

Unseen and Unheard: Loneliness in Informal Caregiving by Older Adults

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Itinerary

- Learn the distinction between social isolation, loneliness and solitude and their impacts on health
- Recognize the signs and symptoms of loneliness
- Understand the outcomes of loneliness
- Identify the many faces of caregiving, the roles, and the data
- Explore practical strategies to develop and maintain meaningful social connections as a caregiver

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 sleep patterns
- Difficulting concentrating
- Not attending events one is invited to even though there are no other plans
- Insomnia/sleep disturbances

Trends in Loneliness

1 | Older Adults and Loneliness

Thirty five to 46% of older adults report feeling lonely (studies consistently show)

2 | Seriously Lonely

Thirteen percent of older adults feel seriously lonely all the time

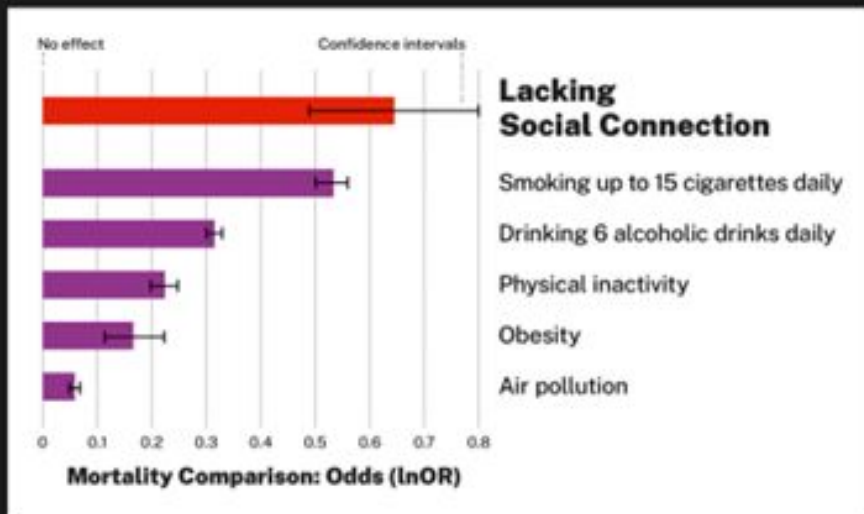
3 | Caregivers Feel Lonely

About 15% of older adult caregivers feel lonely often

Outcomes of Loneliness

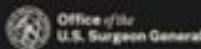
- **Physical Health Outcomes:**
 - Sleep disturbances, difficulty self regulating (CNS), weakened immune system
 - Higher likelihood of chronic heart disease, stroke, hypertension, diabetes, cancer
- **Mental Health Outcomes:**
 - Increased risk of depression and anxiety (#1 symptom), increased risk of suicidality, self harm, and increased likelihood of substance abuse
 - 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.

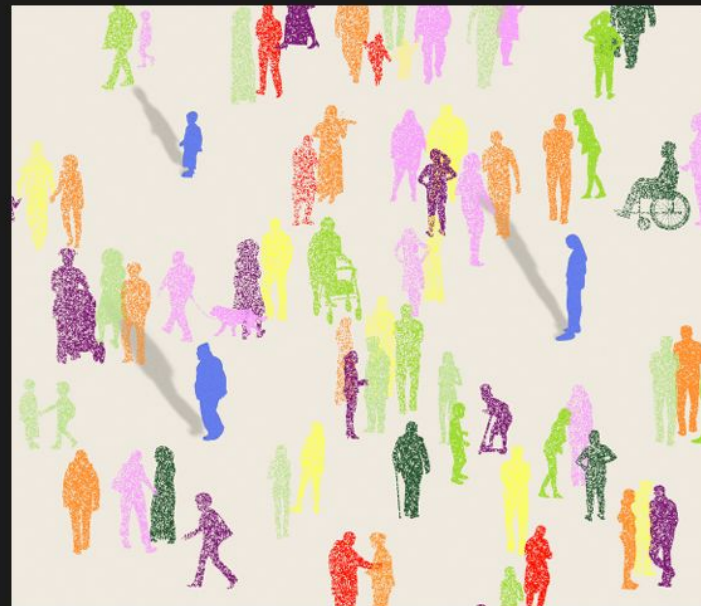


Our Epidemic of Loneliness and Isolation



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)



HEALTHYPLACE.COM



On average, women 55+ provide more than five weeks of full-time, unpaid care a year



Source: Bureau of Labor Statistics, American Time Use Survey 2017-2019 & 2021-2022 (IPUMS)

