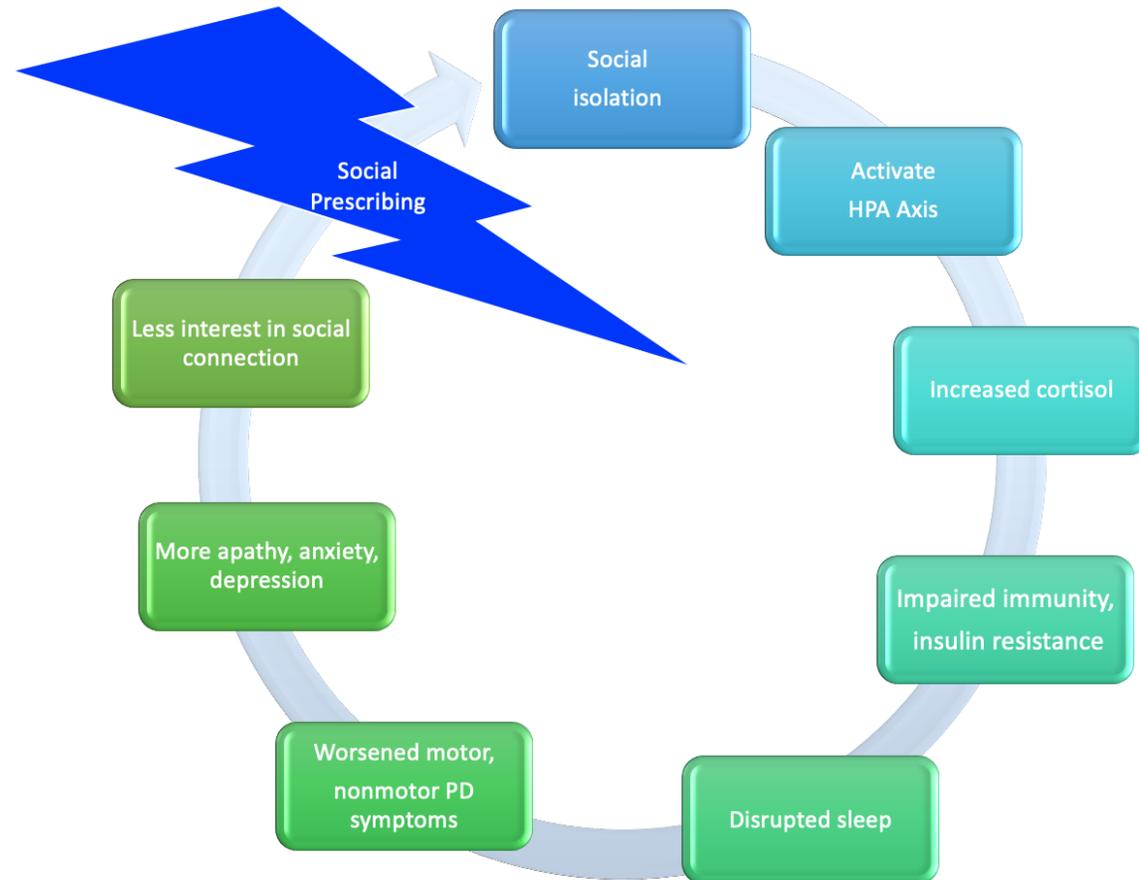
Mindfulness

Home based/online workout

To counteract the downward spiral, and set up new home-bound routines, people with Parkinson's can use a little help from their friends (and physicians)

This is the CC BY 4.0, visual interpretation of @Sparks4PD of the article by Bastiaan R. Bloem and Rick C. Helmich, The Impact of the COVID-19 Pandemic on Parkinson's Disease: Hidden Sorrows and Emerging Opportunities. Journal of Parkinson's Disease 10 (2020) 351–354. <https://doi.org/10.3233/JPD-202038>

