

Caring in Isolation: Understanding Loneliness in the Caregiving Experience

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May 28, 2025

Agenda

- Learn the distinction between social isolation, loneliness and solitude and their impacts on health
- Recognize the signs and symptoms of loneliness
- Explore practical strategies to develop and maintain meaningful social connections as a caregiver
- Familiarize yourself with supportive resources tailored for caregivers for someone with Parkinson's

Defining Terms/Shared Language

- **Social Isolation** is the objective measure of how many people one actually sees in a certain period of time. Those in isolation are not necessarily lonely.
- **Loneliness** is the mismatch between the number of quality relationships one believes one possesses versus the number of quality relationships one would like to have.
 - Loneliness (or social disconnection) is subjective and dynamic.
 - The absence of loneliness does not equate with feeling socially connected.
 - Loneliness is a continuum or gradient.
 - In a society, there are variations in social and individual thresholds of loneliness.
- **Solitude** is the luxury of feeling socially connected, but self selecting to spend time alone.

Types of Loneliness

- Social
- Emotional
- Existential
- Transient
- Situational
- Chronic

Signs and Symptoms of Loneliness

- Abnormal anxiety and increase of demanding and/or critical behavior
- Decreased confidence and self esteem
- Disengagement in a variety of contexts (e.g., relationships, hobbies)
- Changes in appetite and
- Difficulting concentrating
- Not attending events one is invited to even though there are no other plans
- Insomnia/sleep disturbances

Trends in Loneliness

1 | Spousal Caregiving

For spousal caregivers 28.6% feel lonely often or always

2 | Duration of Caregiving

Those caregiving for over one year feel often or always feel lonely 70% of the time

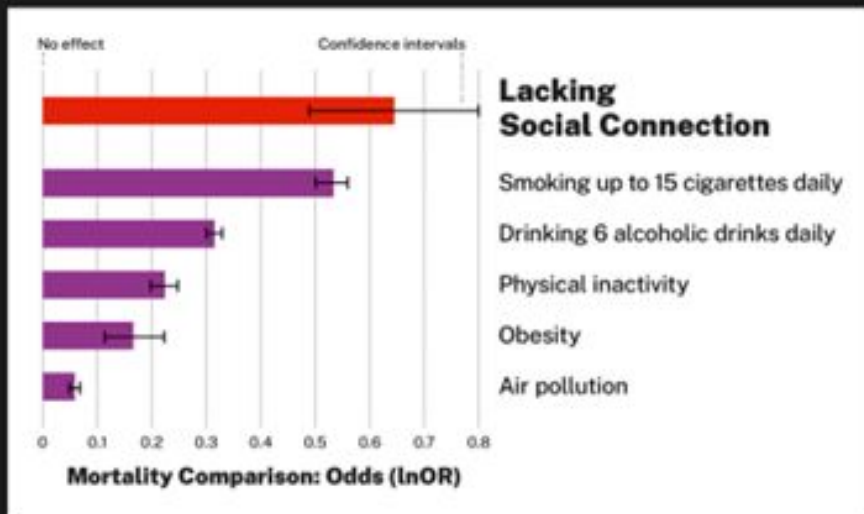
3 | Without family support

Caregivers without family support feel lonely often or always 74% of the time

Outcomes of Loneliness

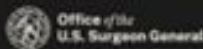
- **Physical Health Outcomes:**
 - Sleep disturbances, difficulty self regulating (CNS), weakened immune system
 - What's ahead: Higher likelihood of chronic heart disease, stroke, hypertension, diabetes, cancer
- **Mental Health Outcomes:**
 - Increased risk of depression and anxiety (#1 symptom), increased risk of suicidality, and self harm, increased likelihood of substance abuse
 - What's ahead: Cognitive decline , increased risk of Alzheimer's and other types of dementia

Lacking social connection is as dangerous as smoking up to 15 cigarettes a day.