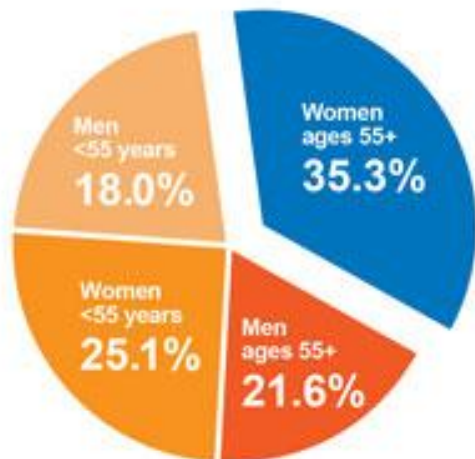
Informal caregiving:
unpaid caregiving by
those who are not
professional trained

Older Adults caregive for....

- Spouse or domestic partner
- Sibling or cousin or other same age family member
- Parent(s)
- Child(ren)
- Grandchild(ren)
- Neighbor or friend

Women 55+ Account for More Than One-Third of All Unpaid Eldercare Providers

Share of unpaid eldercare providers who are:

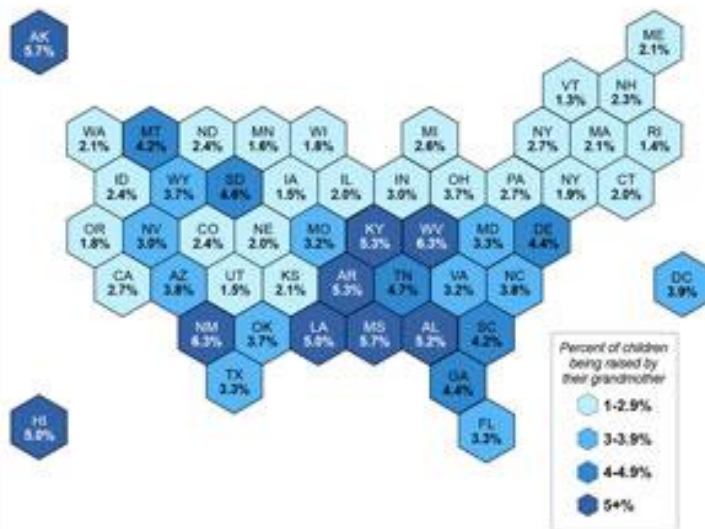


Data: Bureau of Labor Statistics, American Time Use Survey 2017-2019 & 2021-2022 (IPUMS).

Notes: Based on care provided on the prior day.

Nationwide, Grandmothers are Raising More than 2 Million Children

Rates Highest in West Virginia & New Mexico



Source: 2021 American Community Survey data (IPUMS).

Roles of Caregivers

- Household
- Self-care, safety, mobility
- Emotional & social support
- Health and medical care
- Advocacy & care coordination
- Decision making & surrogacy



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

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.

The Loneliness Calendar

August: National Friendship Day (1st Sunday in August)

September: Locate an Old Friend Day (9/20/25)

October: World's Teacher Day (10/5/25)

November: National Gratitude Month

December: International Volunteer Day (12/5/25)

January: #NationalNothingDay (1/16/26)

February: National Random Acts of Kindness Day (2/17/26)

March: World Compliment Day (3/1/26)

April: Earth Day (4/22/26)

May: Digital Wellness Day (5/1/26)

June: Intergenerational Day (6/1/26)

July: Social Wellness Month

“Menu for Connection”

- Self:
 - Make Peace with Yourself, Evaluate Your Routine, Invest in Your Health, Bring a Prop, Get a Pet, Practice Small Acts Kindness, Push Through Rejection, Prepare for Conversation
- Family:
 - Attend Family Gatherings, Be Less Judgemental, Be Vulnerable, Give Yourself a Break

“Menu for Connection”

- Friends and Romantic Partners:
 - Curate Your Social Circle, Organize Concrete Plans, Cast a Wider Net, “Space Gatherings”
- Community:
 - Develop a Smaller Community, Serve your Community, Random Acts of Kindness to Friends, Peers, Professors, and Strangers
- Technology:
 - 7 minute gift, Take Notes on Your Phone, Join affirming podcast/social media communities

Key Takeaways:

- You are not alone if you feel lonely
- Loneliness does not have to last forever



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Thank you for your engagement!



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Foundation for Social Connection Ambassador

Advancing social connection nation-wide rooted in evidence for our collective well-being

Learn more and join the movement at www.social-connection.org