THE CYCLE OF SOCIAL ISOLATION, STRESS AND PD SYMPTOMS: ROLE OF SOCIAL PRESCRIBING



TIPS FOR CLINICIANS:

- **Ask** your patients about their social health- remember the 3 spheres
- **Learn** about "Social Prescribing"
- **Help** patients connect with support groups, identify their tribe or cheerleaders early in disease to support them throughout disease
- **Motor:** Ensure adequate dopamine augmentation. Patient should be able to move with fluidly
- **Non-Motor:** Screen for and manage the contributing symptoms: Apathy, depression, fatigue, anxiety, urinary and bowel urgency, drooling
- Be more **vigilant** given **COVID-19** and take advantage of **virtual** modalities like virtual support groups, **proactive phone calls**





Upcoming Events

[← To COVID-19 Main Page](#) [Past Events](#) [All 2020 Programs →](#) [Video Archive Page →](#)

COVID Fatigue & PD – Social Connection as Medicine
Laurie Mischley, ND, PhD, MHP

Monday November 2nd
12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET
[Register](#)

Driving and Road Safety for People with PD
Ergun Uc, MD

Friday November 6th
12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET
[Register](#)

A Conversation with Rasheda Ali-Walsh
Rasheda Ali-Walsh

Monday, November 9th
12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET
[Register](#)

Defining a Multidisciplinary Approach to PD
Suketu Khandhar, MD

Wednesday November 11th
12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET
[Register](#)



BLOGGING- PARKINSONSECRETS.COM

Social connection is a universal human need. We urge you to pick up the phone and reach out to someone who may have been forgotten and may be lonely or socially disconnected. It could be the only human contact that the person may have had in a long time and could make a world of difference.



This blog is brought to you by Michael S. Okun and Indu Subramanian.



SOCIAL CONNECTION:

- Find Your tribe
- Find your cheerleader/confidant
- Meet your neighbors
- Join a support group (online)
- Exercise class (online)
- Religious/spiritual group (online)
- Volunteer-phone a friend who is more isolated than you (tend & befriend)
- Travel (outside of COVID, perhaps even explore your own city)
- Zoom family time-happy hour, coffee
- Read a book to a grandchild over zoom, facetime



VA: COMPASSIONATE CONTACT CORPS

- Referral from clinicians
- Fill out form with Private info
- Patients are matched to volunteers
- These volunteers used to come in person to the VA
- Can help volunteers as well with wellness
- Found 3 key questions about loneliness- would like to add to the survey
- Have been approached by AARP, Rotary





SELF- CARE FOR ALL

- Sleep- like floss for your brain; 8 hours
- Exercise is medicine
- Diet- your body is a temple; Hydration-40 ounces of water
- Mental stimulation- learn a new language, music
- Checking in with Your Doctor- like an oxygen mask on a plane; put yours on first before you help others
- Find a battle buddy- someone to call and check in with
- Ask for help if you are in trouble-national suicide prevention line