Comparison groups: Complex measures of social integration: high v. low; not smoking v. smoking < 15 cigarettes daily; alcohol abstinence v. drinking > 6 alcoholic drinks daily; physical activity v. inactivity; low BMI v. high BMI; low air pollution v. high air pollution.

Source: Holt-Lunstad J, Robles TF, Sbarra DA. Advancing Social Connection as a Public Health Priority in the United States. *American Psychologist*. 2017;72(6):517-530. doi:10.1037/amp0000103. This graph is a visual approximation.

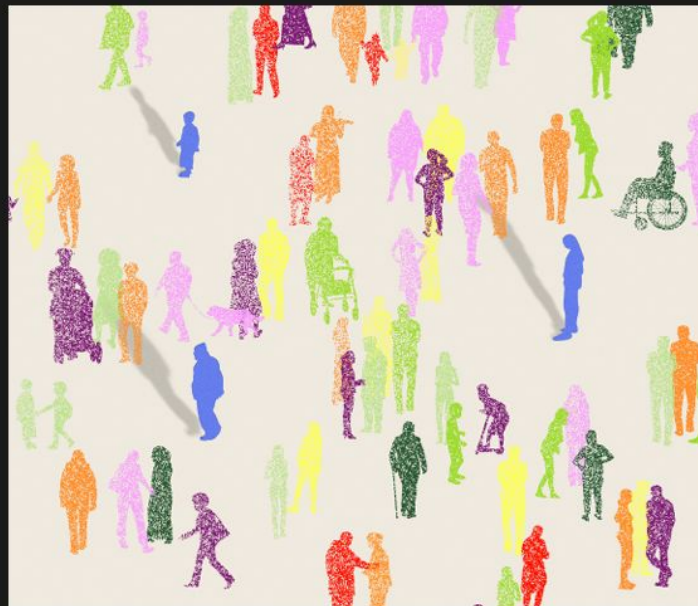


Our Epidemic of Loneliness and Isolation



2023

The U.S. Surgeon General's Advisory on the
Healing Effects of Social Connection and Community



Caregiver Burden

"Caregiver burden is a term that refers to the adverse effect of caregiving on the physical, emotional, social, spiritual, and financial well-being of the caregiver."

(Admond et. al 2024)



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Loneliness and Caregiving: Caregiver Burden

1. **Greater PD symptoms = Greater caregiver burden**

Those with PD who experience these emotions have a disinclination to go out or attend social events which then results in caregivers having the same experiences

2. **Increased motor symptoms and fluctuations**

Caregivers have lower productivity at work, more missed days, loss of income, and more financial strain

3. **Sleep disturbances and nocturnal care**

Increased caregiver burden, depression, anxiety, and fatigue

Where to Start: Reducing Loneliness

1. **Recognize you are not alone**

Connecting with others provides “comfort, validation, and a renewed sense of community

2. **Consider mental health support**

Loneliness and social isolation can feel intense, but there are many options to seeking mental health help

3. **Service to others: Remote volunteering opportunities**

“Service is the antidote to loneliness” _Dr. Vivek Murthy.

4. **Research service from your home**

Parkinson’s Association of the Carolinas; Parkinson’s Foundation

Loneliness and Caregiving: What Works

1. Peer Support

Other caregivers can provide more meaningful relationships due to empathy

2. Accepting help

Accepting help and/or admitting a need for services allows for intervention and a variety of support services

3. Encourage your loved one to get out in the world

Caregivers are well aware that those with PD are hesitant to attend social events or other outside activities, but both of you benefit from interacting with loved ones outside of the home.

What Can We Do to Reduce Loneliness?

Individual actions make a difference! Try these practical steps in the future days and weeks. Consistency is key!

- Limit distractions during conversations to enhance the quality of your time with others.
- Be attentive, encouraging, and express gratitude regularly.
- Avoid habits that contribute to disconnection or isolation.

Key Takeaways:

- You are not alone if you feel lonely.
- And loneliness does not have to last forever.



Q&A
Thank you for
your engagement!

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