1-800-273-8255

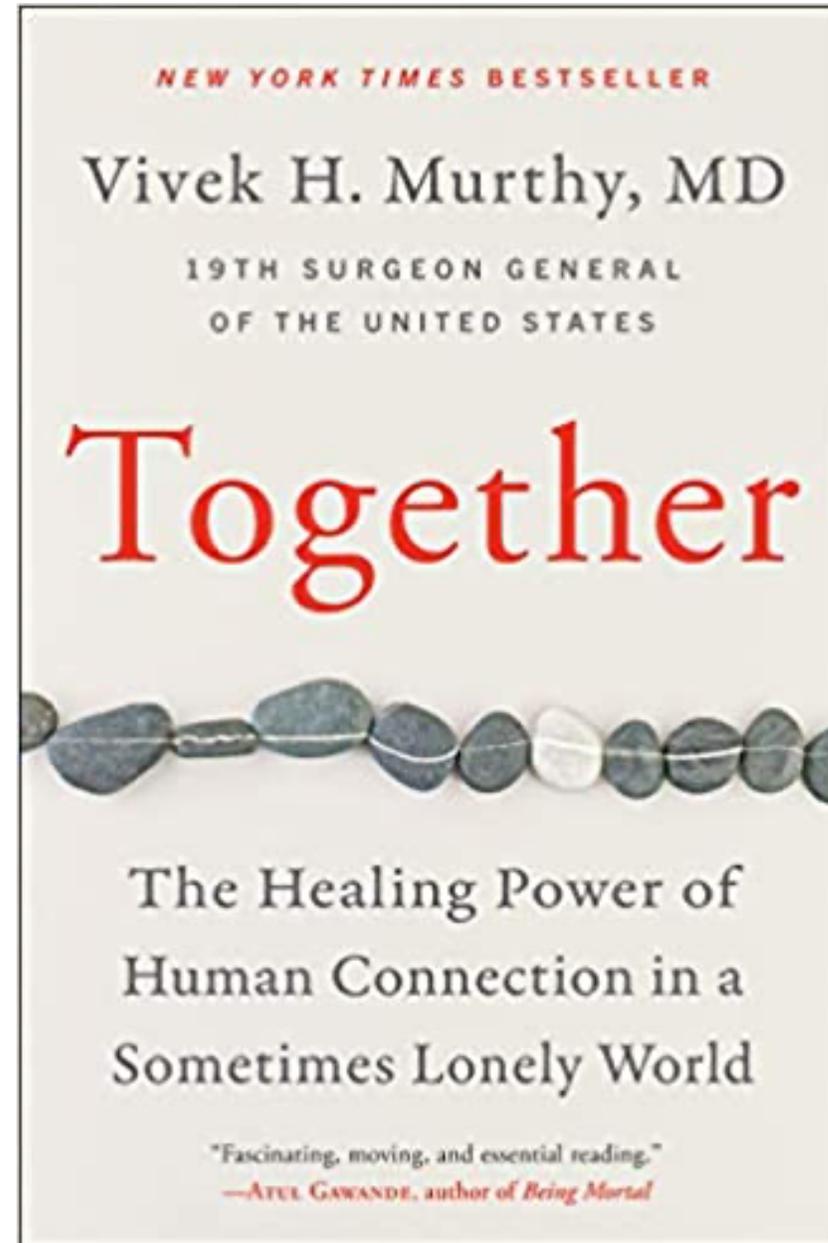


BE KIND TO YOURSELF

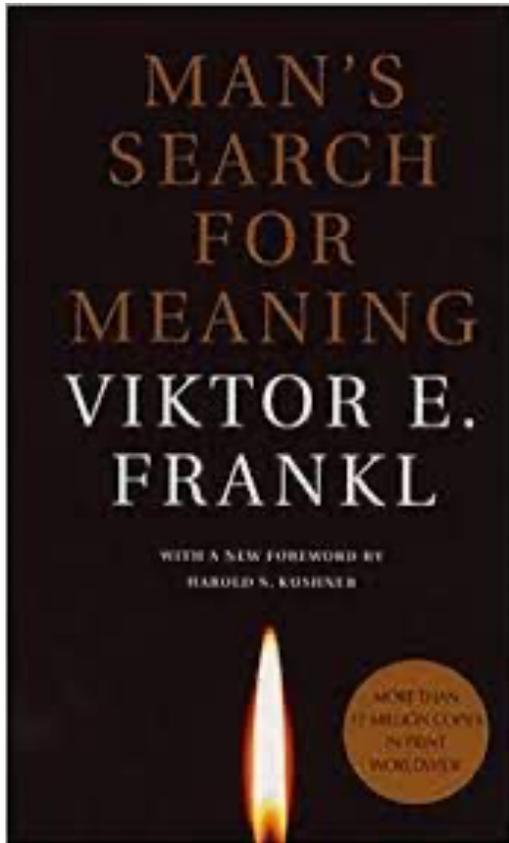
- Especially if you are a caregiver or a health care provider or a parent/grandparent or child of an elderly person
- Each of these jobs can be a full time job in and of itself
- Expecting to do all of these well is impossible-being good enough; letting go of expectations
- Do not compare yourself to others- different people handle stress differently (some are painting their whole house, some are publishing 8 articles/month)
- Many of us are totally emotionally exhausted- we are the pillars of support for everyone around us, it is not sustainable
- Realize this a marathon not a sprint (self-pacing)
- Allow yourself to sleep in or just rest, take a break, alone time
- Give yourself permission to not be perfect.. sometimes just taking a shower and making a sandwich is a lot



VIVEK MURTHY



VIKTOR FRANKL



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.

Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.



SILVER LININGS

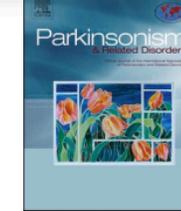
- Taking a moment to pause and reflect; to be present;
- Realizing how uncertain things can be and what we have taken for granted
- Realizing how important social connection and our global connection is to one another
- Having new respect for the planet, mother Earth
- Realizing altruism is important in preserving our future
- Gratitude for people such as teachers, grocery store workers, postal workers



SILVER LININGS IN HEALTH CARE

- Shining a light on the social inequalities that have defined our health care systems to date-opportunity to make a real change including gender specific issues
- Chance to break down barriers of telehealth, insurance, isolation,
- New appreciation for all of the people on the health care team-broken down barriers of doctors vs nurses vs nurse practitioners etc
- Seeing palliative care providers and integrative med practitioners especially yoga, mindfulness teachers as the new heroes of the day
- An opportunity to normalize advanced care planning





Point of view

Hoping for the best, planning for the worst: Palliative care approach to Parkinson disease during the COVID-19 pandemic

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A B S T R A C T

Palliative care emphasizes expertise in handling difficult conversations, discussing patients' wishes and supporting the caregiver(s). Here we outline the palliative approach of hoping for the best while preparing for the worst in several "what if" scenarios for people with Parkinson disease and their families during the COVID-19 pandemic.

The palliative care approach to neurologic disease emphasizes relief of physical, emotional, and spiritual suffering. The COVID-19 pandemic has certainly magnified suffering: through physical illness and death, fears and anxieties, and financial and social instability. There are distinct concerns around the increased vulnerability of those living with chronic illnesses like Parkinson disease (PD). Stress-related psychiatric symptoms such as anxiety and depression are already quite common in PD, occurring in up to 60% of patients [1]. There are mounting concerns about the "what-ifs" among persons with PD (PWP) and their families as this pandemic continues. The pandemic presents an important opportunity to discuss goals of care, and to revisit or establish advance care plans specifically related to COVID-19 or a decline in health. Some clinicians have found it easier to discuss these topics framed within the pandemic which puts all of us at risk, highlighting that documentation of wishes is the best way to ensure appropriate care is delivered and people are protected from interventions that they would not want. Communi-

1. What if a person with moderate to advanced PD develops COVID-19?

PWP may be at an increased risk for higher morbidity and mortality from COVID-19 given their older age, higher male predominance and possible comorbidities of frailty, dysphagia and immobility [3]. PWP are already more prone to pneumonias and infections which can cause sudden changes in behavior and motor function, increasing the risk of complications significantly. If requiring hospitalization, then several possible trajectories could be presented: (1) to pursue aggressive medical interventions such as intubation and mechanical ventilation; (2) to pursue all therapies short of intubation to include only non-invasive ventilation and respiratory therapies; (3) to consider a time-limited trial of aggressive therapies with designated conditions under which such support would be withdrawn; and (4) to forego hospitalization and transition to hospice to focus on comfort and not escalate medical care

